

# Orkney Dementia Strategy Feedback - Collated

August 2020.

Feedback Received (copied verbatim).	Change incorporated / Not Incorporated.	Comments.
<p>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.</p> <p>In terms of the commitment section it might be useful to separate out with distinct <b>hwadonfa</b> that which is currently in place, that which is the provision of information and that which is yet to be actioned.</p>	Change partly incorporated.	<p>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 Progress is likely to be fluid and would become out of date quickly.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.</p> <p>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</p>

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		<p>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.</p> <p>The strategy was written pre Covid-19 and a section has been added to address this (Pages 7 and 30).</p>
<p>The Dementia Strategy is very well written, I had a couple of thoughts whilst reading through,</p> <p>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?</p> <p>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</p>	Change incorporated	<p>Acknowledged support for implementation.</p> <p>Resource/finance – (page 30).</p>

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be a commitment of resources from OHandC 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.
<p>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.</p> <p>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.</p> <p>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</p>	No change incorporated.	<p>Acknowledged</p> <p>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.</p>

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<p>her children were working and also had their own families to consider.</p> <p>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.</p>		
<p>The strategy seems sensible.</p> <p>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.</p> <p>Does NHS Orkney have the money to fulfil this plan? We hope so.</p>	Change partially incorporated.	<p>The strategy was written pre Covid-19 and a section has been added to address this (Pages 7 and 30).</p> <p>No ongoing evidence of shortage of PPE identified in Orkney during COVID Financial/resource aspects (Page 30).</p>
<p>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.</p> <p>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.</p> <p>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.</p> <p>Will there be further consultation from stakeholders to inform on progress and how will this be monitored?</p> <p>I wish you every success in these difficult times and the restrictions this will have in moving forward.</p>	Change partly incorporated.	<p>Comments acknowledged.</p> <p>Investment/finance (Page 30).</p> <p>Involvement of stakeholders in steering group and evaluation is included in the evaluation plans for the strategy.</p>

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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 and 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 health 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, nor 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 highlighted 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 an 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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<p>direct experience of dementia the local media can help keep the public informed.</p> <p>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.</p>		
<p>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.</p>	No change to strategy identified in feedback.	Acknowledged.
<p>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.</p>	Already incorporated within the strategy.	Carer support is covered extensively within the strategy.

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<p>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?</p>	Partly incorporated.	<p>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.</p> <p>Resource and financial aspects (page 30).</p>
<p>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.</p> <p>On the island where I live about one third of the population is over 65,</p>	Not incorporated.	<p>Acknowledged and feedback sought.</p> <p>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.</p>

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<p>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.</p> <p>Thank you for your efforts to make people's old age as pleasant as possible.</p>		
<p>Like so many of OIC draft proposals it all sounds very good - too good to be true.</p> <p>This document again sounds so good on paper - please don't let it become another failure.</p>	No change to strategy identified in feedback.	Acknowledged.
<p>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.</p>	Already incorporated in the strategy.	<p>Incontinence supplies are already available on prescription.</p> <p>The value of partnership working is reflected throughout the strategy.</p> <p>The integrated care pathway detailed in the strategy set out process throughout the experience of dementia.</p>
<p>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?</p> <p>What levels of staff will be required to provide this support – also the costs of staff pay and training.</p> <p>Are there enough people in the local community to train and have availability to support this expected increase in demand?</p> <p>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</p>	Partly incorporated.	<p>Finance/resource (page 30)</p> <p>Carers and post diagnostic support elements addressed in the strategy.</p> <p>The strategy was written pre Covid-19 and a section has been added to address this (Pages 7 and 30).</p>

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<p>person we have seen since Mum's diagnosis (at that time it was Sandra Newlands who 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.</p> <p>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.</p> <p>Aware of someone requiring assessment and support and everything cancelled due to the pandemic. So no support whatsoever for that family.</p> <p>Also, who shouts loudest appears to get the most help.</p>		
<p>General comments</p> <p>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.</p> <p>The emphasis on early diagnosis so that the wider support team can react effectively so that HBMR and/or other OT interventions etc can</p>	Partly incorporated.	Name of team and wording changed accordingly (Pages 19, 20 and 34). Resources (page 30).

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<p>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.</p> <p>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.</p> <p>More specific comments - from main document</p> <p>Page 11 and Page 19.</p> <p>Intermediate Care team needs changed to Intermediate Community Therapy Team.</p> <p>Page 19.</p> <p>Care and 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.”</p> <p>Page 23.</p> <p>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</p>		

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<p>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.</p> <p>Comments from Summary document</p> <p>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.</p> <p>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.</p> <p>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.</p>		
<p>I found the strategy very easy to read and without too much jargon, which was so refreshing.</p> <p>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.</p> <p>It would be appropriate for the AHP and Nursing PEL to support the</p>	<p>No change to strategy identified in feedback.</p>	<p>Acknowledged.</p>

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educational elements of the strategy so please let us know if and how we may help contribute and support this.		
<p>Thank you for sharing the dementia strategy, it all looks good and sensible.</p> <p>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.</p> <p>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.</p> <p>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?</p> <p>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</p>	No change to strategy identified in feedback.	<p>Acknowledged specific elements identified for improvement and these will be noted and forwarded to the steering group.</p> <p>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.</p>

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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).

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<p>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.</p> <p>7. I agree with the philosophy of supporting people in their own homes as outlined 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 our 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.</p>		
<p>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 any of them), concur with the outcome aims etc however my one big question for all is how? For me that is the question that needs to be answered.</p> <p>Well done and many thanks for sharing and allowing me to comment.</p>	No change to strategy identified in feedback.	Acknowledged.
<p>Thank you for the opportunity to review NHSO Dementia Strategy. An excellent document which must have taken some time to pull</p>	No change to strategy.	Acknowledged.

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together. Well done.	identified in feedback	
<p>Thank you for sharing the Orkney Dementia Strategy, it's something I'm very supportive of.</p> <p>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?</p> <p>I'm also not convinced about including OHAC logo on the front cover as it isn't an enduring statutory body.</p> <p>Happy to support its implementation.</p>	Partly incorporated.	<p>Wording altered to ensure that it is clear who 'we' refers to (Page 13).</p> <p>Following discussion it was decided that the OHAC logo would remain on the front cover alongside OIC and NHO.</p>
<p>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.</p> <ul style="list-style-type: none"> <li>• Great to see equal recognition of the needs of people living with dementia and their carers.</li> <li>• Need to consider the impact of COVID on people living with dementia and their carers:           <ul style="list-style-type: none"> <li>- 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</li> <li>- Mental health</li> </ul> </li> <li>• Need to consider long term potential for increased incidence of modifiable dementia risk factors at population level.</li> </ul> <p>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</p>	Partly incorporated.	<p>The strategy was written pre Covid-19 and a section has been added to address this (Pages 7 and 30).</p> <p>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.</p>

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<p>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.</p> <p><b>This came in a second email:</b></p> <p>Thanks, the other area of particular interest was the Dementia friendly Orkney in terms of a place based initiative.</p> <p>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.</p>		
<p>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.</p>	No change to strategy identified in feedback.	Feedback provided no indication that a glossary was needed. The summary document provides an easy read alternative.
<p>Changes to reflect that the IJB can not commit to additional costs.</p> <p>Change from unpaid carers to their carers.</p>	Incorporated.  Incorporated.	(Pages - 4,5,12,20,25).  Wording changed (Page 4).

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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.		