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Agenda Item: 14

Integration Joint Board

Date of Meeting: 30 September 2020.

Subject: Dementia Strategy 2020-2025.

1. Summary

1.1. This report advises Members of the final draft Orkney Dementia Strategy 2020-2025, following consultation, to attain agreement for adoption.

2. Purpose

2.1. To ensure the Integration Joint Board (IJB) has a local Dementia Strategy which will cover all aspects of delegated services for the period 2020-2025, in relation to support and services for people with dementia and unpaid carers.

3. Recommendations

The Integration Joint Board is invited to note:

3.1. That consultation has been undertaken on the draft Dementia Strategy, with the results of the engagement detailed, in full, in the Consultation Report, attached as Appendix 1 to this report.

3.2. The final draft Dementia Strategy (Version 3), attached as Appendix 2 to this report.

3.3. The final draft Orkney Dementia Strategy Summary Document, as attached as Appendix 3 to this report.

It is recommended:

3.4. That the final draft Dementia Strategy 2020-2025, attached as Appendix 2 to this report, be approved.

4. Background

4.1. The Strategic Plan 2019-2022 identifies mental health services as a priority. As dementia sits within the remit of mental health services this local Dementia Strategy is a key component in the overall delivery of mental health services within Orkney. The Dementia Strategy provides a focus to help successfully deliver the priorities of the Strategic Plan in relation to dementia support and services.

4.2. The local Dementia Strategy reflects the aims and objectives presented in various national and local documents, as follows:

- The National Clinical Strategy, which aims to improve the care of people with life limiting illnesses.
- Carers (Scotland) Act 2016 introduces new rights for unpaid carers and new duties for local councils and the NHS to provide support to carers.
- Social Care (Self-directed Support) (Scotland) Act 2013, the aim of which is to allow people, carers and families to make informed choices about what their social care support is and how it is provided.
- Palliative and End of Life Care Strategic Framework, which outlines the key actions to be taken that will allow everyone in Scotland to receive services that respond to their individual palliative and end of life care needs, regardless of setting or diagnosis.
- Age, Home and Community: A Strategy for Housing for Scotland's Older People: 2012-2021, which recognises the important role of housing support in enabling people to live safely and independently at home for as long as possible.
- A Connected Scotland 2018, a strategy for tackling social isolation and loneliness and building stronger social connections.
- The Healthcare Quality Strategy for NHS Scotland, which embraces three quality ambitions and provides a vision for NHS Scotland.
- National Care Standards, which describe what everyone can expect from any care service used and focus on the quality of life an individual might experience.
- Promoting Excellence – A Framework for all health and social services staff working with people with dementia, their family and carers.
- Charter of Rights for People with Dementia and their Carers in Scotland, published in 2009, which aims to empower people with dementia, those who support them, and the community, ensuring their rights are recognised and respected.
- Standards of Care for Dementia in Scotland, which outline the rights, quality of care, support and treatment people should receive to stay well, safe and listened to.
- The Scottish Government's 2020 Vision, which is that by 2020 everyone is able to live longer healthier lives at home, or in a homely setting and that we will have an integrated health and social care system which supports prevention and self-management, admission to hospital only where necessary, high quality, safe, person centred care.
- Connecting People, Connecting Support – identifies how Allied Health Professionals (AHPs) in Scotland can improve their support for people with dementia, their families and carers to enable them to have positive, fulfilling and independent lives for as long as possible.
- Scotland's Digital Health and Care Strategy, which sets out initiatives to maximise the use of digital health and care solutions in order to reshape and improve services, support person centres care and ultimately to improve outcomes.

- Orkney Mental Health Strategy, which sets out strategic outcomes for mental health.

4.3. The local Dementia Strategy will span a five-year period, with evaluation of outcomes and progress being reported through the performance monitoring of the Strategic Plan.

4.4. The Life Changes Trust has pledged up to £45,000 to support an independent evaluation of the impact of the strategy.

5. Consultation Process

5.1. Consultation was completed in line with the IJB's Communication and Engagement Policy which adheres to Scotland's National Standards for Community Engagement. This includes taking cognisance of benchmark levels of community engagement, as well as the equality requirements, especially the Public Sector Equality Duty.

5.2. Principal stakeholders in this engagement process have been identified as:

- People living with a diagnosis of dementia.
- Their families, friends and carers.
- Public sector/statutory service staff.
- Third sector partners.
- Community groups.

5.3. Initial feedback about what currently works well for people with dementia and carers and areas for development was sought through a short life working group inclusive of all stakeholder groups.

5.4. The Life Changes Trust supported a three-day Orkney Dementia Conference which included informal social sessions, storytelling and workshops to identify priorities from a grass roots perspective. This facilitated a wide range of individuals, including people with dementia and unpaid carers, being able to articulate their views and priorities to inform the strategy. Comment and input received from these sessions informed the content of the draft Dementia Strategy.

5.5. A number of methodologies were utilised to provide good opportunity for feedback during the consultation phase. The primary survey was sent directly to people living with dementia with opportunity for both people with dementia and unpaid carers to respond by telephone, letter or email. This survey was also circulated to all relevant stakeholders as identified above. In addition, opportunities for feedback were communicated through Facebook and Twitter as well as local media. Both NHS Orkney and Orkney Islands Council supported feedback through online media. Due to the restrictions of COVID-19 we recognised that face to face engagement was not possible so we secured funding through Age Scotland Orkney to ensure that individual letters could be sent to people with a diagnosis of dementia directly.

5.6. A summary copy of the strategy was made widely available to support accessibility and participation for all.

5.7. The results of the engagement have been collated and are detailed in the Consultation Report, attached as Appendix 1.

6. Summary of main points

6.1. Feedback strongly reinforced that the priorities and commitments align well with the outcomes needed to make a positive difference to the lived experience of people living with dementia and unpaid carers in Orkney. There were pledges of support for implementation from a number of statutory, voluntary and community groups reflecting great synergy to improve care and support in line with the strategy.

6.2. There was some concern about whether the outcomes could realistically be achieved, particularly in the current climate. The main question raised was about how this could be funded. This has been recognised and amendments made to the strategy accordingly. There were also comments about being too aspirational and of fear of failure.

6.3. The need to include the impact of COVID-19 was recognised and amendments made to the strategy.

6.4. The final draft Strategy, which takes account of the engagement, is attached as Appendix 2, together with the summary document, attached as Appendix 3.

7. Contribution to quality

Please indicate which of the Orkney Community Plan 2019 to 2022 visions are supported in this report adding Yes or No to the relevant area(s):

Resilience: To support and promote our strong communities.	Yes.
Enterprise: To tackle crosscutting issues such as digital connectivity, transport, housing and fuel poverty.	No.
Equality: To encourage services to provide equal opportunities for everyone.	Yes.
Fairness: To make sure socio-economic and social factors are balanced.	Yes.
Innovation: To overcome issues more effectively through partnership working.	Yes.
Leadership: To involve partners such as community councils, community groups, voluntary groups and individuals in the process.	Yes.
Sustainability: To make sure economic and environmental factors are balanced.	Yes.

8. Resource implications and identified source of funding

8.1. At present there are no additional resources identified to implement any recommendations within the strategy. However, many of the commitments are about reshaping services, awareness raising and training.

8.2. Any cost implications will need to be determined by the actions of the strategy and will be the subject of future reports to the IJB with details set out in draft Directions, including the source of the funding if applicable.

8.3. It must also be acknowledged that if the status quo remains the model of delivery, significant increased statutory services funding may be required to deal with an increasing number of people reaching crisis without having had the proactive support to delay or prevent crisis.

8.4. Further to this, the opportunity to work as equal partners with the third sector provides increased opportunities to access funding streams with positive social return on investment whereby each £1 invested could have a much higher return.

9. Risk and Equality assessment

9.1. An Equality Impact Assessment was undertaken prior to submission for consultation approval. There is no change to this.

10. Direction Required

Please indicate if this report requires a direction to be passed to:

NHS Orkney.	Not at this stage.
Orkney Islands Council.	Not at this stage.
Both NHS Orkney and Orkney Islands Council.	Not at this stage.

11. Escalation Required

Please indicate if this report requires escalated to:

NHS Orkney.	No.
Orkney Islands Council.	No.
Both NHS Orkney and Orkney Islands Council.	No.

12. Authors

12.1. Gillian Morrison (Interim Chief Officer), Integration Joint Board.

12.2. Lynda Bradford, Acting Head of Health and Community Care, Orkney Health and Care.

12.3. Gillian Coghill, Alzheimer's Scotland Clinical Nurse Specialist, Orkney Health and Care.

13. Contact details

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14. Supporting documents

14.1. Appendix 1 – Consultation Report.

14.2. Appendix 2 – Final Draft Dementia Strategy.

14.3. Appendix 3 – Final Draft Orkney Dementia Strategy Summary Document.

Orkney Dementia Strategy Feedback - Collated

August 2020

Feedback Received (copied verbatim)	**Change incorporated / Not Incorporated**	**Comments**
It is really good that this work has been undertaken and we are sure the people of Orkney will be appreciative. We are concerned however that as the strategy is very aspirational that expectations are raised that ultimately cannot be met. Given the financial and workforce constraints super imposed by the impact of Covid-19 we are thoughtful that we are setting ourselves up to fail in the current climate. In terms of the commitment section it might be useful to separate out with distinct ***hwadonfa*** that which is currently in place, that which is the provision of information and that which is yet to be actioned.	Change partly incorporated	Following discussion, it was felt that altering the layout and adding in more information could cause confusion. Progress is likely to be fluid and would become out of date quickly. A separate document will be available for anyone wishing to have more in depth detail of current progress. This will be presented at the IJB meeting. There is a broad overview of current supports and services in the strategy. It was agreed that the strategy needs to be aspirational. The commitments reflect what people living with dementia and their carers identify as priorities in Orkney and a steering group will be created to take this forward. Comment on financial constraints and commitment has been added.(Page 30). It is acknowledged that the financial aspect would not be

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		achievable if this was all to be resourced by statutory services. The strategy identifies that new and more collaborative ways of working will be required. This will include initiatives such as community led support, tiered approaches to ensure that the right support is delivered at the right time, by the right person in the right place supports increased efficiency and more proactive approaches. It must also be acknowledged that if the status quo remains significant increased statutory services funding will be required to deal with an increasing number of people reaching crisis without having had the proactive support to delay or prevent crisis. The strategy was written pre Covid-19 and a section has been added to address this (Pages 7 & 30).
The Dementia Strategy is very well written, I had a couple of thoughts whilst reading through, Better information and support in how to access self-directed support and Learning disability and dementia - are these something in which Advocacy Orkney could work with you on? Also, is there any timelines for the implementation of the key aspects identified in the strategy I didn't notice any? And, there still needs to	Change incorporated	Acknowledged support for implementation. Resource/finance – (page 30).

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
be a commitment of resources from OH&C to appoint additional resources, has this been sought or committed too?		
I feel it reflects our views very well.	No change to strategy identified in feedback	Acknowledged
I haven't had time to read the strategy but you can't possibly do anything any better than you're doing.	No change to strategy identified in feedback	Acknowledged
Having read the draft strategy, I have to say I am very impressed and in particular the commitments you are making to those suffering from dementia, as well as to carers, whose role is sometimes not fully recognised. An observation is whether this can be delivered in the North and South Isles, where resources are perhaps limited. Also, whilst it is undoubtedly ideal to be able to support the patient at home, I wonder in cases where there is no family in Orkney - or as described in the next paragraph - how this can be realistically achieved. I know of a case where a woman, who does have family in Orkney, developed definite signs of dementia and who was unwilling to move out of her house. Her son and daughter endeavoured to put in place a care package at home, which also met with strong resistance. This was a lady, who in the past was the most gentle of souls, not a bad word for anyone, but her behaviour completely changed as the condition developed. In the end, she had to go in to a Care Home, as	No change incorporated	Acknowledged Strategy sets out commitments to support all people with dementia regardless of having family close by and acknowledges that in very remote/rural areas there is a need to do things differently.

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
her children were working and also had their own families to consider. I hope you are able to meet your commitments, which I totally support by the way and overall, I think it is a very good strategy. Time will tell if it is achievable and I hope it is. Good luck.		
The strategy seems sensible. There is no mention of Covid-19 or PPE. This seems an oversight given that this virus has been shown to disproportionately affect the elderly, particularly individuals with dementia. PPE in the care sector has also been insufficient and represents a substantial cost. Does NHS Orkney have the money to fulfil this plan? We hope so.	Change partially incorporated	The strategy was written pre Covid-19 and a section has been added to address this (Pages 7 & 30). No ongoing evidence of shortage of PPE identified in Orkney during COVID Financial/resource aspects (Page 30).
Firstly I would like to say “Well Done” a great piece of work and I can see a lot of thought has gone into this with key priority areas clearly identified. I feel this is very important for Orkney as the projected figures show an increasing proportion of our older people developing dementia in later life. I feel this strategy requires investment - workforce development to have skilled workers available, there needs to be a clear pathway for staff to achieve this. Will there be further consultation from stakeholders to inform on progress and how will this be monitored? I wish you every success in these difficult times and the restrictions this will have in moving forward.	Change partly incorporated.	Comments acknowledged. Investment/finance (Page 30) Involvement of stakeholders in steering group and evaluation is included in the evaluation plans for the strategy.

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
Have managed at the eleventh hour to have a read of your strategy. Well done, you've put a lot of work into this, it was interesting and informative. Just a few things I have picked up on; on page 11, 13 and 19 if you could refer to us as Crossroads Care Orkney. On page 18 at the bottom if you could call it the Orkney Carers Centre. I know you have put we support generic carers and this should be sufficient to explain that we support carers of people with dementia too but maybe that should be reinforced. At the top of page 19 instead of carers centre I would put Crossroads Care Orkney as the Carers Centre doesn't provide respite, all a bit confusing when you have the two entities together.	Change incorporated	All names changed as requested (Pages 12, 14, 19, 20 & 34).
Thank you for this. My only concern is that a family needs a diagnosis before they can have any support while they could benefit from support from the first symptoms appearing. Is there anything that can be done please?	No change to strategy identified in feedback	Acknowledged The Hub at Age Scotland provides support prior to a diagnosis - this may need to be more widely communicated.
Thank you for sending this to me. I have read it and the longer version. What a huge power of work has been done. Thank you. All good news for dementia progress here in Orkney. it is both strategic and also down to earth – not easy to achieve. If I can be of any help whatsoever please let me know – I will do what I can and offer you my full support. Dementia is close to my heart.	No change to strategy identified in feedback	Acknowledged

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Draft looking good. This will give individuals great support.	No change to strategy identified in feedback	Acknowledged
The Strategy looks good. Glad to see that making medical involvement is to be made more dementia friendly and in own home/ familiar surroundings where possible. This will be really good. Hospitals are frightening for anyone and especially for dementia sufferers.	No change to strategy identified in feedback	Acknowledged
Identifying priorities and actually delivering the necessary services are of course two different things. I am alarmed by the weight placed on the presence of 'unpaid carers'. I appreciate that many dementia sufferers are looked after by members of their family, and that many families would have it no other way. I note that there is a commitment to respite care. The provision of good respite care is fundamental to the continuing heath and therefore the ability to carry on caring of these family carers. However not every dementia sufferer has family, and some have families that are not able to take on the role of carer. I am sorry, indeed slightly appalled, that there is no mention in the strategy of how people with dementia but no-one to care for them are to be looked after. Equally reliance on unpaid care should be reduced as far as possible; care should not be dependent on the lottery of whether a sufferer has local family with the time and skills to look after them, not should the presence of such people be used as a way of	Partially incorporated	The inclusion of people who don't have access to family support has been more specifically added to commitment 3 (Page 18). The strategy sets out support for people regardless of whether they have family. The commitment for carers supports and recognises measures to help carers where they wish to continue caring.

