Review of the National Framework for NHS continuing healthcare

August 2015
1. **Alzheimer's Society**

Alzheimer's Society is the UK’s leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications National Dementia Helpline, website and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

Alzheimer’s Society is part of the Failing to Care coalition, led by Parkinson’s UK, which aims to improve the system of NHS continuing healthcare to ensure good outcomes for all people going through the process of applying for NHS continuing healthcare funding, including people with dementia.

2. **Summary of key points**

**Points on compliance with the Care Act**

- Alzheimer’s Society welcomes this opportunity to contribute to this review of the National Framework for NHS continuing healthcare, ensuring that it is updated to comply with the Care Act.
- Given the complexity of the process, Alzheimer’s Society recommends that the National Framework includes a whole section on information and advice. This will not only support people with dementia and carers going through the process, but also comply with the duties on local authorities to provide information and advice in the Care Act.
- To bring the National Framework in line with the Care Act, Alzheimer’s Society recommends that the Framework clearly states that an assessor should request support from an expert when assessing a person with complex or multiple needs. The expert should have specialist knowledge of the condition of the person being assessed.
- The National Framework must include a clear section on advocacy, making it clear that local authorities (with CCGs) must consider access to an advocate even to those people who do not have substantial difficulty or do have an appropriate person to support their involvement in an NHS continuing healthcare assessment. Advocacy services have the potential to ensure that people with dementia have a fair assessment and good outcomes from the process. This will also ensure that the National Framework complies with the Care Act.

**Points on policy updates to the National Framework**

- We express disappointment that the Department of Health is not considering any policy changes in this review.
- Alzheimer’s Society believes that any person going through the process of applying for NHS continuing healthcare funding should have
access to a care coordinator to support them through the complex process.

- We recommend that data collection is collected consistently across all CCGs. This would improve the accountability of CCGs, ensuring that standards are driven up and outcomes for people with dementia are improved.
- The Decision Support Tool (DST) disadvantages people with dementia and is often misused. Alzheimer’s Society recommends mandatory training for all assessors to ensure correct use of the DST and fair assessment for people with dementia.
- As dementia is a progressive condition, Alzheimer’s Society recommends new guidance on reviews which would ensure ongoing and continued eligibility for people living with the condition.

3. Comments on compliance with the Care Act 2014

3.1 Information and advice

Given the highly complex nature of the process of NHS continuing healthcare, Alzheimer’s Society recommends that a whole section of the Framework is devoted to information and advice. This section should then cover the key points at which information or advice is required, including:

- Consideration for NHS continuing healthcare
- A review of NHS continuing healthcare
- Appealing a decision for NHS continuing healthcare

Anecdotally, Alzheimer’s Society hears that often a person will undergo the checklist for NHS continuing healthcare without them or their family knowing this has even happened. The Care Act 2014 states that a consideration for, or a review of, NHS continuing healthcare should be a trigger for information and advice. Paragraph 44 of the current National Framework must be strengthened to state the duty on local authorities under the Care Act. Alzheimer’s Society recommends the following wording is included in the National Framework:

“Local authorities, working with other partners, have a duty to provide targeted information and advice at key points in people’s contact with care and support and other local services. Where a health or social care professional is considering or reviewing a package of NHS continuing healthcare, they must provide or direct the individual to relevant information and advice to support through the process.”

Reference should also be made in this section of the National Framework to the new information and advice offer from NHS England, which was awarded to Beacon in August 2015.

3.2 Assessment and eligibility

The Care Act 2014 states that “Where it appears that a person may be eligible for NHS continuing healthcare, local authorities must notify the clinical commissioning group.” Alzheimer’s Society recommends that this is reflected in the National Framework under the section on other eligibility issues.
Alzheimer's Society would like to see CCGs and local authorities coordinating and regularly updating each other on assessments and people eligible for NHS continuing healthcare.

In addition, Alzheimer's Society recommends that the point in paragraph 60 on specialist involvement in the assessment process is strengthened to bring it into line with the Care Act. A survey for the APPG on Parkinson's inquiry into NHS continuing healthcare found that 59% of assessments did not involve a professional with specialist expertise or knowledge in the condition which led to inaccurate decisions on funding. Given the complex and unpredictable nature of dementia, and that many people with the condition will be living with another long-term health issue as well as dementia, it is important that dementia specialists are involved in the assessment process. In particular, Alzheimer’s Society has anecdotal evidence that assessors are not recognising current research which shows that people with dementia still experience emotions and have psychological needs, even if they have low levels of cognition. Alzheimer’s Society would welcome a reference to its guidance on assessing the emotional and psychological needs of a person with dementia in the National Framework.

