

Our future – your say: The future of care for people living with dementia

Your Comments

The aim of this consultation is to obtain views from consultees and we would be most grateful if you would respond by completing this form. Please answer each question by writing your comments in the space provided. The closing date for this consultation is **10th May 2013** and we need to receive your completed form on or before that date. You can respond to the consultation document by e-mail, letter or fax as follows:

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So that we can acknowledge receipt of your comments please fill in your name and address or that of your organisation. You may withhold this information if you wish but we will not then be able to acknowledge receipt of your comments.

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We propose to work in partnership with individuals and their carers to support people living with dementia in their own homes, for as long as possible, with appropriate care and support from staff. This will include the use of assistive technology and making appropriate housing adaptations to help the particular needs of the individual.

1. Do you agree with the Trust's overall plan to support people living with dementia in their own homes for as long as possible?

Yes

No

Don't know

Please tell us what you think:

The Commissioner is of the view that the most most important factor concerning the Trusts proposals to support independent living for those with dementia, must take into consideration their rights and best interests. Individuals that are affected are the most important consideration in any decision about residential home care provision. Therefore, consultation with, and consideration of the views of residents is essential. The Commissioner is keen to stress that the care assessment for each individual resident must be thorough and professional.

It is the view of the Commissioner that structures and service models are required to ensure effective and efficient management of patients who remain in their own homes with dementia. Most dementia patients being cared for at home have access to support from the third sector. But for many, this support is not enough, and for a minority it is almost non-existent. This is often due to patients and carers not knowing what support is available to them, or when to access these services. In a survey by the Alzheimer's Society in Northern Ireland (2010), 90% of respondents said people with dementia don't get enough help and support and 88% that carers don't get enough. These figures are alarming to the Commissioner too therefore, it is the intention of the Commissioner to coordinate a project specifically designed to address the low-takeup carer's assessments during her term in office.

It is the view of the Commissioner supported by evidence from the Alzheimer's Society, that there is a huge diversity in provision of care packages and a lack of transparency or rationale with regard to the criteria required to secure particular services. There is also a concern regarding the Trusts intention to reduce 30% of the long term domiciliary packages as stated in the Northern Local Commissioning Draft Population Plan.

Furthermore, the Commissioner is aware that domiciliary care can exacerbate social isolation. Recent research by the Patient and Client Council has found that for older people on their own or whose family do not live close by, the care workers provide a lifeline (2013). The study indicated, domiciliary care meant more to older people than just physical help with everyday activities. Addressing this isolation needs to be dealt with by the social care system especially if the strategic focus of Transforming Your Care continues.

- 2.** Please tell us what you think about developing assistive technology (i.e. devices that can help make life easier or safer for people with dementia and their carers) to help people stay at home for as long as possible.

The Commissioner acknowledges that technology has a role to play in facilitating the shift from traditional models of residential care, to supporting people with dementia in a way that promotes independence and enables them to stay in a familiar home environment for as long as possible. The Commissioner is of the view that assistive technology is a good idea if in accordance with the individual's dementia level.

Furthermore the Commissioner feels it is imperative to emphasise that assistive technology can be effective only when combined with good care (there should be sufficient carers to respond to an alert). Importantly, no one should be forced into using technology if it is not right for them. The person with the dementia must be involved in the decision making and their consent sought and given where possible.

Furthermore, the introduction of technology should not impact on the dignity and privacy of the older person with dementia and must meet with human rights obligations. The reasonableness test needs to apply if assistive technology will be introduced and a balance found between rights and risk to the person living with dementia.

- 3.** Moylinney is an old building designed on an outdated model. It is our intention to develop a replacement supported living housing scheme in the Newtownabbey area specifically designed for people living with dementia. What are your views on the Trust's proposal to develop a supported living scheme?

Agree

Disagree

Don't know

Please tell us your views:

The Commissioner agrees in principle with the Trust's proposal to develop a supported living scheme, particularly since the building is outdated and does not meet good practice. The Commissioner welcomes the proposals to develop a supported living scheme designed to support independence and confidence.

