NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

Care of the dying adult

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

3.0 Guideline development: before consultation (to be completed by the developer before draft guideline consultation)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?
The following equality issues were identified during the scoping process and have been addressed by the committee. It is acknowledged that the care of people with dementia, cognitive impairments or learning disabilities who are in the last few days or hours of life may be especially challenging, particularly in terms of recognising dying and managing pain or other symptoms. The GDG were cognisant of this when reviewing evidence and formulating recommendations. *The needs of these groups were considered at every stage of development and, as specific populations, were included in our review protocols to determine if any evidence existed that would inform separate recommendations. No evidence was found. The GDG invited a co-opted expert, Dr Julian Hughes, to discuss the specific needs and challenges in providing end of life care to people with dementia, cognitive impairments or learning disabilities and to review its draft recommendations. The guideline refers to the recommendations on communication in the NICE guideline on patient experience in adult services (CG138) as a source of further guidance. All recommendations are relevant for these groups but specific references are identified in recommendations 1.2.1 and1.5.17* It is further recognised that there may be ethnic and cultural issues related to managing pain or other symptoms, and the undesirability of potential sedation in the last few days or hours of life. The GDG were cognisant of these when reviewing evidence and formulating recommendations. *These issues were considered throughout development. The GDG invited a co-opted expert, Lynn Bassett, to review its draft recommendations and advise the GDG regarding spiritual needs. This advice, together with the GDG's experience, also informed cultural, religious, social, spiritual and psychological needs-based recommendations. All recommendations are relevant for these groups but specific references are identified in: 1.1.7; 1.3.2; 1.4.7;1.5.7* It is crucial that people important to those dying are engaged in any communication or information sharing as appropriate. National policy has already clarified that these should include, (where possible, with consent) those important to the dying person and as such this has implications for, for example, LGBT relationships. *These issues were considered throughout development. All recommendations are relevant to these groups. In line with language used in the2014 Leadership Alliance for the Care of Dying People document 'One chance to get it right' , recommendations indicate that people important to the dying*

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person should be involved. This guideline has not specified categories of people (e.g. family/friends/partners) as these are particular to each individual dying person. Specific recommendations which include reference to people important to the dying person are: 1.1.4; 1.1.7;1.3.2;1.3.4;1.3.5;1.3.7;1.4.3;1.4.4;1.4.5;1.4.6;1.5.1;1.5.2;1.5.24; 1.5.33; 1.5.34; 1.5.35;1.5.36;1.6.1. Crucially, the guideline also acknowledges that all decisions should be informed by the dying person's wishes. This may include a decision not to include others in decision-making or information sharing and the guideline makes specific reference to this issue in recommendations: 1.2.1;1.2.2;1.2.7;

It is noted that consideration may also need to be given to people in their last few days of life who are from traveler communities when drafting any recommendations from the proposed review areas. This may have particular relevance to the role of anticipatory prescribing.

Two recommendations were made that are potentially linked to this issue. Recommendation 1.6.2 addresses the need to prescribe medications in a timely manner. 1.6.4 identifies that access to medications prescribed in anticipated need for symptom control is affected by place of care and particularly a time frame of access to that medication.

The spiritual needs of those in the last few days are important to consider and whilst faith and belief are protected characteristics in terms of the act, we are aware that spiritual needs may be met by appropriate faith and belief support, other non-religion based needs should also be considered important. We considered spiritual needs in the broadest sense within the context of each of our review questions.

These issues were considered throughout development. The GDG invited a co-opted expert, Lynn Bassett, to review its draft recommendations and advise the GDG regarding spiritual needs. Specific recommendations linked to this issue include:1.1.1; 1.1.2;1.1.7;1.3.2.

3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

Homeless people's access to pharmacological management for symptom control.

The GDG were aware that homeless people (as well as those from traveller communities) had special problems with regards to accessing pharmacological management for symptom control. This applies for both regular medication and 'as required' medication. Another issue arises when anticipatory prescribing is needed and the dying person is in a setting where secure storage of such medication is not feasible. The GDG's experience was that in most cases, such people nearing the end of life are usually brought into a place of care where NHS staff can care for them and medication can be offered safely and securely.

Access to services at end life for people in prison

The GDG discussed the needs of prisoners at end of life but felt that as prison health care services were supported by NHS staff, provided that prisoners and their healthcare staff had access to specialist palliative care support when needed, then all the recommendations would apply. Medications could be offered safely and securely in the same way as for any other groups. No specific recommendations for this group were made.

3.3 Were the Committee's considerations of equality issues described in the consultation document, and, if so, where?

Dementia, Cognitive impairments or learning disabilities

The recommendations, that cover this population are discussed in detail in the linking evidence to recommendations statement in the Communication (section 6.6) and pharmacological management of pain (section 9.5) chapters.

Ethnic and cultural groups

The recommendations, that cover this population are discussed in detail in the linking evidence to recommendations statement in the recognising dying (section 5.8), shared decision making (section 7.5), general pharmacological considerations (section 9.3) and maintaining hydration (8.6)chapters.

LGBT community

The recommendations that cover this population are discussed in detail in the linking evidence to recommendations statement in the in chapters: Shared Decision Making (section 7.5), Communication (section 6.6), Noisy Respiratory Secretions (section 9.29) and Anticipatory Prescribing (section 10.8).

Traveller community

Recommendations that cover this population were discussed in the linking evidence to recommendations statements in the Anticipatory prescribing chapter (section 10.8)

Homeless people

Recommendations that cover this population were discussed in the linking evidence to recommendations statements in the Anticipatory prescribing chapter (section 10.8)

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No.

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?
No.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?
The GDG considered the needs of homeless people in the last days of life and access to medication for symptom management. No specific recommendations were made for this group as the GDG felt if the person had no permanent residence, they would not be discharged from care and therefore all recommendations would apply. Similarly, arrangements would be made for prisoners in terms of access to medications for symptom management by NHS staff providing health care services in that setting NICE have commissioned an update of the Improving supportive and palliative care in adults guideline to include issues related to service delivery extending beyond a cancer focus. This guideline may address access to services.