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saving money on services. People with dementia have complex needs not all of which can be met by untrained family members however willing.		
If someone chooses to care for someone with dementia they also need financial support.	Already incorporated in strategy	Commitments for post diagnostic support include access to financial support for carers. This will be an element of the integrated care pathway.
Well thought out	No change to strategy identified in feedback	Acknowledged
The document is very comprehensive but I would like to see a bit more emphasis on staffing structures and training and supervision of staff. Training needs to be provided at varying levels and it would be good to see some funded places for existing staff to, say, HNC level. The corona virus crisis has highlight a lack of respect for the work carried out by care staff, in some areas, and this needs to be born in mind with salary levels being equal to the skill levels. Good management is at the heart of a good service. Quality and standards evaluations of dementia should be carried out regularly by and independent body. Information has been covered with, understandably, an emphasis on I.T. but it is still important to have very visible, paper forms of information distributed widely in public places. The wider public also have an important role to play, especially in a place like Orkney which is largely caring and aware of people's habits. Where there is no	Already covered in strategy	Training and skills are addressed in the strategy.

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direct experience of dementia the local media can help keep the public informed. The need for consistency was highlighted in the report especially in the number of care staff involved with an individual person with dementia. This is understandably difficult to maintain at times and it would be helpful if all people with dementia, if agreeable, had a printed life story with photographs to help with communication.		
On reading the strategy paper it does seem that you are taking a holistic approach to the problem which ensures that the dementia sufferer, the family carer and the health professionals are all definitively tied to concept in order to bring a successful result. The need for regular liaison between these categories seems to be recognised as an essential component of this strategy. At all stages the views of the individual with dementia, their family and the professionals must be pooled for the best outcome.	No change to strategy identified in feedback	Acknowledged
I don’t not have direct experience of a family member suffering from dementia however observing friends who are affected I'm surprised by how little carers and family members seem to know about their role in supporting the affected individuals. Consequently I would have thought the priorities would have included carer and family support to ensure their role provides the best possible care for affected individuals. Possibly more relevant than, for example, 'we want more emphasis on what matters to carers....' Generally the Strategy summary document seems to convey a real intent to drive progress in supporting those affected by dementia - hopefully this will be delivered.	Already incorporated within the strategy	Carer support is covered extensively within the strategy

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On paper these are covering all aspects of dealing with this increasing problem. Sadly we do not live in an ideal world. This strategy requires resources that are well outside the potential of the services existing in Orkney both now and in the foreseeable future the ways things and finances are going. Perhaps a less expansive and more practical approach would be attainable. Many of the services - especially the Allied Health Professionals are over-stretched already. We do not live in an ideal world - we are experiencing this at present - with directives being issued without the resources to implement them. These will only get worse if expectations are too high to start with. Your groups should crawl before they run with fewer aims and services which can be carried out both for dementia sufferers and more importantly their carers. Much better use for example could be made of existing staff e.g. wardens of sheltered housing, day centres and homes. If all the things in this document were able to be implemented it would be great. What about the 'oil fund'? Or is it a 'fig-box' of the islanders' imagination?	Partly incorporated	The commitments reflect what people living with dementia and their carers have identified as priorities in Orkney and a steering group will be created to progress the strategy. Resource and financial aspects (page 30)
Many people on Orkney and elsewhere do not fully understand dementia. Training of carers is important. Some of the language used is difficult to understand for many people. Please use plain English. Please explain Human Rights. We don't have a list of them. By 'assistive technology' what exactly do you mean? Generally speaking I agree and support your efforts and welcome a more enlightened attitude to dementia. On the island where I live about one third of the population is over 65,	Not incorporated	Acknowledged and feedback sought. We asked two separate members of the community to feed back on the need for a glossary. Indication was that this was not necessary in view of the summary document.

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
and from time to time we get cases of dementia. Should I ever get it I wish to remain in my home here in familiar surroundings until I die. Thank you for your efforts to make people's old age as pleasant as possible.		
Like so many of OIC draft proposals it all sounds very good - too good to be true. This document again sounds so good on paper - please don't let it become another failure.	No change to strategy identified in feedback	Acknowledged
More financial support/vouchers for items such as incontinence supplies. Sounds good but would like to see a list of partner organisations (local) and 'roadmap' of process from intake through to regular support routines.	Already incorporated in the strategy	Incontinence supplies are already available on prescription. The value of partnership working is reflected throughout the strategy. The integrated care pathway detailed in the strategy set out process throughout the experience of dementia.
Your priorities appear to be ok. There is nothing stating how this support is to be funded. Is there a budget already – what is it and will it be at least doubled to cope with the expected needs in the future? What levels of staff will be required to provide this support – also the costs of staff pay and training. Are there enough people in the local community to train and have availability to support this expected increase in demand? Where do carers start!! What/where will people and their carers know they can go as a first port of call. As an unpaid carer at the moment, in conjunction with my brother, we care for our Mother. The only	Partly incorporated	Finance/resource (page 30) Carers and post diagnostic support elements addressed in the strategy. The strategy was written pre Covid-19 and a section has been added to address this (Pages 7 & 30).

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
person we have seen since Mum's diagnosis (at that time it was Sandra Newlands wo was excellent) is carer from Crossroads. My brother (who still works) has no access to any other support than me as there is nothing available after work hours. Also all this was before Covid 19 – what will need to be added to the strategy to provide support at a time such as this. Aware of someone requiring assessment and support and everything cancelled due to the pandemic. So no support whatsoever for that family. Also who shouts loudest appears to get the most help.		
General comments We feel that the ethos of the strategy is great but, from an OT point of view, there needs to be more funding behind it so that dedicated OT time can be committed. We are very keen to roll out HBMR and to be more actively involved in early interventions. We need a clear pathway and recognition of the need to establish an Occupational Therapist with a dedicated dementia remit to enable more effective joint working as part of the wider MDT. The emphasis on early diagnosis so that the wider support team can react effectively so that HBMR and/or other OT interventions etc can	Partly incorporated	Name of team and wording changed accordingly (Pages 19, 20 & 34). Resources (page 30)

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
be put in place at an early stage would be great. Working closely with the Dementia support worker, building relationships and making OT interventions part of an integrated pathway would be fantastic but, additional OT capacity is required if we want to make this a reality. The information on what the Service aims to be sounds good but also needs to have the funding to employ and train the staff and carers. Staff have expressed some concerns about capacity to commit to developments as well as to the present services that we already have. More specific comments - from main document Page 11 and Page 19 Intermediate Care team needs changed to Intermediate Community Therapy Team Page 19 Care & Repair cannot access grants without OT recommendation so text is misleading. Suggest instead – "The Occupational Therapy Service can refer on to local housing providers or Care and Repair where assistance is required with disability adaptations." Page 23 AHPs are key to maintaining optimum quality of life for people with long term conditions, including dementia. They provide a range of support and therapies to help people to live as independently and as well as possible in their own communities. They are currently developing open access and therapy sessions to people through the Hub at Age Scotland and will build on these opportunities. We don't think we take part in this - is this something dietetics/SALT/physio are		

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
doing? We need to continue to support this access within this community setting to ensure that people can access the right support at the right time in the right place. Comments from Summary document Allied Health Professionals (e.g. occupational therapists, dietitians) will be available to assist you in finding solutions and help you increase your independence and resilience. Allied Health Professionals (e.g. occupational therapists, dietitians) will be available to assist you in finding solutions and help you increase your independence and resilience and that of the person you are caring for. Whilst this is not incorrect the capacity for specialist Occupational Therapy intervention is very limited. We do not want to raise expectations that we cannot fulfil.		
I found the strategy very easy to read and without too much jargon, which was so refreshing. I think the aims are very clear and don't feel I have much more to comment on. It is a shame that we aren't able to do HBMR just now. I am also sad that our student placements were cancelled. We have two more coming this year so it may be that we ask you if you have any suitable projects they could carry out. It would be appropriate for the AHP and Nursing PEL to support the	No change to strategy identified in feedback	Acknowledged

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
educational elements of the strategy so please let us know if and how we may help contribute and support this.		
Thank you for sharing the dementia strategy, it all looks good and sensible. I am interested in the diagnostics pathway I know Richard Brunt has been looking at this within clusters too and there is progress being made. I do feel though we would benefit from a memory consultant / either psychiatry or old age medical consultant to review some of our more complex patients. I agree with Gillian's comments made at the mental health task and finishing group that a general adult psychiatrist is not adequate. We have had some complex cases with interesting dementia pictures in the past and I think visiting specialist would be a great advantage. I also feel that support for Gps and carers is lacking when it comes to managing the agitated and aggressive dementia patients is much needed at the moment all we can do is use medications to sedate or transfer off island. Support for carers - there continues to be a lack of knowledge within families as to where they can find support so I feel the development of a post diagnostic support team is really good news. I am also really interested to hear from you who you think should be delivering the diagnosis of dementia - the psychiatrist / the GP or the someone within the post diagnostic support group? Regarding a dementia friendly Orkney I think it would be good for local cafe's etc to advertise themselves as dementia friendly perhaps have specifically set up tables that are prioritised for people with dementia and the staff training in how to communicate effectively etc	No change to strategy identified in feedback	Acknowledged specific elements identified for improvement and these will be noted and forwarded to the steering group. The MH task and finish group will also provide an avenue to recognise these points as we go forward. They are all in keeping with the ethos of the strategy.

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
Perhaps having a specific day set for folk with dementia a bit like the breast feeding progress within Orkneys cafes ?		
Good to see the dementia strategy document. I think the aims all sound very reasonable. Can I make a few additional suggestions/comments? 1. Post diagnostic support - why should this be time limited at all? We don't stop providing services in other areas after a year or two 2. Respite provision - we must find a way of supporting our carers much more effectively - we need clarity and transparency about costs (I would suggest that respite should be either free for some weeks a year, or subsidised) 3. We need to extend the provision of training and support to care homes and sheltered housing. Care home staff do very well but get little or no ongoing training or support but are readily criticised if anything goes awry. In general our care facilities are understaffed and this puts huge and unreasonable demands on those staff. 4. Similarly to above our care home and sheltered housing residents should have the same access to services as everyone else in or community - AHPs, specialist nursing, mental health services, podiatry etc. We must make our care homes and sheltered housing part of our community, not isolated units. 5. In regard to above, planning of new facilities must consider these things - we could bring the community in - involve schools, have day care facilities, run falls clinics, have lunch clubs, offer care apprenticeships etc. By bringing the community in we break down the stigma and isolation, provide stimulation, treat people as people and potentially inspire the next generation of carers. 6. Why not consider building some sheltered units alongside care homes so that people who have to leave their own homes have the opportunity	No change to strategy identified in feedback	Acknowledged and agreed that the specific elements in this feedback will be noted and forwarded to the steering group once the strategy is agreed. The strategy has been amended to clarify that post diagnostic support should be open ended. (page 18)

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
of a transition between independence and complete dependence - they can live in a supported environment, potentially facilitated by technology, share services from the care home (a lunchtime meal for example, a tuck in or review visit, medication supervision if needed...) and have the option of transition into the home if care needs increase. 7. I agree with the philosophy of supporting people in their own homes as outlines in the document but if this is to be realised we need to support our unpaid carers far better and be able to recruit more paid carers who need stability of contracts, realistic Ts and Cs that recognise their skills, peer support and supervision and a proper career structure. We grotesquely undervalue or carers. I know all of this sounds expensive and ambitious but as you have highlighted in your demographic data, we have major challenges ahead - we need to be ambitious and imaginative - we have not invested remotely enough in community care in the last few years - that has to change. Hope this is of some help.		
I have now had the opportunity to read this in detail. It is a very well written and researched document which lays out the facts in a reasonably easy to read format. I think it could perhaps be shortened by reducing some repetition and this might encourage more people to read it. I have inserted a number of comments and in general this commends the commitments (I can't argue with an y of them), concur with the outcome aims etc however my one big question for all if it how? For me that is the question that needs to answered. Well done and many thanks for sharing and allowing me to comment.	No change to strategy identified in feedback	Acknowledged
Thank you for the opportunity to review NHSO Dementia Strategy. An excellent document which must have taken some time to pull	No change to strategy	Acknowledged

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
together. Well done.	identified in feedback	
Thank you for sharing the Orkney Dementia Strategy, it's something I'm very supportive of. My comment is the use of "we", we will do x, we will ensure y. Whilst the logo of the two statutory bodies are on the front cover does it need confirmation that the "we" is the NHS and Council? I'm also not convinced about including OHAC logo on the front cover as it isn't an enduring statutory body. Happy to support its implementation.	Partly incorporated	Wording altered to ensure that it is clear who 'we' refers to (Page 13). Following discussion it was decided that the OHAC logo would remain on the front cover alongside OIC and NHSO.
The health improvement team considered the strategy and welcomed the opportunity to comment and consideration of how to support the strategy from a public health perspective. • Great to see equal recognition of the needs of people living with dementia and their carers. • Need to consider the impact of COVID on people living with dementia and their carers: - Isolation - Prevention of (Early) diagnosis of dementia and other long term conditions - warning signs missed due to isolation, not seeing GP etc. and other services - Mental health • Need to consider long term potential for increased incidence of modifiable dementia risk factors at population level. In the full version there isn't a commitment 4 - commitment 3 is followed by commitment 5. We also felt that the summary and the full	Partly incorporated	The strategy was written pre Covid-19 and a section has been added to address this (Pages 7 & 30). Following discussion, it was determined that the commitments did not match up between the full document and the summary document. This was due to wording being altered to make the summary paper more accessible and will not be changed at this point.

