

Consultation Response

NICE: Carers – Provision of support for Carers

Ref: 2019

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Age UK is the country's largest charity dedicated to helping everyone make the most of later life. The Age UK network comprises of around 150 local Age UKs reaching most of England. Each year we provide Information and Advice to around 5 million people through web based and written materials and individual enquiries by telephone, letters, emails and face to face sessions. We work closely with Age

Cymru, Age NI and Age Scotland. Local Age UKs are active in supporting and advising older people and their families in the care market.

About this consultation

The National Institute for Health and Care Excellence (NICE) has recently held a surveillance review which is their way of checking whether the guideline on ‘Care of dying adults in the last days of life’ needs to be updated. Age UK welcomes the review of all guidelines to ensure they consider all aspects of relevant evidence and information.

Key points and recommendations

- We believe there are some areas on the ‘Care of dying adults in the last days of life’ guideline that could do more to support health and care professionals. This includes communication about death and dying, shared decision making, and recognising when someone is in the last days of life.
- We highlight that despite representing 85% of people who die, those aged over 65 are still experiencing poor care at the end of their lives.

Age UK comments

Overall need to update the guideline	
Q-01	Do you think that recommendations in the guideline need to be updated?
	Yes
In brief, please provide any further details	
<p>The NG31 is a clear and concise document that could help inform health and care professionals and people who are dying, their families, carers and loved ones about caring for an adult in the last days of life. We believe there are some areas that the guidance could do more to emphasise, as laid out further in this document.</p>	
Q-02	Are there specific areas of this guideline that you think need to be updated?
	Yes
<p>The areas included in the guideline are:</p> <p>1.1 Recognising when a person may be in the last days of life</p> <p>1.2 Communication</p> <p>1.3 Shared decision-making</p> <p>1.4 Maintaining hydration</p> <p>1.5 Pharmacological interventions</p> <p>1.6 Anticipatory prescribing</p>	
<p>When thinking about which areas of the guideline that you think should be updated please consider why this is the case. Please also consider in your answer any recommendations which you believe have a negative impact on health and wellbeing or service provision and your reason for the concern.</p>	

For example, due to specific changes in practice, needs and opinions of people using services and their families, or new research.

If you answered 'yes', please provide details.

Specific areas of the guideline you feel should be the main focus of this review:

1. **Communication**
2. **Shared decision making**
3. **Recognising when a person may be in the last days of life**

Reasons for your choice of specific areas for the main focus of this review:

1. **Communication:** having conversations with people about death and dying can be difficult. We know that people often feel uncomfortable about the prospect of this conversation and this can apply not only to the person who is dying and their family, but also those health and care professionals involved in their care. The current guideline makes an assumption that there will always be a healthcare professional as part of a multidisciplinary team available who is confident in having these very important conversations. In practice this is not always reality, so we therefore recommend that this section is reviewed to take this into account and both give guidance on what to do if there is no professional who feels confident in conversations about dying and most importantly focus more on empowering all health and care professionals to feel confident and have the adequate training to be able to have conversations about death and dying.
2. **Shared decision making/recognising when a person may be in the last days of life:** the guidance should do more to sufficiently capture the need to record information, both clinical and relating to patient/family wishes, and to do so clearly and accurately. Handover of information about dying patients was cited in the Neuberger review as a factor in poor care, meaning a change of work shift could undermine the quality of care someone is receiving. The guidelines should place specific emphasis on accurately capturing and recording patient wishes, the outcomes of clinical assessment and any changes observed during reviews in a way that can be handed over to staff at the end of a shift or to out of hours staff. They should also include how this information should be communicated to family and carers if changes occur while they are not there – there is a general assumption in the guidance that there will always be a family member or carer available to discuss the care needs of a dying patient, which is unrealistic.

Other factors influencing the need to update the guideline

Q-03 Do you have any information about the implementation of the guideline in practice?

Yes

For example:

- Which recommendations have had the biggest positive impact in this area?
- Are you aware of key recommendations which are not being implemented in practice?
- What are the barriers stopping implementation?
- Are services being commissioned as described in the guideline?

If you answered 'yes', please provide details.