The Care Act guidance is clear: when assessing a person with complex or multiple needs, an assessor may require support of an expert to carry out the assessment. Furthermore, where the assessor does not have the necessary knowledge of a particular condition, they have a duty to consult someone who has the relevant expertise.

Alzheimer's Society recommends the following wording is inserted into the National Framework:

“When assessing a person with complex or multiple needs, an assessor may require support of an expert to carry out the assessment, to ensure that the person’s needs are fully captured. This should be decided on a case-by-case basis. Where the assessor does not have the necessary knowledge of a particular condition, for example of spinal injury, learning disability or dementia, they have a duty to consult someone who has the relevant expertise. This is to ensure that the assessor can ask the right questions relating to the condition and interpret these appropriately to identify underlying needs.”

The National Framework also includes a helpful section on what eligibility should not be based on. This can improve clarity around this complex issue and we believe that this section should be more prominent in the Framework. Alzheimer’s Society recommends this is included in the core values and principles section.

3.3. Advocacy
Alzheimer’s Society recommends that advocacy is included in the Framework as a discrete section to emphasise the importance of advocacy in relation to NHS continuing healthcare. Firstly, the Framework must state that where a person’s needs are being jointly assessed by the NHS and local authority or
where support is planned, commissioned and funded by both, a person should have access to an independent advocate. The Society recommends the following wording so it reflects the Care Act:

“Local authorities have a duty under the Care Act to provide independent advocacy services where a person’s needs are being assessed by the NHS and the local authority, or where a package of care is planned, commissioned or funded by both a local authority and a CCG, known as a joint package of care. Where it appears a person may be eligible for NHS continuing healthcare, local authorities must notify the relevant NHS body.”

Secondly, the advocacy guidance in the Care Act is very clear that local authorities (with CCGs) must consider access to an advocate even to those people who do not have substantial difficulty or do have an appropriate person to support their involvement in an NHS continuing healthcare assessment. This is because the process is incredibly complex for all individuals, even those with experience of working in the health and social care sectors. Alzheimer’s Society recommends using the following wording:

“Local authorities (with CCGs) will therefore want to consider the benefits of providing access to independent advice or independent advocacy for those who do not have substantial difficulty and/or those have an appropriate person to support their involvement.”

3.4 Integration and cooperation
The Care Act guidance on integration, cooperation and partnership states that assessments could be carried out at the same time by the same person wherever possible. This point must be reiterated in the National Framework in the section on assessments. Alzheimer’s Society recommends the following wording:

“Where feasible, the local authority should identify opportunities to conduct assessments at the same time by the same person. Where this is not possible, the assessor for NHS continuing healthcare should read previous assessments (provided there is a lawful basis for sharing information) and not ask for any information which has already been collected.”

3.5 Carers
Paragraph 54 of the National Framework must be updated to reflect the rights of carers in the Care Act. The Framework should make it clear that any support offered by the carer should not be taken into account when determining eligibility for NHS continuing healthcare. Instead the care provided by carers can be taken into account during the care and support planning stage. Alzheimer’s Society recommends the following in paragraph 54 in order to reflect the Care Act guidance:

“Authorities must only take consideration of whether the adult has a carer, or what needs may be met by a carer after the eligibility determination when a care and support plan is prepared.”
4 Alzheimer's Society recommendations for policy updates in the National Framework

Alzheimer’s Society is disappointed that the Department of Health is not considering any policy changes as part of this review. The complexity of the process of applying for NHS continuing healthcare, combined with a lack of knowledge and awareness of dementia among some health and care professionals means that people with dementia are unfairly disadvantaged by this system. In the period between April 2013 and March 2014, Alzheimer’s Society’s National Helpline received 1411 enquiries, which highlights the challenges people with dementia have with accessing NHS continuing healthcare. Alzheimer's Society's main concerns with the current National Framework are detailed in the following sections.

4.1 Access to a case coordinator
To support people with dementia and carers through the process of applying for NHS continuing healthcare funding, it would be hugely beneficial for them to have a case coordinator. Currently, it is rare for that a person with dementia is given the contact details of an individual to help coordinate their case, despite that case coordination is included in paragraph 26.1 of the practice guidance.

Alzheimer’s Society recommends that case coordination is included in the section on information and advice of the National Framework to ensure that all people going through this complex process are well supported.