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
version were to some extent contradictory. For example the summary states 'In the strategy we make 9 commitments to people with dementia' and 'In the strategy we make 9 commitments to unpaid carers of people with dementia' whilst in the full version there are 11 commitments (or 10 if there is no commitment 4) and they aren't the same as the 9 commitments detailed in the summary version. THIS CAME IN A SECOND EMAIL: Thanks the other area of particular interest was the Dementia friendly Orkney in terms of a place based initiative. Obviously as a public health team we are very supportive but due to COVID-19 are limited in our capacity to contribute to some areas that we would normally wish to support more so apols for that.		
An exercise was undertaken with two independent members of the community to gauge necessity to change language in the full draft document or to include a glossary. The community members indicated it was a clear document and liked the fact it was aspirational.	No change to strategy identified in feedback	Feedback provided no indication that a glossary was needed. The summary document provides an easy read alternative.
Changes to reflect that the IJB can not commit to additional costs Change from unpaid carers to their carers	Incorporated Incorporated	(Pages - 4,5,12,20,25) Wording changed (Page 4)

Feedback Received (copied verbatim)	Change incorporated / Not Incorporated	Comments
Could this please be clearer that the final chapter was not COVID-19, as y understanding is that no-one with dementia has died of COVID-19 in Orkney to date?	Change incorporated	Wording altered to reflect perspective of comment (Page 7)
Could 'Planning for the future: the IJB's Strategic Plan feature here please? Can this please link to our and core values of being person-centre, caring, enabling and empowering, and link to our priorities including 'revisiting models of care and support', mental health and valuing and supporting unpaid carers	Change incorporated	Plan already detailed in strategy – values added and plan included in appendix 1
Could the IJB Strategic Plan also feature in Appendix 1 please.	Incorporated	Appendix 1 amended
Could this possibly occupy a page of its own, lengthwise, so we can see what it says? Such a pity not to have something so informative not quite big enough.(Models of dementia care)	Partially incorporated	Models enlarged (Page 19)
Can we say 'within the resources available' here at the end of this sentence? We can't commit right now to growth, but we need to be aspirational and look to funding opportunities as they arise.	Incorporated	Wording changed
Maureen may want to add a bit of detail in here?	Not incorporated	Opportunity to comment previously provided and no amendment advised
Grammatical changes have been made without change to context.		

Orkney Dementia Strategy 2020 -2025

Draft 3

Version	Lead /Author	Changes made
Draft 1 (2 March 2020) Draft 2 (31August 2020) Draft 3 (5/9/2020)	Gillian Coghill, Alzheimer Scotland Clinical Nurse Specialist. Contact: gilliancoghill@nhs.net	Draft 2 Draft 3
Initial Circulation/review.		
Sally Shaw, Executive Director, Orkney Health and Care.		
Gillian Skuse, Dementia Orkney and Age Scotland Orkney.		
Arlene Crocket and Anna Buchanan, Life Changes Trust.		
Approval		
Approved by IJB	24.3.20	For consultation
Submitted to IJB	30.9.20	For adoption
Consultation		
In line with OHAC Communication and Engagement Policy (2018)		
Review by Gillian Morrison (Interim Chief Officer, OHAC)	Changes recorded in Consultation Report	4/9/2020
Adoption approved by:	Date:	
Final document to be reviewed:		

Contents

Foreword

People living with dementia and unpaid carers agreed that they have common goals for this strategy and requested that a combined foreword be included to reflect this unity.

People living with dementia and unpaid carers:

A diagnosis of dementia can be very hard to accept and has an impact, not just on the person living with dementia but on those closest to them. Acceptance can be difficult, and individuals need to be supported in this area. It is our hope that the Orkney Dementia Strategy will help to support people living with dementia, their loved ones and carers, and that the support provided will be truly person-centred. Resources need to be offered which address the big issues such as innovative solutions to respite, care home provision and services that help people live independently in their own homes for as long as possible. We support a strategy that is realistic, practical and implemented in a timely manner, appropriate to our local context. It is crucial that people with appropriate skills are recruited to support those living with dementia and that future needs are planned for.

As carers and people living with dementia, we welcome this strategy and look forward to seeing it implemented across Orkney.

Interim Chief Officer, Orkney Health and Care, Gillian Morrison:

I am delighted to share this foreword with people living with dementia and their carers. The Orkney Dementia Strategy is a significant document which outlines the proposed collaborative approach to dementia support and services in Orkney.

In Orkney there are 474 people currently estimated to be living with dementia. This is projected to almost double by 2041. These demographics demonstrate that we must facilitate change to build capacity and resilience to ensure a sustainable future for dementia in Orkney.

Sally Shaw (Chief Officer) and colleagues have worked extensively with stakeholders to ensure that this strategy reflects all perspectives but most importantly we have listened to the people at the heart of the experience – people living with dementia and their carers. This grass roots approach is essential to ensure that our resources are aligned to the outcomes that make a real difference to the lived experience.

Development of the strategy has reinforced the high value placed on existing supports and services which we will continue to learn from, value and build on.

Moving forward, we will use the resources available to us to strive to achieve the broad range of identified outcomes to support a structured, person centred pathway for people with dementia so that they feel valued, informed, involved and supported at every stage of their condition.

The strategy reinforces that we need to do some things differently and to find ways to overcome the challenges we face including limited resources. However, there is a

great deal of energy and dynamism to do our best, nurturing a whole systems approach which values the contribution and potential of many disciplines, individuals and groups. We will continue to work together with people with dementia, unpaid carers and our other partners to find innovative solutions through open, honest and transparent dialogue to ensure that we develop high quality, grass roots informed supports and services.

Purpose

The purpose of the Orkney Dementia Strategy 2020-2025 is to set out a renewed vision for dementia care and support in Orkney. It draws on a wide range of evidence and inter-related policies, including Scotland's Third National Dementia Strategy. Most importantly of all, it draws on the experiences and views of people living in Orkney whose lives are affected by dementia. Some of these people are living with dementia and others are unpaid carers, often family, supporting people living with dementia.

What is dementia?

Dementia is a syndrome which can affect memory, thinking, orientation, comprehension, calculation, learning, language, emotional expression, behaviour, motivation and judgement. Consciousness is not affected.

Dementia results from a variety of diseases and injuries that affect the brain, such as Alzheimer's disease or stroke. Although dementia mainly affects older people, it is not a normal part of ageing and can affect younger people. It is one of the major causes of disability among older people worldwide. It can be overwhelming, not only for the people who have it, but also for unpaid carers and families.

Older people are also at an increased risk of developing neurological disorders, such as Parkinson's disease, strokes, delirium, and multiple physical health issues and disability. Therefore, it is essential to provide whole systems and joined up personalised support which recognises the complexities and interactions between multiple conditions.

Dementia is a major cause of disability in people aged 60 and over. It contributes 11.2% of all years lived with disability, which is more than stroke (9%), musculoskeletal disorders (9.8%), cardiovascular disease (5%) and all forms of cancer (2.4%)[1].

There is often a lack of awareness and understanding of dementia, resulting in stigmatisation, inequality and barriers to diagnosis and care. The impact of dementia on carers, family and wider society can be physical, psychological, social and economic[2].

We need to adopt a social model of dementia as a disability, recognising the challenges people with dementia face and affording the same priority to reduce impact, as we do for physical disabilities.

Dementia is one of the foremost public health challenges worldwide. There is currently no cure for dementia. However, there are treatments, therapies and supports which are effective in maintaining skills and independence and contributing positively to the experiences of people with dementia and unpaid carers.

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[1]The Dementia Epidemic - Alzheimer Scotland, 2007
https://www.alzscot.org/sites/default/files/images/0000/1945/Dementia_epidemic_web.pdf
[2] World Health Organisation – Dementia /- a public health priority.
https://www.who.int/mental_health/publications/dementia_report_2012/en/https://www.who.int/mental_health/publications/dementia_report_2012/en/- a public health priority

Dementia in the context of the COVID-19 Pandemic

Whilst many people will have experienced detriment from the pandemic we must recognise the compounded impact for those affected by dementia. Emerging research highlights that the pandemic has been especially dangerous for people already living with conditions such as heart disease, respiratory problems and diabetes for example. But statistics show that the most common pre-existing condition among those who died from COVID-19 was not a physical ailment at all, it was dementia[3]. Yet people with dementia were not afforded the protection of being included in the shielded group. In the early weeks of the pandemic it was recognised that there were a higher number of deaths than usual. Statistics show that people living with dementia were twice as likely to die than those with cancer[4]. Research, at this stage can only be in its infancy and further studies are required to fully understand why people with dementia have been so devastatingly affected.

Carers have highlighted the profound impact of the sudden expansion of their roles due to reduced access to services and support. People living with dementia and carers tell us that this support is their life line.

There has been widespread concern about the separation from loved ones during the pandemic. This has also had greater impact for some people with dementia who have difficulty in understanding or remembering information about why their families are not with them, why they are being encouraged to physically distance or why staff are wearing masks. Digital solutions have provided a positive mechanism for communication but we need to recognise that this can also be very difficult or even distressing for some people with dementia. Paid carers have worked hard to support communication where possible.

For some people there was concern that due to separation, recognition of loved ones will have gone, for others this was their final chapter which, they lived and died not understanding why their loved ones were not present. Their deaths were not directly linked to COVID-19.These recent examples reinforce the need for dementia to be considered specifically in relation to human rights and risks. Equality only works when we consider the specific adjustments to achieve true equity.

There has been much effort towards reducing some of the negative impacts and this should be commended. We have an opportunity to support and build on some of the innovative practice, excellent community resilience and spirit evident during COVID-19 times. We need to capture the learning from this as we go forward, with a recognition that things will be different and some initiatives may take longer than originally anticipated.

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[3] Kuo et al (2020)' https://www.economist.com/international/2020/08/03/for-those-affected-by-dementia-the-pandemic-has-been-especially-grim [accessed 28/5/2020]

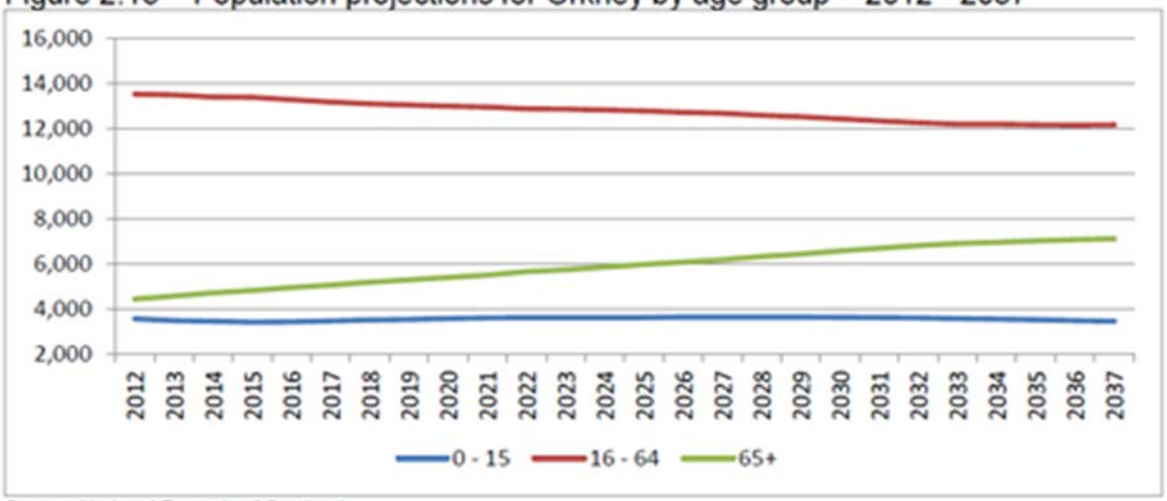
[4] National Records of Scotland (2020a) Deaths Involving Coronavirus (COVID-19) in Scotland Week 16. Available at: https://www.nrscotland.gov.uk/files//statistics/covid19/covid-deaths-report-week-16.pdf [accessed on 28/05/2020]

Demographics and national and local context

Orkney has around 70 islands, populated by around 22,000 people. Our overall population is projected to increase by 5.5% by 2037 with the largest increase in the age 75+ population. It is projected that, by 2037, the shift in the following age ranges will be as follows:

- 0 -15 will decrease by 3%
- 16 - 64 will decrease by 10%.
- 65 - 74 will increase by 20%.
- 75+ will increase by 116%.

Figure 2.13 – Population projections for Orkney by age group – 2012 - 2037



Source: National Records of Scotland

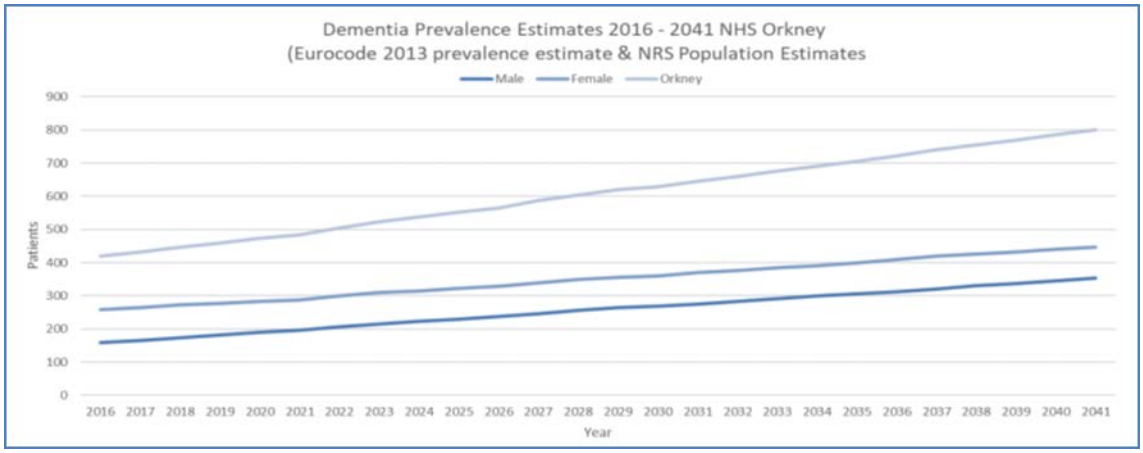
This increased longevity is something to be celebrated. Older people continue to make a significantly positive contribution to our communities and those who are unpaid carers provide many thousands of hours of care. They must be valued as equal partners and experts in their own right. The economic value of the contribution made by unpaid carers in the UK is £132bn a year[5].

There is currently no robust data to identify the numbers of people who provide unpaid care for people with dementia in Orkney. Although Orkney compares favourably with national statistics on support for carers, there is scope for improvement as only 49% say they feel supported to continue their role[6].