1. Though the clinical factors of someone in the last few days of life may be the same, there are very different practical barriers to delivering effective end of life care in hospital, a care home, and a person's own home, for example. Availability of nursing support, for example, particularly out of hours in the community is frequently cited as a factor in poor end of life care as is availability of pain relief. Poor skills in some care home staff, often the result of low

wages and high staff turnover, means there may be an unreasonable expectation that certain tasks can be carried out. And therefore, implementation of the guideline can be challenging given their generic nature.

2. As the guideline makes recommendations particularly aimed at health and care professionals, we believe there should also be recommendations aimed at commissioners and providers. These should include guidance on appropriate skills mix and staff numbers as well as the amount and type of commissioned services relevant to a local area, particularly where there are large concentrations of older people or care and nursing homes.
3. The guidance has an underlying assumption that the skills and training to carry out the recommendations exist in the range of settings described. The lack of education and training is regularly cited, in relation to poor standards of care at the end of life. A significant skills gap also exists in recognising the transition from, for example, severe frailty to dying (see for example, Gardiner, C., et al, *Barriers to providing palliative care for older people in acute hospitals*, Age and Ageing, 2011). Indeed, there may be a long period where someone is living with multiple conditions and frailty for whom a sudden change can lead very quickly to entering the dying phase. This is even more challenging to recognise when their needs are non-specific, i.e. relating to general declining health rather than the symptoms of a condition, and an event like a fall is just as likely to precipitate dying as a stroke (an event this guidance appears to exclude under “major trauma”). Skills and training relating to end of life care and older people in general are still very poor and recommendations to providers and commissioners (see above) must include having sufficient professionals with appropriate levels of training and ensuring that care of the dying is fully incorporated into the operations and pathways of any setting.

Q-04 Are you aware of any issues for specific groups of patients or people using services?

Yes

For example, inequalities in relation to age, disability (including learning disability and mental health), gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation, as outlined in the [Equality Act 2010](#), as well as inequalities arising from socioeconomic factors and from the circumstances of certain population groups, such as looked after children and homeless people.

If you answered ‘yes, please provide details.

Caring for older people, particularly the oldest old, means having a strong understanding of sometimes complex needs and having the skills to deliver proactive, planned support. This can mean constantly negotiating the pathway of active treatment (for example surgery; aggressive cancer therapies); management of long-term conditions and other challenges to wellbeing such as frailty; and where necessary an end of life care pathway (even if this is ultimately over a prolonged period). All the time, quality of life goals and individual preferences should be the guide to care and support. These pathways (active treatment; management; end of life) are fluid, often unstable and can be experienced at the same time. The ability to plan and move between them is a crucial feature of high quality care for older people. However, much of the discrimination older people experience both in end of life care and wider NHS services, can be attributed to the failure of the system to achieve this. Older people can find they are pigeon-holed, often without a detailed assessment of their needs, as either for active treatment or not appropriate for active treatment. However, there is still no guarantee such a moment that end of life care discussions would take place.

We know that despite representing 85% of people who die, those aged over 65 are still experiencing poor care at the end of their lives. For example:

- Only 16.4 percent of people gaining access to specialist palliative care services are 85 or over
- Research suggests that between 50 and 70 per cent of people would prefer to die at home, however only 19 per cent of deaths in people aged 75+ occur at home, compared to 34 per cent of people aged 15-64.
- People over 65 are most likely to die in hospital compared to other age groups and based on the VOICES survey of bereaved relatives, quality of care for those who died in hospital remains significantly lower to other places of death.

- People over 80 experience the worst overall quality of care in the last two days of life compared with other age groups, covering such areas as pain relief, nutrition and emotional needs.
- There is huge variation in the numbers of older people living in care homes who die in hospital, ranging from none to every resident death.
- People 65-79 in care homes have a poorer experience with regards to dignity and respect at the end of life compared with other age groups, though it is slightly better for people over 80. A report by the Nuffield Trust showed a two-fold difference between certain areas of the country in the proportion of people using social care in the month prior to death, suggesting that your access to services is highly dependent on where you live.
- The most recent national survey of bereaved people showed that people over 80 were least informed about the fact they were likely to die. This age group, perhaps unsurprisingly, were also least likely to have said where they would like to die and relatives were less likely to say the person had enough choice over place of death

Q-05 Any other comments?

No

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