4.2 Determining a primary health need
With regards to point 35 of the National Framework, Alzheimer’s Society has concerns that the definition of unpredictability is unclear. Dementia can be a fluctuating condition, for example, a person’s behaviour may change throughout the day, but this is often not taken into account by assessors. However, the fluctuations in need are different to the progression of the condition. Currently, it can be the case that the fluctuating needs are seen as ‘predictably unpredictable’. The confusion arises as a result of the wording in the ‘unpredictability’ section and how many facets of a person’s needs it attempts to cover.

Given this complexity and the misuse of ‘unpredictability’ in the National Framework, it is essential that this is addressed in the update. We recommend that the term unpredictability is replaced by two terms, ‘fluctuation’ and ‘progression’.

4.3 Data collection
Alzheimer’s Society has welcomed attempts to improve the accountability through the new Operating Model and the inclusion of NHS continuing healthcare in the NHS England Assurance Framework.

Nevertheless, Alzheimer’s Society has concerns that the lack of data collection for NHS continuing healthcare has led to a lack of CCG
accountability and inconsistent implementation of the National Framework across England. Data collection is vital for improving the system and Alzheimer’s Society recommends that the National Framework includes a section on the data which CCGs should be collecting. To support this, a detailed list can be included under paragraph 75.2 of the guidance stating that CCGs should collect data on:

- Condition of applicant
- Total number of applications
- Total number found eligible
- Total number ineligible
- Total number with jointly-funded packages
- Length of each component part of the process e.g. referral to checklist, checklist to DST, DST to decision, appeal to appeal outcome
- Total length of the process
- Number of appeals
- Number of successful appeals
- Number of unsuccessful appeals
- Number of withdrawals of eligibility on review

We recognise that the assessment must be based on needs and not on the condition itself; however, a lack of condition-specific data makes it very difficult for the NHS England to identify where issues lie.

**4.4 Decision Support Tool**
The Decision Support Tool (DST) in its current form disadvantages people with dementia. Although the Framework currently states that the assessor should consider the interaction between the needs, this does not always happen. Some of the domains are more applicable to people with dementia, for example, cognition which is impossible to consider as a priority need, and communication or emotional and psychological needs, which are impossible to consider as priority or even as severe needs. This means that a person with dementia can lose out on NHS continuing healthcare funding. This highlights the need for assessors to consider the interactions between the domains when making the decision.

Furthermore, the DST is often used inappropriately, rather than as a tool to support decision making. An over-prescriptive use of the DST means that assessors are focussing on semantics of the words in the DST, rather than understanding the needs of the person.

Alzheimer’s Society recommends mandatory training for assessors and this should be reflected in the National Framework, ensuring that all assessors have the necessary skills and knowledge to conduct assessments.

**4.5 Reviews of people with dementia**
Dementia is a progressive condition and any person with dementia will need more support as the condition deteriorates. Despite paragraph 38 of the National Framework stating that deterioration should be taken into account when considering eligibility, Alzheimer’s Society has anecdotal evidence that funding is taken away from many people with dementia when their case is
reviewed. It may appear that the needs of a person with dementia have been reduced, but this can be as a result of the following:

- The dementia has progressed to a stage that the individual is no longer able to carry out some basic activities (such as walking), or previous challenging behaviours have ceased (such as aggression). While it could be the case that a person with dementia is at less of a risk of falling if they are no longer able to walk, it does not follow that their health needs have lessened.
- The impact of an intervention from an NHS continuing healthcare package of care has improved outcomes for the person with dementia. Removal of the intervention could, therefore, be a step backwards and lead to a deterioration in a person’s condition.

While we recognise that a person’s needs may change over time and they may require more support in time, it would never be the case that the needs of a person with dementia will reduce.

Alzheimer’s Society recommends there should be new guidance within the National Framework regarding a need for there to be a presumption of ongoing and continued eligibility for people with progressive or non-improving needs. The guidance must be updated to state that the sole focus of reviewing people with long term conditions that have progressive or non-improving healthcare needs should be on ensuring the clinical well-being of the patient and that the individual’s needs are being adequately met, and not on re-examining their eligibility.

5 Conclusion
Alzheimer’s Society is pleased to have had the opportunity to feed into this review of the National Framework. We believe that the National Framework can be strengthened by taking into accounts new duties under the Care Act 2014, thus improving outcomes for people with dementia who go through the process of applying for NHS continuing healthcare funding.

Nevertheless, as part of the Failing to Care coalition, Alzheimer’s Society has campaigned for many changes to the National Framework which would require policy changes from the Department of Health. We believe that this update of the National Framework will only scratch the surface in terms of the changes required to improve outcomes for people with dementia. Alzheimer’s Society will be happy to work with the Department of Health on a future policy review of the National Framework.

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