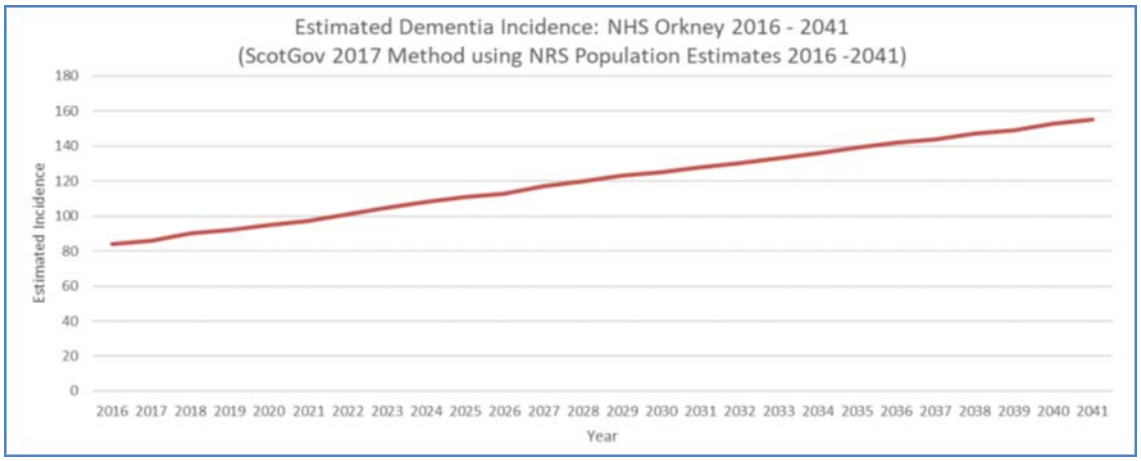
A projected increase in numbers of people with dementia presents a range of challenges, not only for the people who develop dementia, and their families and carers, but also for the statutory and voluntary services that provide care and support. Unless more cost-effective ways of providing support can be developed, there will be a need for a significant increase in expenditure. There are no easy solutions and transformation will take time and commitment. We need to develop innovative ways to build capacity and resilience within financial constraints.

[5] Carers Trust facts and figures – see https://carers.org/key-facts-about-carers-and-people-they-care
[6] Orkney Islands Council Annual Performance Plan 2018/19- https://www.orkney.gov.uk/Files/OHAC/IJB/IJB_performance_report_2018_2019.pdf

If the estimated prevalence rates remain similar, the number of people living with dementia in Orkney is set to almost double between 2016 and 2041, increasing from 419 to 800 people.



If the estimated incidence rates remain the same, the number of patients newly diagnosed per year is estimated to increase by 84% by 2041.



We need to consider these long-term projections cautiously as further work is needed to fully understand the variables of health promotion and healthy living in a population which is living longer.

Orkney has a higher than average proportion of older people[7] and this population is increasing faster than the national average. A strategic needs assessment was commissioned by Orkney Health and Care in 2016 which highlights some of the needs associated with an ageing population, such as increasing numbers of people with long term conditions and complex needs. In addition, significant numbers of our working age population are leaving the islands, and so fewer people are available to provide the care and support required.

Remote and Rural

Some of our most remote islands have the highest percentage of older people which brings unique challenges in providing equitable access to care and support. We

[7] Scotland's Census 2011 - https://www.scotlandscensus.gov.uk/census-results

need to explore how we can develop innovative ways to support the most remote and rural communities.

Minority Ethnic Communities

According to the 2011 census, Orkney has a much lower percentage of minority ethnic groups. We need to recognise that it is likely that any minority group could experience increased isolation within small communities and we must ensure that we have the correct supports available to ensure needs are sensitively and appropriately met for everyone.

Younger People Living with Dementia

There is recognition that younger people living with dementia will have some similarities in their need for support but we must also recognise and address their different needs and priorities Links to wider local and national policy

This five-year strategy provides a framework for improvement in support and services for people with a diagnosis of dementia and those who provide unpaid support for them throughout communities in Orkney. It provides the local context and priorities in line with Scotland's National Dementia Strategy 2017-20 and also aligns to the vision, objectives and priorities within Planning for Our Future: 2019/22, NHS Orkney's Local Delivery Plan, and other related organisational strategies[8].

The common themes that emerge across current policy drivers are that service developments should:

- Be designed with and for people, their carers and communities.
- Be safe, effective, and person-centred.
- Involve partnership and whole systems working to improve care.
- Aim to reduce inequalities and promote equality.

The Orkney Dementia Strategy 2020-25 will align with our 2020 vision for health and care in Scotland, which works to enable all people, including those with dementia, to live well for longer at home or in a homely setting and core values of being person-centre, caring, enabling and empowering, and link to our priorities including 'revisiting models of care and support', mental health and valuing and supporting unpaid carers as set out in Planning Our Future (OHAC Strategic Plan)

In delivering the Strategy, work will align with NHS Orkney's Local Delivery Plan by:

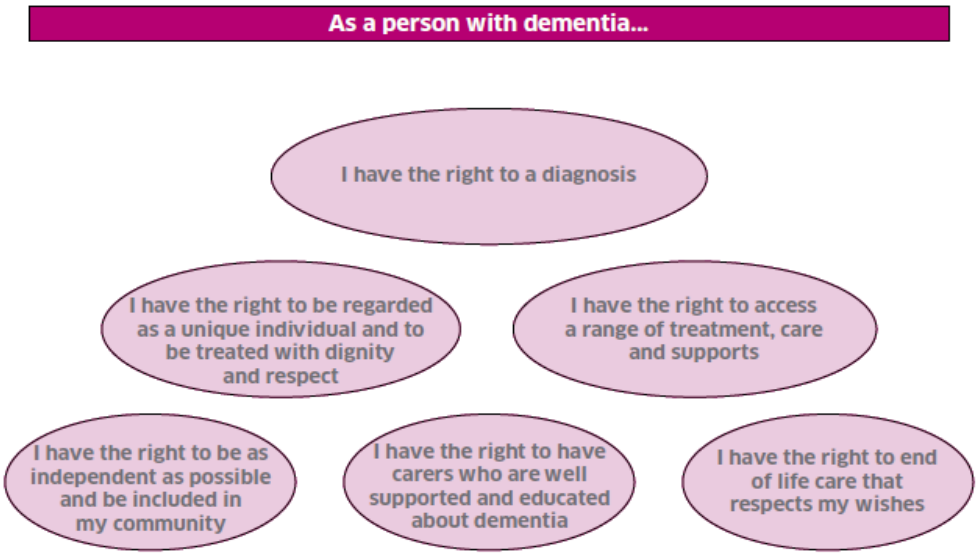
- Improving the delivery of safe, effective patient centred care.
- Optimising the health gain for the population through the best use of resources.
- Pioneering innovative ways of working to meet local health needs and reduce inequalities.
- Creating an environment of service excellence and continuous improvement.
- Being trusted at every level of engagement.

[8] Links to all relevant policy strategies or plans are included in Appendix 1.

Scotland has been at the forefront of developments in dementia policy. The Scottish Government made dementia a national priority in 2007, set a national target on improving diagnosis rates in 2008 and published an initial three-year National Dementia Strategy in 2010, underpinned by a rights-based approach to care, treatment and support. We expect a Fourth National Dementia Strategy to be published in 2021.

This strategy aligns to the Standards of Care for Dementia in Scotland and the Promoting Excellence Framework.

Standards of Care for Dementia in Scotland



Current support and services

There are some excellent services currently provided by the statutory, third sector and informal community-based groups across Orkney.

The Hub at Age Scotland Orkney was funded as part of the Dementia Orkney Project by a grant from Life Changes Trust and match funding by Dementia Friendly Orkney. Their aim is to “improve the quality of life for people living with dementia, their carers and families, through projects which promote health and well-being”. This, in particular has been evidenced as being pivotal in helping people to manage their condition, access information, support, sign posting, training and resources. They hold a monthly dementia carers support group which is facilitated jointly between Age Scotland Orkney and NHS Orkney, running simultaneously with meaningful activity sessions for people with dementia. Unpaid carers have reported that this support has been crucial in continuing their caring role positively for longer. This project is funded until August 2020 and further funding is being sought. They also provide a resource centre and awareness sessions for community groups and businesses to support inclusion and dementia friendly communities.

A social return on investment (SROI) has been independently and expertly evaluated for the Dementia Orkney project. The SROI analysis demonstrates that Dementia Orkney activities create positive social value for multiple stakeholders which far exceeds the investment with a delivery of £5.14 for every £1 invested. Support for continuation of this positively evaluated resource is vital in view of the robust evidence of positive return on financial investment, alongside the positive impact for people with dementia and unpaid carers.

There are community groups offering highly valued regular dementia specific support through the Young at Heart Cafe and Dementia Friendly Orkney weekly singing sessions which need ongoing support to continue their vital contribution.

Alzheimer Scotland continues to jointly fund the Clinical Nurse Specialist role which has also had positive feedback in relation to accessible support and development of services. Alzheimer Scotland is currently working alongside statutory and voluntary groups in Orkney to enhance community-based support, particularly in remote and rural areas, through a dementia advisor role which they will fully fund.

Cognitive Stimulation Therapy (CST), an evidence based psychological therapy, is implemented in the community through a mix of facilitators from Age Scotland Orkney (ASO), Voluntary Action Orkney (VAO), community volunteers and NHS Orkney. This is a very recent addition to therapeutic support and has only been offered to an initial group. This needs to be offered to everyone with a diagnosis of dementia as a standardised part of post diagnostic support for all people at the mild or moderate stage of their dementia.

Voluntary organisations provide generic support for carers and people with dementia such as Crossroads Care Orkney, Age Scotland Orkney, Voluntary Action Orkney, Citizen's Advice Bureau, Advocacy Orkney, Red Cross, churches and Dial-a-Bus amongst others. These are excellent examples of positive support in the wider context. Carers have particularly identified Crossroads Care Orkney' carer support as a highly valued service.

Life Changes Trust has awarded funding through a small grants programme for local organisations across Orkney. This approach to funding will strengthen confidence amongst local groups who are already providing, or are looking to provide, support to people affected by dementia in their community.

Orkney Health and Care is the main statutory provider of support. Many of its services have been well evidenced as positive in providing support, including mental health nurses, day care, extra care housing, care homes, care at home, Intermediate Care Team and GPs.

Other statutory services, including Orkney Islands Council, NHS Orkney, Police Scotland and Scottish Fire and Rescue Services, work together with a wide range of other partner agencies, to provide a range of person-centred services and interventions to support individuals to remain safely, within their own homes and communities.

Our Vision

The Orkney Dementia Strategy 2020-25 aligns to our vision of a rights-based integrated health and care system.

NHS Orkney, Orkney Islands Council and Orkney Health and Care (We) are committed to adopting the principles of Scotland's Third National Dementia Strategy 2017-2020 whilst ensuring that local priorities are given prominence. This Strategy is a five-year document that provides a framework for partnership working and scope for future development based on robust evaluation.

This strategy recognises the complexities and individual experience of dementia, and focuses on strength-based support, enablement, support to live well for longer, early intervention and development of personal and community resilience. This Strategy envisages access to the right support, at the right time, in the right place throughout the entire dementia journey, with a focus on supported self-management and ensuring community-based health treatment wherever possible.

Development of services

Orkney Health and Care and NHS Orkney's vision is to work in close partnership with individuals, carers, communities, statutory and voluntary sector providers. We fully value grassroots, community-led approaches and will build upon existing services, to improve and develop additional support through effective and efficient use of all resources available in Orkney.

When developing services, we will focus on:

Enabling individuals and communities: ensuring the right support is provided at the right time, in the right place, for the right reason. We need to ensure that it is easy for all to navigate through what currently may appear to be a complex health and social care system. We need to support dementia enabled and dementia friendly communities.

Prevention and Early intervention: it is recognised that investment in prevention and early intervention initiatives helps people to understand and manage their condition for longer, assists avoidance of crisis, and is likely to achieve improved outcomes for people with dementia and people who provide unpaid support. Where a crisis occurs, we will support people locally where possible.

Resilience: enabling individuals and communities to develop mechanisms to cope positively where possible and to manage the impacts of their health and social care needs is essential, in order to achieve a sustainable demand for statutory services.

What people in Orkney have said

This Strategy reflects the needs and aspirations of people living with dementia and unpaid carers in Orkney. It recognises learning from organisations that support and care for people with dementia, and it reflects national dialogue and priorities.

Orkney has unique opportunities and challenges and it is these that must be prioritised and addressed. This Strategy is built on good engagement, diverse dialogue and learning from the pockets of excellent practice which currently exist within the voluntary, health and social care sectors. Our engagement prior to writing this Strategy has also highlighted areas for development. Engagement has involved people with dementia, carers, volunteers and professionals from all relevant areas of health, social care, third sector and community-based supports and services. This has contributed positively to inform strategic and operational information, needs and aspirations.

We consulted widely to ensure that services are designed with and for people with dementia and unpaid carers. Development of this Strategy has been completed in partnership with people with dementia, unpaid carers, and people from statutory and third sector organisations.

We listened to the views of local individuals and groups, gathering local and national information, research and statistics. Initial feedback was sought from a short-life Focus Group which represented a wide range of stakeholders. A diagrammatic representation of findings was produced and can be seen at Appendix 2.

Questionnaires were issued to people with a diagnosis of dementia and unpaid carers, voluntary and statutory groups and services, asking them for views on what is currently working well and areas for development. This has provided additional learning to support the development of services over the next 5 years.

Feedback from people living with dementia and those who support them

Question 1 – What services or supports have been helpful or positive?

A range of positive services and supports were identified across both professional and voluntary bodies e.g. Age Scotland Orkney, Crossroads Care Orkney, Care and Repair, NHS Orkney, Orkney Islands Council as well as localised services specific to the outer islands. Being provided with information relating to their diagnosis e.g. financial concerns was considered very helpful as were local media sources in advertising events.

Question 2 – What was good about them?

The prevailing thread of the feedback was that the services identified as positive take time to talk to people and offer emotional support as well as practical support. The specialist knowledge base in Orkney was acknowledged as well as the value in being part of groups that allow people to access peer support.

Question 3 – What could improve experiences and well-being for people with dementia and those who support them?

The need for greater partnership working was identified so people don't have to attend multiple appointments to provide the same information. Better respite solutions are needed as well as consistent support to the outer islands.

Feedback from professionals

Question 1 – What aspects of support services are working well for people with dementia and those who support them in Orkney?

Positive services were predominantly identified as sitting in the voluntary sector e.g. Age Scotland Orkney and Dementia Friendly Orkney as well as the clinical nurse specialist for dementia. It was felt that there were good opportunities for people to be active in easily accessible areas and that people living with dementia access appropriate support and care. Awareness raising was considered a positive step in Orkney.

Question 2 – How could we improve support and services for people with dementia and people who support them?

The prevailing thread here was that increased staffing levels and better respite solutions are needed across Orkney as well as streamlined support at point of diagnosis and beyond. It was acknowledged that there is a need for awareness raising to continue and that Care Homes need a greater level of support.