The Commissioner is of the opinion that any recommendations for changes to where a person is cared for must demonstrably be as good or better than the current living arrangements or care provision. It is essential that tailored care packages incorporate a risk assessment which include decisions from all stakeholders about what is an acceptable level of risk and how these risks can be managed. Furthermore, residents and families must be involved in each stage of the process in order to prevent distress and to win confidence with the proposals. For example 40% of people with dementia experience walking about as a problem (Alzheimer's Society). Therefore, systems need to be in place to prevent people with dementia coming to harm. Any supported living schemes must include tailored technology packages for each resident and risk assessed according to the person's state of dementia.

In our meeting with Trust colleagues the Commissioner's officers were impressed that design considerations for the new build proposal that reflected best practice especially in light of actual experience within the Trust area.

4. Improvements to the design of the accommodation for people living with dementia can reduce the affect dementia has on a persons ability to live with a level of independence and with contentment. Do you support the Trust's proposal for improving accommodation for people with dementia?

Yes No Don't know

Please tell us your views:

The Commissioner welcomes the improvement of accomodation specifically tailored for people with dementia. However, the Commissioner is concerned that where recommendations for changes are made these must also account for the stress and fear that this process can cause.

Furthermore, it is the view of the Commissioner that any process which leads to home closure and the involuntary transfer of residents must be accompanied by ongoing and active attention to their health and well-being. This should include meaningful consultation, planned provision and transfer and continuation of care by familiar staff during the transition.

5. Do you agree with our proposal that when permanent resident numbers in Moylinney reduce below 10 the Trust should make alternative

appropriate arrangements for the care of the remaining residents as it will make the use of Moylinney untenable, as over 60% of the bedrooms will be unoccupied?

Yes

No

Don't know

Please tell us your views:

It is the view of the Commissioner that any proposed relocation of current residents must be communicated to the patient and involve their families. The Commissioner understands the practical decisions that must be taken and appreciates that large accommodations can lose quality if under-occupied.

6. Do you agree with our proposal to examine a range of options to meet the current provision of daycare within Moylinney to include the use of existing statutory daycare services, direct payments and daycare provided in the voluntary and independent sector?

Yes No

Don't know

Please tell us your views:

Dementia is prevalent across social, economic, gender, race and sexual orientation and people live with dementia in a wide range of personal relationships, geographic environments and settings. Consequently, it is the opinion of the Commissioner that the Trust needs to create bespoke services for people with dementia.

The Commissioner agrees that personalisation, including direct payments can deliver benefits for people with dementia, but concerted attention is needed to support people with dementia so they benefit from this provision. Other existing statutory services must have the applicable specialisms.

7. The Trust is committed to promoting Equality of Opportunity and Good Relations. Having considered our EQIA please tell us if you feel our proposals will have an impact on any of the nine equality categories?

The Commissioner feels the Trust needs to consider the impact of staff with dependents in terms of relocation (predominately staff from a female background).

Additionally, given the diversity amongst older people, there is a need for adequate disaggregated data on older people to measure the potential impact of all options as set out in the consultation document. The Commissioner is of the view that the Northern Trust should review it's data processes to ensure that the data available is capable of disaggregation at an appropriate level to ensure suitable monitoring of the impact of the resettlement of dementia patients on equality grounds, as set out in Section 75 of the Northern Ireland Act 1998.

The Commissioner would like to have more information on how the Trust will ensure future services are welcoming to persons of different religious beliefs. Additionally, the Commissioner feels any relocation should be positioned in an area that is welcoming to all persons.

Furthermore the Commissioner feels consideration should be given to collect information on political opinion.

**Thank you for taking the time to respond
to this consultation process.**

Trust Response and Freedom of Information Act (2000)

The Northern Health and Social Care Trust will publish an anonymised summary of the responses received to our consultation process. However, under the Freedom of Information Act (FOIA) 2000, particular responses may be disclosed on request, unless an exemption(s) under the legislation applies.

Under the FOIA anyone has right to request access to information held by public authorities; the Northern Trust is such a public body. Trust decisions in relation to the release of information that the Trust holds are governed by various pieces of legislation, and as such the Trust cannot automatically consider responses received as part of any consultation process as exempt. However, confidentiality issues will be carefully considered before any disclosures are made.
