

The Relatives & Residents Association response to the Consultation on the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care in England



1. The Relatives & Residents Association (R&RA)

1.1 The Relatives & Residents Association (R&RA) exists to promote the rights and well-being of care home residents by providing advice and support to them and their relatives, especially at times of crisis.

1.2 Being the only national charity concentrating wholly on the specific and detailed needs of older people who are in residential care because of frailty, ill-health, dependency and, often, dementia, R&RA is well-placed to comment on the proposed National Framework for NHS Continuing Healthcare and NHS-funded nursing care.

2. Introduction

The R&RA welcomes the decision to develop a national framework for assessing eligibility for NHS Continuing Healthcare. It has long been concerned with the variation in eligibility criteria and consequent unfairness that older people have experienced across the country. It remains concerned, however, as R&RA described in its response to the House of Commons Inquiry into NHS Continuing Care, that:

- people will remain confused about the distinction that will still be made between NHS Continuing Healthcare and NHS-funded Nursing Care;
- health and social care staff will themselves remain unclear about the criteria to be applied under the new framework;
- that periodic re-assessment will be finance-driven (i.e. with the restriction of full funding rather than changing health need being the driving factor);
- older people will still have a burning sense of injustice about the financial burdens imposed on those who narrowly miss eligibility for NHS Continuing Healthcare.

3. The assessment of primary health need

The consultation document sets out four categories of key indicators of a primary health need (nature, complexity, intensity, unpredictability). It is only in Annex B that it goes on to describe eleven generic care domains. The document as a whole does not describe how the interplay of the categories and domains will work in practice. Therefore it is impossible to understand or take a view on how satisfactorily the new national framework will work in practice in relation to real-life cases. The R&RA is concerned that older people with dementia in particular will continue to be excluded from eligibility. While the document states several times that it is need and

not condition that will determine eligibility, it does not demonstrate, through examples, how this will work in specific cases.

4. Decisions about continuing care

4.1 R&RA approves the decision-tree set out in the Assessment Framework in paragraph 30 but knows that the test will be in its application in practice. For those in hospital or in close contact with their GP, it will be relatively straightforward to start the process at the beginning (with the screening for eligibility for NHS Continuing Healthcare). For others, it will depend on the level of knowledge, understanding and awareness of a variety of staff (e.g. care home staff, domiciliary agencies and care workers, district nurses) and families as to when and whether the process is triggered or not. Training and awareness-raising will be essential across throughout the NHS and social care services.

4.2 Self-funders will be particularly vulnerable in this context. Although the document mentions NHS responsibility for assessing the registered nurse contribution in relation to self funders (paragraph 50), this will also apply in assessing eligibility for continuing care. How will this be assured – and monitored? Self-funders often have no-one to look after their interests.

4.3 As already noted, R&RA fears that periodic assessment and re-assessment (after three months and then at least annually), will be driven by the need to contain expenditure. Callers to the R&RA advice line are increasingly reporting that relatives in receipt of continuing care are being re-assessed more and more frequently (more than just annually) and their eligibility is often reclassified – so that they dip in and out of eligibility leading to repeated local authority financial assessments or calls on their own financial resources. This unsettles individuals and families and causes them continuing worry and confusion.

5. Registered nursing care

The R&RA believes that the current three-banded RNCC has been unsatisfactory and supports the proposal to introduce a single flat rate. Most people find current system difficult to understand and are bewildered by the three levels. They also think that continuing care is the equivalent of a fourth RNCC band. The introduction of a single band will solve the first problem but the difficulty in understanding the difference between the nursing contribution and full continuing care will remain. A further matter for concern is that the elimination of the three banded system will mean a substantial number of losers. On the basis that the flat rate will be based on a national average (£97 for the current year) – those people who have previously been rated as band 3 (currently £133) will lose out considerably. It is also likely that those currently assessed as band one, will simply fall out of the system altogether because the bar will be raised and their requirement for registered nursing input will be seen as too low.

6. Re-assessments and disputes

Paragraph 54 emphasises the need for the NHS and local authority to conduct joint re-assessments if any changes are to be made and to keep individuals and families properly informed. R&RA's experience is that currently patients and their representatives are very poorly informed about forthcoming changes in eligibility status. It is not confident that this will improve under the new framework. It is important to remember that the individuals involved are vulnerable, in poor health and often with dementia. Their families are often elderly themselves and easily confused and worried by such major change in the circumstances of their relatives. R&RA is concerned that people will not know how to challenge decisions and that the 'local disputes procedures' will be inadequate and insufficiently independent.

7. Conclusion

While welcoming the introduction of a national framework, the R&RA has a number of reservations:

- Staff responsible for undertaking assessments will need thorough and sensitive training to use the new framework fairly and in a person-centred way;
- All health and social care staff who have contact with older people will need careful training in awareness of, and understanding, the whole system to ensure that anyone who may be eligible receives NHS continuing healthcare;
- There will need to be some transition arrangements for those on RNCC band 3 who will lose £36 per week at current rates. Since most care homes build the RNCC rate into their overall fee, they are likely to look for the shortfall from the resident him/herself;
- Individuals and their families must be provided with jargon-free information about the new system;
- Individuals and their families must always be given detailed and jargon-free copies of all assessments and re-assessments;
- Patients and their relatives should be told of their rights of appeal and to see records held on them; they should also be given information about disputes/complaints procedures;
- Implementation of the new system should be evaluated.

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