See Appendix 3 for more detail of feedback from questionnaires.

The Life Changes Trust[9] supported a three-day collaborative dementia learning event in Orkney in May 2019. This brought together people with dementia, unpaid carers, the statutory and third sectors and the independent sector. We engaged people by holding Screen Memories sessions and a Dance and Jive event. Storytelling sessions supported participants to talk safely and openly about their experiences of living with dementia.

The aim of facilitating storytelling sessions was to produce priorities for discussion at a conference held at The Pickaquoy Centre, which was attended by 109 people including people with dementia and unpaid carers. Five key priorities emerged for people with dementia and unpaid carers:

1. We want better information and support in how to access self-directed support.

2. We want diagnosis to be delivered in a supportive way, in a familiar environment, with better access to post-diagnostic support.

3. We want more emphasis on what matters to carers, both collectively and individually.

4. We want better respite solutions, both planned and reactive.

[9] www.lifechangestrust.org.uk

5. We want more emphasis on dementia friendly and dementia enabled communities.

The information we gleaned from all the activities mentioned has been pivotal in shaping this Strategy from a grass roots perspective, influenced and informed by the people who are experts on what matters most in their lives.

What we will do

Risk reduction

We know that there is no single measure which can prevent dementia and the highest risk factor for developing dementia is age, this is a non-modifiable risk factor, as are genetics. There is, though, evidence that some risk factors for developing some types of dementia can be reduced and so we need to increase the availability of information and support which would help people live longer lives with a reduced risk of some types of dementia. Modifiable risk factors would include physical inactivity, high blood pressure, type 2 diabetes, obesity, smoking, depression, social isolation, low levels of education, and midlife hearing loss[10].

Commitment 1:

We will engage with communities, voluntary and statutory services to increase awareness of modifiable risks associated with dementia and will support people to make positive changes to reduce risks.

Timely diagnosis

Orkney has historically reported lower than national average rates for diagnosis. There are several variables in this which need to be fully understood. There have been improvements in rates steadily in the last three years with a 20% increase recorded between 2016 and 2019. This said there is still a need to improve on this to ensure access to appropriate support and prevent crisis.

We are aware that people often seek diagnosis at an advanced stage of the illness. Earlier diagnosis supports better outcomes in relation to access to therapies, independence, longer stay at home and control over future care and decision making.

Dementia sits within the generic older people's team in the community mental health team which results in fluctuations in available resource. The service has not grown in line with increased demand. We recognise the need to ensure access to specific older age psychiatry to support diagnosis and more complex post diagnostic support within Orkney as well as a review of support and resource within the community mental health team and specific older age psychology. This is strongly borne out in feedback from all stake holders indicating the need to provide a more accessible and supportive community-based service.

[10] Livingstone at al (2017)

Learning Disabilities and Dementia

There is a greatly increased prevalence of dementia in the learning disabilities population. Historically in Orkney there have been lengthy delays and difficulty in accessing baseline assessments, diagnosis and specialist advice. This is an area for development.

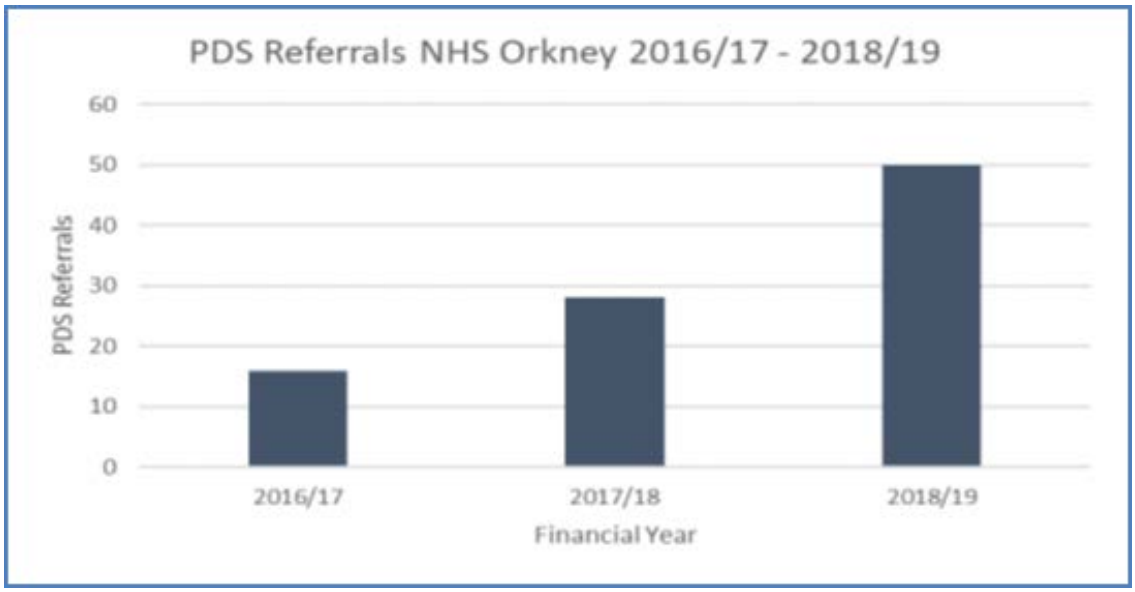
Commitment 2:

We will work collaboratively to improve awareness of the benefit of diagnosis, the process and rate of diagnosis in Orkney. This will involve a multi-agency approach between community groups, voluntary and statutory services and a full review of current assessment and diagnostic service provision.

Post Diagnostic Support

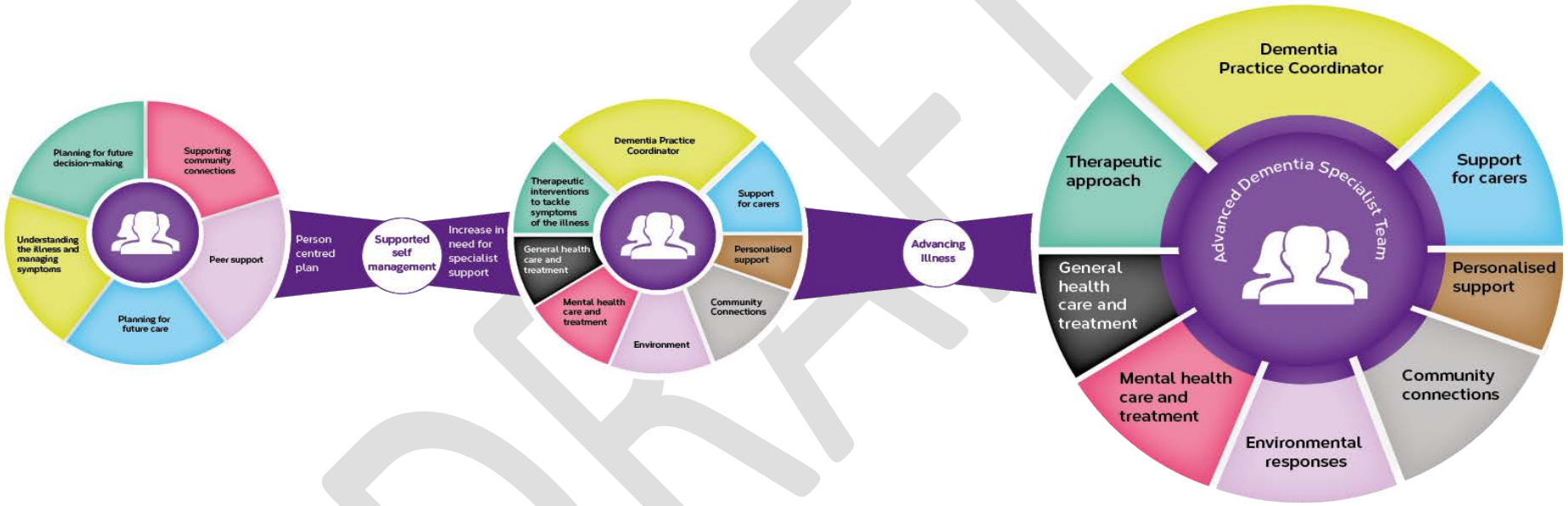
Post-diagnostic support helps people to understand and adjust to their diagnosis and its likely impact – both practically and emotionally. It helps people to plan for future care, including through advanced care planning for the delivery of preferred end of life care. There is also the benefit of support for those close to the person in recognition of their needs and the impact on them. It can contribute to people with dementia living a better quality of life and living as independently as possible and as part of their community for as long as possible.

Over the past three financial years the number of post diagnostic support referrals has increased by 212%; while this is an extreme increase the actual numbers are small. This is likely to be attributable to several variables.



We plan to test a post diagnostic support integrated pathway which will outline best practice in line with the Alzheimer Scotland 5 pillars of community support. We believe that, once tested, this will ensure best practice and equity as well as a mechanism to measure and report performance of quantitative and qualitative measures to inform on successes and areas for development.

Alzheimer Scotland 5 pillar, 8 pillar and advanced practice models



Post diagnostic support will be open ended. Following the initial 5 pillar post diagnostic support period, transition will be facilitated in line with the need for support. This may be self-management or transition to more integrated care through the 8 pillars and advanced models as detailed in the diagram below. This will recognise the diverse needs and complexities at each stage of the illness. We will continue to build on existing support and services, information and advice including access to Self Directed Support which will be standardised as part of the integrated care pathway. All information will continue to be available at the central point of The Hub with a commitment to replicate this valued practice throughout our community.

We have recruited a new post-diagnostic support worker for Orkney who will be located at the Age Scotland Hub in Kirkwall.

as above).

Commitment 3:

We will support a trial of an integrated care pathway for every person newly diagnosed with dementia. We will also review current support and services to facilitate provision of grass roots informed, multi-agency post diagnostic support beyond the minimum period of one year by realigning resources.

Not every person will have access to family support. This should be recognised alongside supporting carers who wish to continue to provide care.

Support for unpaid carers

Carers will be able to access timely support with recognition of the value of their contribution, and the importance of their own needs to support continued well-being.

Unpaid carers have reported that the monthly dementia specific carers support group has been crucial in continuing their caring role positively for longer and we will continue to provide multi-disciplinary support for this.

Carers of people living with dementia will have their needs considered and views listened to, valued and respected. We will establish a carers' forum through the Dementia Carers Group to support implementation of this Strategy. This will help us to understand and prioritise supports that will help carers to feel positive and supported to continue their caring role where this is their wish in any setting, including hospital and care homes. We will support carers through anticipated and actual changes and transitions of care, recognising that this often involves a process of loss and grief.

Generic carers (including dementia) support will continue to be provided through the Orkney Carers Centre as this is highly valued within Orkney.

Commitment 4:

We will fully involve people living with dementia and carers in the delivery and evaluation of this strategy, recognising their vital role as valued experts and equal

partners in care, whilst recognising and supporting their individual needs and well being.

Time off/respite

Access to respite is provided through residential care homes, day centres, carers centre, community groups and using Self Directed Support options. In view of the feedback we need to recognise that things need to be done differently in the future if we wish to support people to live in their own homes for as long as possible. In particular carers have told us that we need to provide reactive and overnight solutions.

Commitment 5:

We will work collaboratively across all sectors to explore options to deliver innovative and flexible respite solutions which are designed with and for people with dementia and unpaid carers.

People living in their own homes or a homely setting

People want to remain in their own homes where possible. Well-designed accessible housing supports:

- Growing older in a person's own community which supports a sense of belonging
- Increases well-being and independence.
- Extends the length of time that people can remain living at home and delays residential care.
- Reduces challenges and accidents – through familiar understandable environments.

The draft Orkney Housing Strategy 2017-2022 will contribute positively to support people with dementia through a range of measures, ensuring appropriate housing:

- Is of the right size and location across all tenures.
- Is built to modern standards and of future-proofed design.
- Mainstreams barrier-free, dementia friendly design.
- Promotes the provision for the use of assistive technologies.

The Disabled Grants and Small Repairs Grants are delivered through Orkney Care and Repair following referral from occupational therapy services.

Care at home is provided by Crossroads Care Orkney, Age Scotland Orkney and the local authority.

The Intermediate Community Therapy Team facilitates earlier discharge and prevention of admission to hospital.

The Mobile Responder Service provides both routine and emergency responder services to people in their own homes.

Telecare Service provides assistive technology to help people to live independently in their own homes. Technology available for people with dementia is greatly increasing and further work needs to be done to identify and source appropriate technological solutions through the Tech Enabled Care approach outlined in the Scottish Digital Health and Care Strategy.

There are extra care housing services in St Margaret's Hope, Westray and Kirkwall which can also provide accommodation and support for people with dementia.

Day care is available in Kirkwall, Westray and Dounby.

There are three care homes in Orkney with designated dementia units. The prevalence of people diagnosed or strongly suspected to have dementia in care homes in Orkney is currently 55%, which is well below the 69% Dementia UK report. This number fluctuates and is skewed by the small numbers involved. In 2016 the percentage was 76%.

We will ensure that information on what is available in the way of assistive technology is easily accessible. This will include technology which can promote health, prevent deterioration, promote independence, provide support, monitor health and well-being, help people to connect with others and support alternatives to residential care.

Commitment 6:

We will continue to support people to live in their own homes wherever possible by continuing to build resilience and capacity in line with demand on current cross sector community based services, as well as exploring new and innovative solutions, including assistive technology.

Hospital Care

There is a strong recognition that hospital admission can have significant adverse effects for people with dementia. Projected population increases mean that the cost of providing hospital-based or greatly increased numbers of care home places in the future is not sustainable and we have a wider policy ambition to shift the balance of care from acute to community-based settings with an emphasis on enabling people to live well in their own homes or in homely settings through building resilience and development of integrated systems.

- 42% of unplanned admissions to hospital for people over 70 have dementia (Sampson, E, 2009).
- 20% of admissions for people with dementia are for preventable conditions (Public Health England, 2014).
- Over a quarter of hospital beds in the UK are currently occupied by people with dementia, up to 40% for those over 75.
- The average stay of a person with dementia is three weeks but it can be much longer if rehabilitation is a problem or there is nowhere suitable to go.

- 47% of people with dementia who go into hospital are physically less well when they leave than when they went in.
- 54% of people with dementia who go into hospital are mentally less well when they leave than when they went in (Alzheimer's Society, 2009).

Over the past three years in Orkney there has been a significant rise in patients over 65 with a diagnosis of dementia being discharged to a care home compared to patients not diagnosed with dementia in the same age group. This has risen from 9.52% to 33.33% between 2016 and 2019. There is also a significant difference between elective and emergency admission discharge destinations with elective patients much more likely to be discharged home.

