Circular HSC (SQSD) (NICE NG61) 9/17

Subject: NICE Clinical Guideline NG61 – End of life care for infants, children and young people with life-limiting conditions: planning and management

From the Deputy Chief Medical Officer
Dr Paddy Woods

Circular Reference: HSC (SQSD) (NICE NG61) 9/17

Date of Issue: 30 January 2017

Related documents:
HSC (SQSD) 3/13

Superseded documents
None

Summary of Contents:
This guideline covers the planning and management of end of life and palliative care in for infants, children and young people (aged 0–17 years) with life-limiting conditions. It aims to involve children, young people and their families in decisions about their care, and improve the support that is available to them throughout their lives.

Enquiries:
Any enquiries about the content of this Circular should be addressed to:
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Stormont Estate
Belfast
BT4 3SQ

SGU-NICEGuidance@health-ni.gov.uk

Status of Contents:
Action

Implementation:
As per circular. Generally, Clinical Guidelines should be implemented within 12 months of endorsement.

For action by:
Chief Executive of HSC Board – for distribution to:
All HSC Board Directors – for cascade to relevant staff

Director of Integrated Care, HSC Board – for cascade to:
Head of Pharmacy and Medicines Management
Family Practitioner Services Leads – for cascade to relevant Family Practitioner groups

Chief Executive of Public Health Agency – for distribution to:
Director of Public Health and Medical Director – for cascade to relevant staff
Director of Nursing and AHPs – for cascade to relevant staff

Chief Executives of HSC Trusts – for distribution to:
Medical Directors – for cascade to relevant staff
Directors of Nursing – for cascade to relevant staff
Heads of Pharmaceutical Services – for cascade to relevant staff
Directors of Acute Services – for cascade to relevant staff
HSC Clinical and Social Governance Leads
Directors of Social Services – for cascade to relevant staff
Directors of Finance – for cascade to relevant staff
AHP Leads – for cascade to relevant staff

Chief Executive, Regulation & Quality Improvement Authority – for cascade to: relevant independent healthcare establishments

Chief Executives of HSC Special Agencies and NDPBs

For Information to:
Chair of HSC Board
Chair of Public Health Agency
Chairs of HSC Trusts
Chair of RQIA
NICE Implementation Facilitator NI
Members of NI NICE Managers’ Forum

Available to download from
Dear Colleagues

NICE Clinical Guideline NG61 - End of life care for infants, children and young people with life-limiting conditions: planning and management

https://www.nice.org.uk/guidance/ng61

The Department has recently reviewed the above NICE guidance and has formally endorsed it as applicable in Northern Ireland.

In accordance with the process outlined in circular HSC (SQSD) 3/13, the following actions should be taken (https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/hsc-sqsd-3-13.pdf)

1. HSC Board / PHA
   a. Identify a Professional Lead who will consider the commissioning implications of the Clinical Guideline and co-ordinate with any other relevant commissioning teams. This Lead will identify any areas where regional planning / investment / commissioning are required, or where there is material risk to safety or quality. These will then be actioned immediately through normal commissioning arrangements or through bespoke arrangements reflecting the nature of the issue / risk.
   b. Ensure that relevant guidance is sent to the appropriate Family Practitioners.
   c. Seek positive assurance from the HSC Trusts that the required initial actions have been undertaken within a 3 month period, and that the Guideline has been implemented within a further 9 months (unless otherwise notified by the HSC Trusts).
   d. Where significant investment/ commissioning needs cannot be met within the usual timeframe, agree appropriate arrangements with HSC Trusts. Report to DoH as required at 6 monthly accountability meetings.

2. HSC Trusts
   a. Proceed with targeted dissemination, agree a clinical/management lead to coordinate implementation and consider what has to be done to achieve implementation using a risk based assessment and baseline review as appropriate to support planning. These initial actions should be undertaken within a three month period.
   b. Implement the Guideline within a further 9 months (apart from any elements where significant issues have been raised with the HSC Board/PHA).
   c. Provide positive assurances to the HSC Board that required initial actions have been taken within the 3 month planning period and that the Guideline has been implemented within a further 9 months, where appropriate.
   d. Where significant investment/ commissioning needs cannot be met within the usual timeframe, notify the HSC Board/PHA at the earliest opportunity through the bi-monthly director level meetings and agree appropriate arrangements with them to achieve implementation.

3. RQIA
   a. Disseminate the Guideline to the independent sector as appropriate.

4. HSC Special Agencies and NDPBs
   a. Take account of this Guideline in training and other developments as appropriate.
To inform the planning process, please find attached details from the Departmental review. You should consider and take account of other relevant Departmental policies and strategies in your planning, as well as any legislative / policy caveats identified in the course of the Departmental review.


Dr Paddy Woods
Deputy Chief Medical Officer
Appendix 1

**Endorsed NICE guidance - Details from Departmental review**

| Reference Number | NICE Clinical Guideline – NG61  
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| Summary of guidance | This guideline covers the planning and management of end of life and palliative care for infants, children and young people (aged 0–17 years) with life-limiting conditions. It aims to involve children, young people and their families in decisions about their care, and improve the support that is available to them throughout their lives. It includes recommendations on:  
- Advance Care Planning  
- emotional and psychological support and interventions  
- managing distressing symptoms, such as pain, agitation, seizures or respiratory distress  
- hydration and nutrition  
- recognising that a child or young person is likely to die within hours or days  
- care and support for parents, carers and healthcare professionals after the death of a child or young person  
- care at home |
| Related strategically relevant DoH/ HSC policies | A Strategy for Children’s Palliative and End-of-Life Care 2016-26  
| Inter-Departmental interest | None |
| Legislative / policy caveats | This advice does not override or replace the individual responsibility of health professionals to make appropriate decisions in the circumstances of their individual patients, in consultation with the patient and/or guardian or carer. This would, for example, include situations where individual patients have other conditions or complications that need to be taken into account in determining whether the NICE guidance is fully appropriate in their case. 

Where this guidance indicates that informed consent should be obtained and documented, the DoH guidance *Reference Guide to Consent for Examination, Treatment or Care (2003)*, gives advice on the law concerning consent to intervention. Available at: [https://www.health-ni.gov.uk/articles/consent-examination-treatment-or-care](https://www.health-ni.gov.uk/articles/consent-examination-treatment-or-care)

A booklet ‘*Your life and your choices: plan ahead (Northern Ireland)*’ has been developed by the Public Health Agency and Macmillan Cancer Support to help provide the public with information on Advance Care Planning and can be accessed at [http://be.macmillan.org.uk/be/p-21065-your-life-and-your-choices-plan-ahead-northern-ireland.aspx](http://be.macmillan.org.uk/be/p-21065-your-life-and-your-choices-plan-ahead-northern-ireland.aspx)

This guidance makes reference to Social Care guidance which has not been endorsed by the Department. |