There will continue to be times when admission to hospital is the best option to access appropriate care and treatment. It is well recognised that hospital can be a challenging and difficult place for people with dementia. There are positive steps which can reduce the negative impact. This strategy supports further initiatives to deliver high quality care for people with dementia in hospital in line with the 10 Dementia Care Actions (Appendix 3) in Hospital and the Care of Older people in Hospital Standards.

Care outwith Orkney

During 2017-18, there were 47 people who required psychiatric assessment and treatment, which resulted in admission to Royal Cornhill Hospital (RCH), Aberdeen. This represented a rise of 47% in admissions outwith Orkney, from the previous year. There is a consistent split of two thirds of admissions being linked to General Psychiatry and the remainder being associated with Old Age Psychiatry.

There is currently no capacity to support people with stress and distress when there is a heightened level of distress or an identified risk to other service users, resulting in outwith Orkney placement, sometimes with no opportunity for repatriation, causing distress to all concerned. Such behaviour in people with dementia is usually temporary and can often be a result of inexperienced responses from staff and families and poor design of facilities and approaches. As such it is likely that, with the right response from carers and families and the right environment, it is possible to minimise distress to a level that can be managed by experienced staff in Orkney.

We need to review services and consider alternatives to support more complex needs to avoid outwith Orkney placement safely where possible and to ensure that all admissions adhere to the principles within The Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003 and care could not safely or effectively be provided in Orkney. This is likely to include a safe place and skilled staff.

We need to support a remodel of care and services to provide optimal health care for people living with dementia which supports care in their own home and locally based wherever possible and which ensures they are discharged from hospital safely and timeously when they are clinically deemed fit for discharge. Integration of health and social care provides the ideal context to make this happen.

We need to understand and deliver improvements to achieve better outcomes for people admitted to hospital. The 10 Care Actions (Appendix 6) provide a framework to support implementation of Standards of Care for Dementia in acute care.

We recognise that development of alternatives will be challenging and will require creative and innovative planning as well as professional learning and development to facilitate alternatives which provide care and support in different ways.

Commitment 7:

We will review support and services to explore options to safely reduce transfers outwith Orkney and, where possible and appropriate, hospital admission will be avoided or reduced. Where hospital is the optimal location for care – adverse effects of admission will be reduced.

A knowledgeable and skilled workforce

There is good recognition of the need to upskill within health and social care settings and for unpaid carers. There have been a number of training programmes delivered successfully but this requires to be more structured with needs mapped to the NHS Education for Scotland/Scottish Social Services Council Promoting Excellence Framework which details the knowledge and skills all health and social services staff should aspire to achieve in relation to the role they play in supporting people with a diagnosis of dementia, and their families, and carers. This will need agreement of organisation commitment and resources.

We are working with national colleagues to set up an Orkney community of practice which will support a platform to share and draw on best practice and ensure better connections and shared resources which are readily available.

We need to undertake a training needs analysis mapped to the Promoting Excellence Framework throughout statutory and voluntary services to ensure people with dementia and carers are supported by people with the appropriate level of knowledge and skill.

We need to provide opportunities for training for unpaid carers.

We need to recognise the unique challenges that people with dementia experience, including palliative and end of life stages, and ensure that our workforce is skilled in providing person centred, high quality support and services.

Commitment 8:

We will undertake a robust cross sector training needs analysis in line with the Promoting Excellence Framework. We will support training in line with results to ensure support for people with dementia is provided by a knowledgeable and skilled workforce.

Positive contribution of Allied Health Professionals (AHPs)

The AHPs are a distinct group of health professionals who apply their specific expertise to improve health, prevent illness, diagnose, treat and rehabilitate people of all ages and conditions working across all sectors and specialties.

The potential contribution of AHPs is set out in Connecting People, Connecting Support 2017-2020 - transforming the allied health professionals' contribution to supporting people living with dementia in Scotland. This aims to increase awareness of AHP-led support available to people living with dementia, offering them informed choice on potential beneficial interventions. This supports better access to support from AHPs from early diagnosis and throughout the illness to enable people to live as well as possible for as long as possible.

AHPs are key to maintaining optimal quality of life for people with long term conditions, including dementia. They provide a range of support and therapies to help people to live as independently and as well as possible in their own communities. They are currently developing open access and therapy sessions to people through the Hub at Age Scotland and will build on these opportunities. We need to continue to support this access within this community setting to ensure that people can access the right support at the right time in the right place.

Participation in a national pilot of home-based memory rehabilitation was funded by the Integrated Care Fund. This has been evidenced positively in other areas and supports self-management, independence and living well with a diagnosis of dementia for longer. The pilot was small but positive and has resulted in two occupational therapy staff undertaking training to implement this on an ongoing basis. There is still work to do around capacity and evaluation but the longer-term aspiration is to be able to offer this therapy to all people who fit the appropriate criteria.

Commitment 9:

We will embed accessible, preventative and reactive allied health support into post diagnostic support to promote independence, optimise strengths, build resilience and prevent unnecessary crises.

Rights, equality and non-discriminatory practice

There is often a lack of awareness and understanding of dementia, which means that people do not get the care they need or are treated unfairly because of their condition. All people in the world are entitled to human rights and these rights are inherent to the dignity of every human. In Orkney we will take a human rights-based approach to dementia that is consistent with:

- Human Rights Act 1998.
- Equality Act 2010.
- United Nations Convention on the Rights of Person with Disabilities.
- United Nations Principles for Older Persons.
- The Charter of Rights for People with Dementia and their Carers in Scotland.

- Promoting Excellence Framework for health and social care staff in Scotland.
- Standards of Care for Dementia in Scotland.
- Health and Social Care Standards, Scotland.

We take seriously our duty to eliminate unlawful discrimination, both direct and indirect, against people with dementia and we will advance equality of opportunity for them.

People with dementia must be afforded equal rights, including dignified and respectful treatment at all times. This includes adherence to requirements and the principles of mental health and incapacity legislation, including capacity assessments, person centred plans and earlier identification of people with palliative care needs, to promote informed advance care planning, linking with the rights based programme for care homes, ensuring dementia is recognised as an equal priority in every relevant work stream, initiative, policy and procedure.

Commitment 10:

We will ensure that every person diagnosed with dementia will experience Rights Based support and services throughout their dementia journey. This will include recognition of dementia as a priority in every relevant work stream, initiative and procedure.

Dementia Friendly Communities

Scotland's strategy for tackling isolation and loneliness – 'A Connected Scotland 2018' – is highly relevant when considering dementia. Age UK reports that:

- Lacking social connections can damage a person's health as much as smoking 15 cigarettes a day.
- Loneliness increases risks of developing certain diseases such as dementia.
- Social isolation increases risk of dying by 29%.
- Half a million people in the UK do not see or speak to anyone 6 days a week.

Evidence shows that providing opportunities for befriending and peer support can be very effective in reducing isolation and loneliness among people with dementia and unpaid carers. Dementia Friendly Communities should have community connections at their heart. Investment in these types of work has been shown to improve wellbeing, reduce loneliness, improve general health and help people to stay healthier, increasing their ability to manage and deal with symptoms.

They also:

- Increase confidence to engage with and venture into the local community.
- Benefit the wider community by challenging stigma through combating discriminatory attitudes towards dementia.
- Lead to direct healthcare savings as individuals, their carers and family feel able and confident to manage their health better, for example:
    - Fewer GP appointments.

- Fewer calls to social services.
- Fewer calls to NHS 111 or 999.
- Fewer admissions to Accident and Emergency or care homes.

There are several dementia specific social opportunities within the Hub, Young at Heart Cafe and Dementia Friendly Orkney Singing. These are evidenced as highly valued through feedback. We need to build on these dementia specific activities and support dementia friendly inclusion in non-dementia specific activities and community groups. There is a need to increase these opportunities in more remote and rural areas.

We are currently working with Alzheimer Scotland to enhance community-based support, particularly in remote and rural areas, through a dementia advisor role which they will fully fund.

Accessibility

We need to ensure that community initiatives support inclusion, access and are understandable to all. This includes adhering to dementia friendly design and signage which will help way finding.

Transport

Dial-a-Bus and the Red Cross provide vital transport services which are highly valued on mainland Orkney. However, there is recognition that further support would be beneficial to help people to continue to be active and more independent within their own communities.

Plans are in place to develop a local transport strategy following publication of the National Transport Strategy. We need to ensure that this recognises, and addresses needs and aspirations for, people with dementia.

Community Led Support

Community Led Support is gathering momentum in Orkney. This will help us to work with communities in a more collaborative and supportive way moving from service led to community led solutions, focusing on what matters to people rather than what is the matter with people.

Awareness to promote dementia friendly communities

Awareness and dementia friends' sessions have received positive feedback from community groups and businesses. We recognise that there is a need to roll out opportunities to all communities within Orkney, including remote and rural areas. The addition of an Alzheimer Scotland Dementia Advisor, in collaboration with the Dementia Orkney Co-ordinator role, would support increased awareness and promotion of dementia friendly communities throughout Orkney.

Commitment 11:

We will support Orkney to become a dementia friendly, inclusive place where people with dementia are valued and welcomed as part of their own community by their own community.

Outcomes

We will work towards, and evaluate against, the following outcomes for people with dementia and unpaid carers

People living with dementia, and unpaid carers of people with dementia, are able to say:

- I have my rights upheld and do not experience inequality, stigma or discrimination.
- Orkney is a dementia friendly, inclusive place where I feel valued and welcomed as part of the community, by my own community.
- I see people working collaboratively to review, redesign, resource and deliver high quality joined up, efficient and effective support and services with and for me.
- I am supported by a skilled, knowledgeable workforce.
- In Orkney there is increased awareness of: modifiable risks for dementia, signs of dementia, benefits of diagnosis and how to access a diagnosis in a community setting.
- As an unpaid carer, I am valued as an expert and equal partner in care and support. I am able to access support in the right way at the right time in the right place. My contribution is recognised as being valuable and my own needs are met, as well as the person I care for.
- I have the opportunity to access high quality, person centred post diagnostic support through all stages of my illness.
- I am able to remain in my own home where possible.
- I am only admitted to hospital where this can't be avoided and I stay there only for as long as necessary. There is a plan in place to get me home as soon as possible.
- I have access to flexible, innovative, planned and reactive respite solutions.
- I find it easy to access advice and information in a way I can understand. I understand what support (including self-directed support) is available to me and there are people available who can guide me clearly to the help I need when I need it.

National Health and Wellbeing Outcomes

The nine National Health and Wellbeing Outcomes are high-level statements of what health and social care partners are attempting to achieve through integration and ultimately through the pursuit of quality improvement across health and social care.

1. People are able to look after and improve their own health and wellbeing and live in good health for longer.

2. People, including those with disabilities or long-term conditions, or who are frail, can live, as far as reasonably practicable, independently and at home or in a homely setting in their community.

3. People who use health and social care services have positive experiences of those services, and have their dignity respected.

4. Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services.

5. Health and social care services contribute to reducing health inequalities.

6. People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and well-being.

7. People using health and social care services are safe from harm.

8. People who work in health and social care services feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide.

9. Resources are used effectively and efficiently in the provision of health and social care services.

Measurement and evaluation

We recognise that this Strategy, whilst vitally important, is only a first step towards achieving improved outcomes for people living with dementia and unpaid carers. It establishes organisational direction and defines what good would look like for people with dementia and unpaid carers in Orkney.

Priorities and actions will be developed into an updated implementation plan which will be the mechanism to move from strategic rhetoric to operational reality. This plan will be agreed and prioritised in line with the outcomes and commitments detailed in this Strategy, guided by a renewed Dementia Steering Group which will be representative of all stakeholders and will support a grass roots approach. Representatives from both people with dementia and unpaid carers will act as a conduit to ensure that feedback and communication are valued both to and from the steering group. The action plan will establish clear, realistic targets for progression of all outcomes and actions, which will be regularly reported through the Programme Boards, to the Integration Joint Board (IJB). The Dementia Steering Group will guide the actions and compile updates and reports. Evaluation of progress of each task will be subject to ongoing evaluation with findings reported annually to the IJB.

A performance management framework will be developed to demonstrate and report on progress. This will include both qualitative and quantitative evaluation of a range of indicators in line with identified outcomes and will be informed by appropriate representation including a grass roots led process.

We are also extremely fortunate to have access to a two-year funded external evaluation from the Life Changes Trust up to the cost of £45,000. This promotes unique recognition of the value of evaluation and will support resources required to ensure that the voices of often marginalised people are included and heard. It also provides a fully independent perspective which is often difficult to achieve in small sized localities. This will provide a framework against which we will be able to

effectively evaluate, inform and direct initiatives which deliver on the priorities identified within this Strategy.

Summary

This Strategy aspires to highlight the importance of risk reduction, early diagnosis and access to high quality post diagnostic support which is dynamic to needs, strengths and identified personal outcomes for people with dementia. It recognises the positive contribution and need to support carers, volunteers and staff and has been developed from a grass roots perspective. It supports Community Led Support and the need for integrated systems, which promote enablement and uphold rights for people with dementia, the building of dementia friendly communities and increasing community capacity to enable people with dementia to live well, without stigma as a valued part of their community and in their own homes when possible.

This Strategy evidences the importance of planning and developing services and supports for and with people living with dementia. It addresses the challenges involved in meeting the needs of the growing number of people who will be diagnosed with dementia, recognising the unique challenges and strengths of the Orkney community. It supports the right care, in the right place at the right time by the right people.

We need to ensure that dementia is prioritised and kept firmly on the agenda in all relevant policies, procedures and plans. Dementia also needs to be kept in public consciousness through local and national awareness raising and media coverage.

There is recognition of the need to do things differently, both in relation to people's experiences and to ensure a sustainable model of support. We need to work together with all relevant people and groups to design and deliver the best care and support we can. This provides us with an opportunity to make changes which support the appropriate level of priority and investment needed for dementia in Orkney.

We must recognise that we will face challenges in a time where statutory services are being asked to make savings, these challenges are not insurmountable barriers. We must use them as a catalyst for positive change through innovative ways of working, engaging with those at the heart of services to support continued grass roots feedback, evaluation, prioritisation and consultation. This is not about trying to do more with less; it is about a collaborative response, which will involve a change in culture and thinking. We need to consider this in context of the wider health and social care system, shifting the emphasis of investment towards proactive, person centred approaches which will not only improve outcomes for people, but will also reduce costs in other parts of the service. This preventative approach is closely aligned with national policy and drivers. It must also be acknowledged that if the status quo remains the model of delivery, significant increased statutory services funding will be required to deal with an increasing number of people reaching crisis without having had the proactive support to delay or prevent crisis.

We have already seen what can be done with determination and positive thinking through the Dementia Orkney Project and the Life Changes Trust small grants project. Let these be an exemplar for moving forward.

Never has there been more need to aspire to improve outcomes for people living with dementia and unpaid carers, than in the recovery from the COVID 19 situation.

Appendices

Appendix 1 – Relevant policy, drivers and legislation

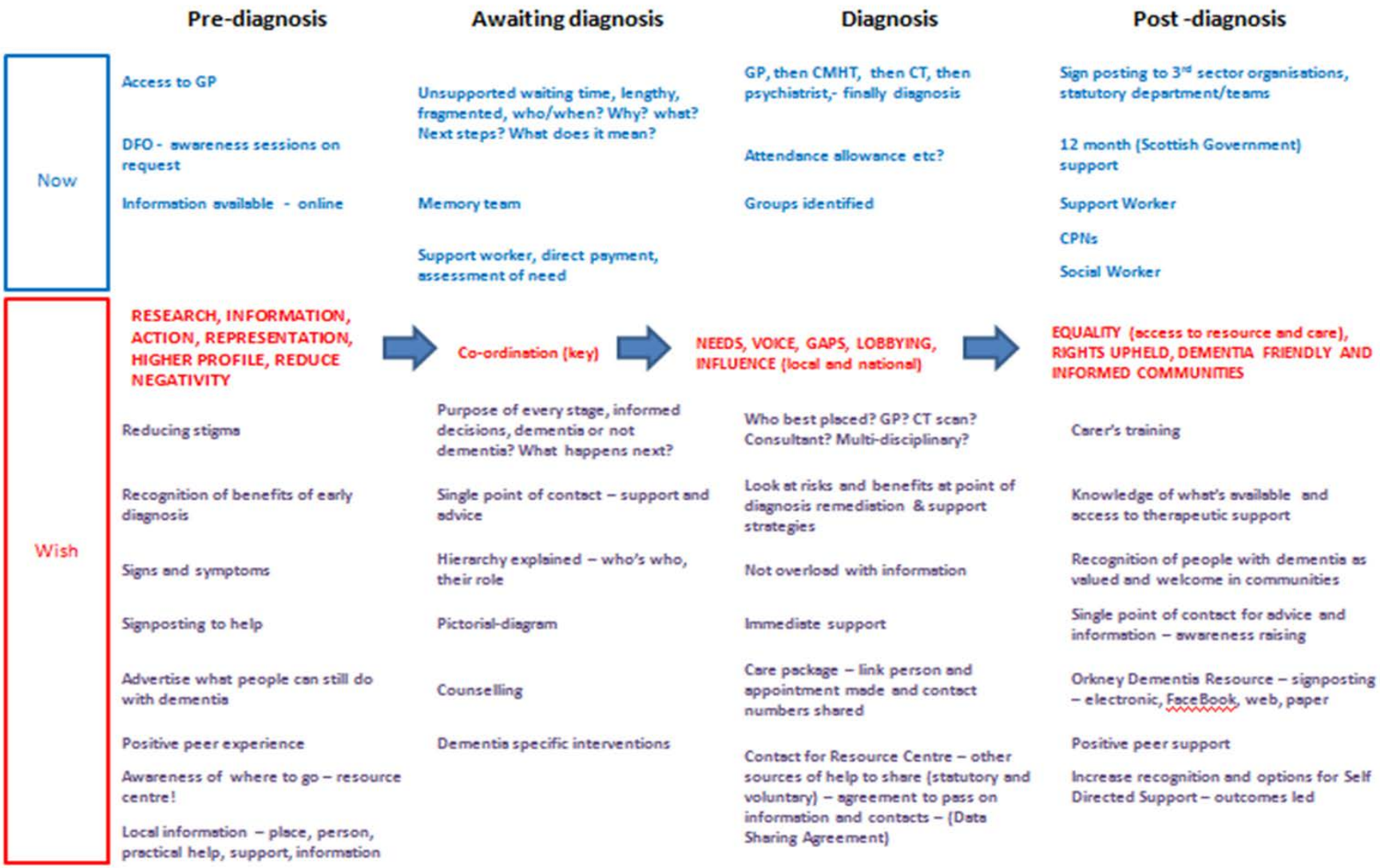
There are several related policies that underpin and reinforce the national and local strategic direction. These include:

- Integration of Health and Social Care and Primary Care Transformation sets out that authorities must plan and deliver well co-ordinated care that is timely and appropriate to people's needs.
- National Clinical Strategy - aims to improve the care of people with life limiting illnesses
- The Carers (Scotland) Act 2016 introduces new rights for unpaid carers and new duties for local councils and the NHS to provide support to carers.
- Self-Directed Support. The aim of the Social Care (Self-directed Support) (Scotland) Act 2013 is to allow people, carers and families to make informed choices about what their social care support is and how it is provided.
- Palliative and End of Life Care Strategic Framework outlines the key actions to be taken that will allow everyone in Scotland to receive services that respond to their individual palliative and end of life care needs, regardless of setting or diagnosis.
- Age, Home and Community: A Strategy for Housing for Scotland's Older People: 2012–2021 recognises the important role of housing support in enabling people to live safely and independently at home for as long as possible.
- A Connected Scotland 2018 – a strategy for tackling social isolation and loneliness and building stronger social connections.
- The Healthcare Quality Strategy for NHS Scotland embraces three quality ambitions and provides a vision for NHS Scotland.
- National Care Standards, describe what everyone can expect from any care service used and focus on the quality of life an individual might experience.
- Promoting Excellence – a Framework for all Health and Social services Staff Working with People with Dementia, their Family and Carers.
- Charter of Rights for People with Dementia and their Carers 2009 – aims to empower people with dementia, those who support them and the community, to ensure their rights are recognised and respected.
- Standards of Care for dementia in Scotland - outlines the rights, quality of care, support and treatment people should receive to stay well, safe and listened to.
- The Scottish Government's 2020 Vision is that by 2020 everyone is able to live longer healthier lives at home, or in a homely setting and, that we will have an integrated health and social care system which supports prevention and self-management, admission to hospital only where necessary, high quality, safe, person centred care.
- Connecting People, Connecting Support – identifies how allied health professionals (AHPs) in Scotland can improve their support for people with

dementia, their families and carers to enable them to have positive, fulfilling and independent lives for as long as possible.

- Scottish Digital Health and Care Strategy. Sets out initiatives to maximise the use of digital health and care solutions in order to reshape and improve services, support person centres care and ultimately to improve outcomes.
- Orkney Mental Health Strategy – sets out strategic outcomes for mental health.
- Planning For Our Future – Integrated Joint Board - Strategic Plan (Orkney Health and Care) 2019-22

Appendix 2 – Pipeline Diagram – Dementia Focus Group



Appendix 3 – Stakeholder questionnaire findings

Feedback from Focus Group and Questionnaire

Orkney Dementia Strategy – People with dementia and those supporting feedback

Question 1 – What services or supports have been helpful or positive?

- Day Centres.
- Transport provision.
- Family support.
- Support from Community Psychiatric Nurse.
- Here2Help.
- Befriending.
- Island trusts.
- Island medical professionals.
- Medical professionals providing information about availability of benefits and discounts.
- Information about Power of Attorney.
- Friends.
- GPs.
- Age Scotland Orkney.
- The Hub.
- Home Care.
- Crossroads Care Orkney.
- Carers' Support Group.
- Care and Repair.
- Social Work.
- Assessment and diagnosis to get access to relevant support.
- Memory café.
- Cognitive Stimulation Therapy group.
- Support from psychiatrist.
- Care homes.
- Mental health nurses.
- Dementia Nurse Specialist.
- Intermediate Community Therapy Team.
- Independent living scheme.
- Health and social care staff.
- Advertising what's on local radio.
- Good and regular post diagnostic support.
- Specialist consultant psychiatrist.

- Someone to phone for isles people.

Question 2 – What was good about them?

- Provides respite.
- Staff having time and patience.
- Sympathetic understanding.
- Tailored to the needs of the people with dementia and their carers.
- Means everything having help.
- Person with dementia enjoys the day centre.
- Age Scotland Orkney staff very friendly, easy to talk to, provided information on available help if and when needed.
- The Hub allows us to enjoy doing things as a family.
- Professionals all very helpful.
- ILSS helped with continuing to provide care at home which ensured the best outcomes.
- Allows people with dementia to live at home for as long as possible.
- Assessment done sympathetically – preserving dignity.
- Creates new and positive friendships.
- Helps to discuss condition and treatment.
- Care home is warm and person with dementia is looked after.
- Specialist knowledge base.
- Consistency with home carers that attend is very important.
- Cared about the person with dementia.
- Having company.
- Having time to go out and attend to things.
- Enjoying freedom.
- Activities enjoyed by person with dementia.
- Respite in own home.
- Peer support – meeting with others in a similar position.
- Staff who listen and are helpful.
- Activities with friendly rivalry – friendship – socialising – chatting, laughter and a cuppa.
- A central point for advice and support.
- Dementia specific Carers group providing a platform for discussing problems/concerns and sharing good practice.
- Cognitive Stimulation Therapy was very therapeutic and enjoyable.
- Having weekly access to a hub has created friendships.
- Nursing knowledge accessible at the hub for advice and support.
- Dementia Friendly Orkney working together creates opportunities.
- Keeping families together longer.

- Consistent people who help.
- Help offered rather than asked for.

Question 3 – What could improve experiences and well-being for people with dementia or those who support them?

- My life would be improved if my anxieties were controlled.
- Reviews need to encourage identification of difficulties and discuss coping strategies.
- Increased contact from relevant professionals.
- Permanent Psychiatrist – consistent.
- More support to outer isles.
- Video links to support for outer isles.
- Increased allocation of advocates.
- Loneliness is a problem for people living alone – possibility of lodgers providing help and company to older people?
- Turnover of named persons is too high – need named person.
- Improved collaborative working between GPs, hospital, dementia professionals and social work.
- Having one trained point of contact.
- Increased activities in care homes and more 1-1 time with person with dementia.
- Quicker diagnosis.
- Home care being able to order repeat prescriptions.
- Support with difficult conversations.
- Anticipatory Care Planning.
- Advocacy role in assessment of needs.
- Better designed care home with increased staffing.
- Reduction in needless medical appointments.
- Consistency with care provision.
- Funded help with domestic tasks to allow carers to concentrate on caring.
- Accommodation provided in exchange for support/company – lodgings type.
- Happy with level of support.
- Better information on what help is available where and how to access that.
- Better communication of results of assessments.
- Quicker access to support after diagnosis.
- Less repetition of testing and assessments – better communication between the people undertaking these assessments.
- Support in home needs to be more available overnight and weekends.
- Recognition that technology has its place but doesn't replace human support.
- Improved value placed on families as being the expert on their loved one when they enter residential care.

- Improved communication with families of people in residential care – families should not feel that the care home has taken ownership of their family member.
- Increased access to help with medication at home.
- Regular reviews.
- Better liaison.
- Bench marking.
- Reviews to include opportunities for highlighting what is difficult.

Orkney Dementia Strategy – professional's feedback

Question 1 – What aspects of support services are working well for people with dementia and those who support them in Orkney?

- The Hub.
- Resources room.
- DFO Singing Group.
- Being active in easily accessible areas.
- Radio advertising what's on.
- The Clinic Nurse Specialist for Dementia.
- Dementia specific groups/ activities.
- Raising awareness.
- Day Centres and respite services.
- Very little support for care homes.
- Safe unit.
- People accessing appropriate support and care e.g. care home.

Question 2 - How could we improve support and services for people with dementia and people who support them?

- Keep raising awareness.
- Improve dementia support – more staff.
- Respond to referrals quicker to optimise service use and support.
- Give family support quicker and offer respite services quicker.
- Increase support at weekends – Day Centres or drop-in sessions.
- More up to date items in the resources room.
- Appointing a Post Diagnostic Support Worker.
- Ensuring the appropriate professional support is allocated at point of diagnosis.
- Easy access calendars of events- leaflets or online and in medical practices (GP, dentists etc).
- More funding directed towards dementia support and services.
- Reduce diagnosis time which in turn will reduce delays in treatment and support.
- Clarity on who should be contacted for professional support.
- More frequent medication reviews.

- Increased access to dementia training.
- Increased staffing.
- Better facilities.
- Regular support to prevent crisis rather than reactive support.
- Regular reviews.
- More sensory activity items in care homes.
- More meaningful activities.
- Better support and liaison from Community Mental Health Team for care homes.
- Better communication and support for people who need special diets in care homes.
- Improved internal communication by care home staff.
- Support form GPs who understand dementia.
- Wider publicity.
- Drop in/ reactive support.

Appendix 4 – Storytelling Report May 2019

Orkney Final Storytelling Report.d

Appendix 5 Commitments mapped to outcomes. People living with a diagnosis of dementia	Outcomes										
	PWD1	PWD2	PWD3	PWD4	PWD5	PWD6	PWD7	PWD8	PWD 9	PWD 10	PWD 11
1. We will engage with communities, voluntary and statutory services to increase awareness of modifiable risks associated with dementia and will support people to make positive changes to reduce risks					✓						
2.We will work collaboratively to improve awareness of the benefit of diagnosis, the process and rate of diagnosis in Orkney. This will involve a multi-agency approach between community groups, voluntary and statutory services and a full review of current assessment and diagnostic service provision.			✓		✓						
3.We will support a trial of an integrated care pathway for every person diagnosed with dementia. We will also review current support and services to facilitate provision of grass roots informed, multi-agency post diagnostic support beyond the minimum period of one year.			✓				✓				✓
4.We will fully involve carers in the delivery of this strategy, recognising their vital role as valued experts and equal partners in care, whilst recognising and supporting their individual needs and wellbeing.						✓					
5.We will work collaboratively across all sectors to explore options to deliver innovative and flexible respite solutions which are designed with and for people with dementia and unpaid carers.										✓	
6.We will continue to support people to live in their own homes wherever possible by continuing to build resilience and capacity in line with demand on current cross sector community based services, as well as exploring and resourcing new and innovative solutions, including assistive technology.								✓			
7.We will review support and services to explore options to safely reduce off island transfers and where possible and appropriate hospital admission will be avoided or reduced. Where hospital is the optimum location for care – adverse effects of admission will be reduced.									✓		
8.We will undertake a robust cross sector training needs analysis in line with the Promoting Excellence Framework. We will support training in line with results to ensure support for people with dementia is provided by a knowledgeable and skilled workforce.				✓							✓
9.We will embed accessible, preventative and reactive allied health support into post diagnostic support to promote independence, optimise strengths, build resilience and prevent unnecessary crises.			✓				✓				
10.We will ensure that every person diagnosed with dementia will experience right based support and services throughout their dementia journey. This will include recognition of dementia as a priority in every relevant work stream, initiative and procedure.			✓							✓	
11.We will support Orkney to become a dementia friendly, inclusive place where people with dementia are valued and welcomed as part of their own community by their own community.		✓									

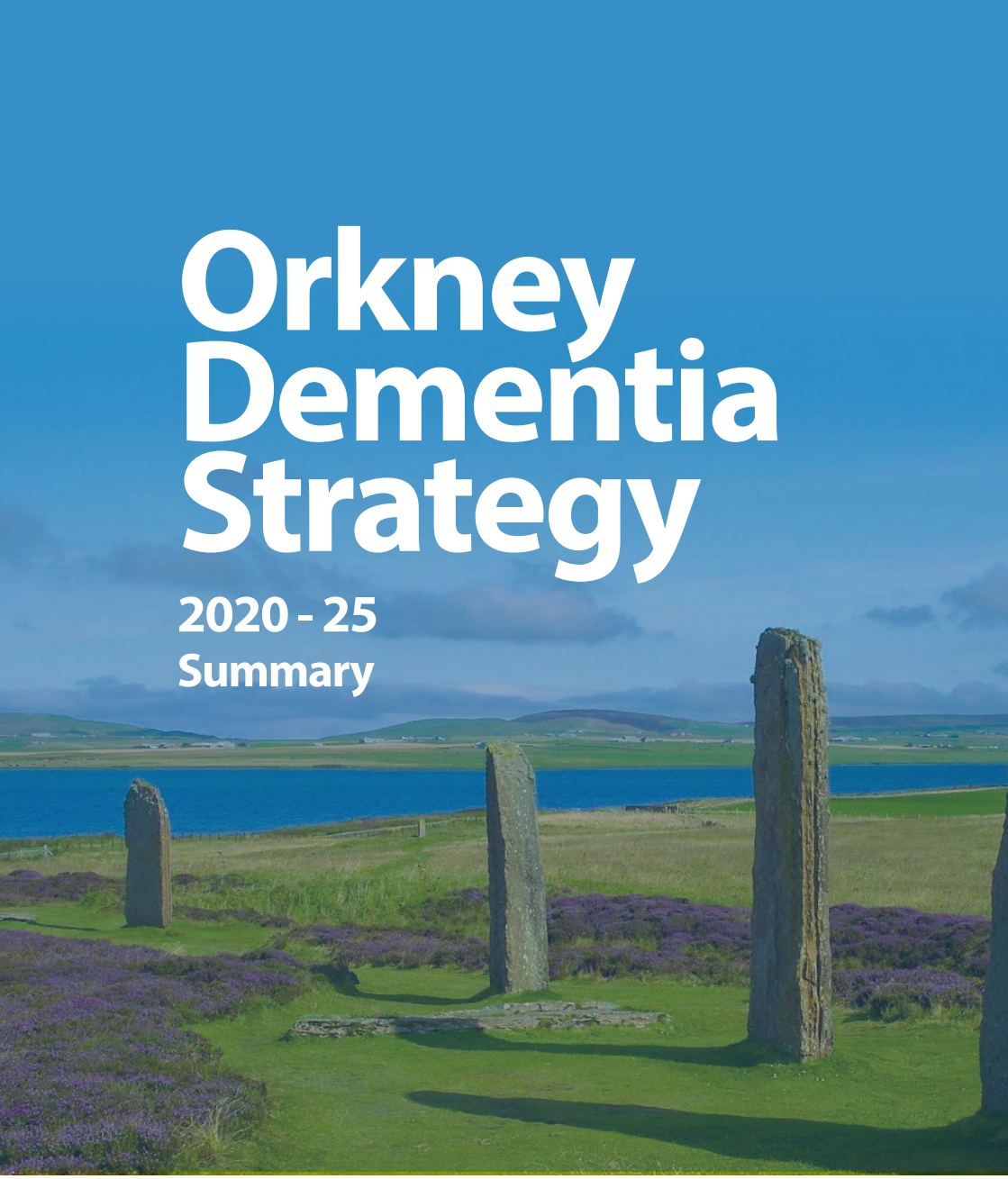
Unpaid Carers (UPC)	Outcomes										
	UPC 1	UPC 2	UPC 3	UPC 4	UPC 5	UPC 6	UPC 7	UPC 8	UPC 9	UPC 10	UPC 11
1. We will engage with communities, voluntary and statutory services to increase awareness of modifiable risks associated with dementia and will support people to make positive changes to reduce risks.					✓						
2.We will work collaboratively to improve awareness of the benefit of diagnosis, the process and rate of diagnosis in Orkney. This will involve a multi-agency approach between community groups, voluntary and statutory services and a full review of current assessment and diagnostic service provision.			✓		✓						
3.We will support a trial of an integrated care pathway for every person diagnosed with dementia. We will also review current support and services to facilitate provision of grass roots informed, multi-agency post diagnostic support beyond the minimum period of 1 year.			✓				✓				✓
4.We will fully involve carers in the delivery of this strategy, recognising their vital role as valued experts and equal partners in care, whilst recognising and supporting their individual needs and wellbeing.						✓					
5.We will work collaboratively across all sectors to explore options to deliver innovative and flexible respite solutions which are designed with and for people with dementia and unpaid carers.										✓	
6.We will continue to support people to live in their own homes wherever possible by continuing to build resilience and capacity in line with demand on current cross sector community based services, as well as exploring and resourcing new and innovative solutions, including assistive technology.								✓			
7.We will review support and services to explore options to safely reduce off island transfers and where possible and appropriate hospital admission will be avoided or reduced. Where hospital is the optimum location for care – adverse effects of admission will be reduced.									✓		
8.We will undertake a robust cross sector training needs analysis in line with the Promoting Excellence Framework. We will support training in line with results to ensure support for people with dementia is provided by a knowledgeable and skilled workforce.				✓							✓
9.We will embed accessible, preventative and reactive allied health support into post diagnostic support to promote independence, optimise strengths, build resilience and prevent unnecessary crises.			✓				✓				
10.We will ensure that every person diagnosed with dementia will experience right based support and services throughout their dementia journey. This will include recognition of dementia as a priority in every relevant work stream, initiative and procedure.			✓							✓	
11.We will support Orkney to become a dementia friendly, inclusive place where people with dementia are valued and welcomed as part of their own community by their own community.		✓									

National Outcomes (NO)	Outcomes										
	NO 1	NO 2	NO 3	NO 4	NO 5	NO 6	NO 7	NO 8	NO 9	NO 10	NO 11
1. We will engage with communities, voluntary and statutory services to increase awareness of modifiable risks associated with dementia and will support people to make positive changes to reduce risks.	✓										
2.We will work collaboratively to improve awareness of the benefit of diagnosis, the process and rate of diagnosis in Orkney. This will involve a multi-agency approach between community groups, voluntary and statutory services and a full review of current assessment and diagnostic service provision.		✓	✓								
3.We will support a trial of an integrated care pathway for every person diagnosed with dementia. We will also review current support and services to facilitate provision of grass roots informed, multi-agency post diagnostic support beyond the minimum period of 1 year.				✓							
4.We will fully involve carers in the delivery of this strategy, recognising their vital role as valued experts and equal partners in care, whilst recognising and supporting their individual needs and wellbeing.						✓					
5.We will work collaboratively across all sectors to explore options to deliver innovative and flexible respite solutions which are designed with and for people with dementia and unpaid carers.		✓									
6.We will continue to support people to live in their own homes wherever possible by continuing to build resilience and capacity in line with demand on current cross sector community based services, as well as exploring and resourcing new and innovative solutions, including assistive technology.		✓									
7. We will review support and services to explore options to safely reduce off island transfers and where possible and appropriate hospital admission will be avoided or reduced. Where hospital is the optimum location for care – adverse effects of admission will be reduced.		✓					✓				
8.We will undertake a robust cross sector training needs analysis in line with the Promoting Excellence Framework. We will support training in line with results to ensure support for people with dementia is provided by a knowledgeable and skilled workforce.								✓	✓		
9.We will embed accessible, preventative and reactive allied health support into post diagnostic support to promote independence, optimise strengths, build resilience and prevent unnecessary crises.	✓		✓	✓	✓						
10.We will ensure that every person diagnosed with dementia will experience right based support and services throughout their dementia journey. This will include recognition of dementia as a priority in every relevant work stream, initiative and procedure.			✓		✓						
11.We will support Orkney to become a dementia friendly, inclusive place where people with dementia are valued and welcomed as part of their own community by their own community.		✓									

Appendix 6 – 10 Care Actions

Orkney Dementia Strategy

2020 - 25
Summary



NHS Orkney

OHAC orkney health and care

Orkney Islands Council

Why does Orkney need a dementia strategy?

Dementia can result from a variety of diseases and injuries that affect the brain, such as Alzheimer's disease or stroke. Although dementia mainly affects older people, it is not a normal part of ageing and can affect younger people. It can be overwhelming for people living with the condition and also for unpaid carers and families.

Orkney has a population of 22,000 people. Our population is living longer and this is something to be celebrated. Older people continue to make a significantly positive contribution to our communities. Unpaid carers provide many thousands of hours of care each year and should be valued as equal partners in care – experts in their own right. The Carers Trust reports that the care provided by unpaid carers in the UK each year is worth £132bn to the economy.

The number of people living with dementia in Orkney is set to double to around 800 people by 2041.

It is important that people living with dementia in Orkney, and carers, receive high quality support at the time they need it. We have a high percentage of older people on some of our most remote islands and so we need to develop innovative ways to support them.

We need a strategy that is:

- designed with and for people with dementia and unpaid carers
- safe, effective and focused on the person
- delivered in a way that means everyone is working together to deliver the best services and support
- committed to reducing inequalities and promoting equality

Clearly there is a medical aspect to dementia but in the dementia strategy we talk about **'people', not 'patients'.** We are adopting a social model of dementia as a disability, recognising the challenges people with dementia face and giving the same priority to eliminating barriers for them as we do for physical disabilities.

The strategy will run for five years, which will give us enough time to monitor progress as we deliver it and evaluate what it achieves.

How has the strategy been created?

We consulted widely to ensure that services are designed with and for people with dementia and unpaid carers. The development of the strategy has been completed in partnership with people with dementia, unpaid carers, and people from statutory and third sector organisations.

We listened to the views of local individuals and groups, held focus groups and conducted a survey.

The survey asked people:

- what support or services have been helpful or positive
- what was good about them
- what could improve experiences and well-being for people with dementia and those who support them

In May 2019, the Life Changes Trust helped us host a three-day collaborative dementia learning event in Kirkwall. Storytelling sessions supported people with dementia and carers to talk safely and openly about their experiences of living with dementia.

Five key priorities emerged for people with dementia and unpaid carers:

1. We want better information and support in how to access self-directed support.
2. We want diagnosis to be delivered in a supportive way, in a familiar environment, with better access to post-diagnostic support.
3. We want more emphasis on what matters to carers, both collectively and individually.
4. We want better respite solutions, both planned and reactive.
5. We want more emphasis on dementia friendly and dementia enabled communities.

These priorities echoed the findings of the focus groups and the survey. Overall, people felt that there needs to be far greater awareness about dementia across Orkney. The Dementia Strategy hopes to address all of these priorities.

What difference should the strategy make for people with dementia?

We want the strategy to make a real difference in the lives of people with dementia. If it doesn't do this, the strategy will not have achieved its aims.

In the strategy we make 9 commitments to people with dementia:

1. We will take an approach that respects your human rights and upholds them.
2. We will review the ways in which we diagnose dementia so this happens in a supportive way. We will make sure you know how you can access appointments to discuss dementia and receive an assessment.
3. Just now, everyone with dementia is entitled to one year of support after a diagnosis. We want to extend support beyond one year and so we will create a clear route for providing that support and will test it as it is delivered to ensure it works.

4. We will work with a wide range of organisations to deliver innovative and flexible options for respite care.
5. We will support you to live in your own home wherever possible and we will explore new and innovative solutions, including assistive technology.
6. We will do our best to safely reduce 'out of Orkney' transfers and, where possible and appropriate, hospital admission will be avoided or reduced. If you must go to hospital, we will make sure that you are able to leave as soon as possible.
7. We will make sure that every worker who helps support you because you have dementia has the proper knowledge and skills to do so.
8. Allied Health Professionals (e.g. occupational therapists, dietitians) will be available to assist you in finding solutions and help you increase your independence and resilience.
9. We will support Orkney to become a dementia friendly, inclusive place where you are valued and welcomed as part of your own community by your own community.

What difference should the strategy make for unpaid carers of people with dementia?

We also want the strategy to make a real difference in the lives of unpaid carers of people with dementia, such as family members and friends. If it doesn't do this, the strategy will not have achieved its aims.

In the strategy we make 9 commitments to unpaid carers of people with dementia.

1. We will take an approach that respects your human rights and upholds them.
2. We will review the ways in which we diagnose dementia so this happens in a supportive way. We will make sure you know how you can access appointments to discuss dementia.

3. We will fully involve you, as a carer, in the delivery of this strategy, recognising your vital role as a valued expert and equal partner in care, whilst recognising and supporting your own needs and well-being. We will establish a carers' forum through the Dementia Carers Group to support the implementation of the Orkney Dementia Strategy. This will help us to understand and prioritise supports that will help carers to feel positive and supported to continue their caring role, where this is their wish, in any setting including hospital and care homes. We will support carers through anticipated and actual changes and transitions of care, recognising that this often involves a process of loss and grief.
4. We will work with a wide range of organisations to deliver innovative and flexible options for respite care.
5. We will support your caring role in your own home wherever possible and we will explore new and innovative solutions, including assistive technology.

6. We will do our best to safely reduce 'out of Orkney' transfers and, where possible and appropriate, hospital admissions will be avoided or reduced.
7. We will make sure that every worker who helps support you in your caring role has the proper knowledge and skills to do so.
8. Allied Health Professionals (e.g. occupational therapists, dietitians) will be available to assist you in finding solutions and help you increase your independence and resilience and that of the person you are caring for.
9. We will support Orkney to become a dementia friendly, inclusive place where you, as an unpaid carer of a person with dementia, are valued and welcomed as part of your own community by your own community.

How will we know if it is effective or not?

We will monitor our progress in meeting these commitments and will evaluate how they have made a difference for people living with dementia and unpaid carers.

We will do this in 3 ways

First, there will be a Dementia Steering Group that will be representative of all stakeholders and will support a grassroots approach. People with dementia and unpaid carers will be part of this group.

Second, there will be an Action Plan that will set out targets for progress. The Dementia Steering Group will monitor progress and will provide regular reports to the Integration Joint Board.

Third, the Life Changes Trust will help fund an evaluation of the Orkney Dementia Strategy. This will help with designing a performance management framework so we know what we should measure and what other information we should collect. This evaluation will be independent to the Orkney Integration Joint Board and so will give a level of outside scrutiny that will help us learn and grow.

We would be very pleased to hear from you if you would like to provide us with feedback.

Please contact us using the following details:

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NHS Orkney

OHAC orkney health and care

Orkney Islands Council