From the Deputy Chief Medical Officer
Dr Paddy Woods

Circular HSC (SQSD) (NICE NG42) 28/16

Subject: NICE (Clinical) Guideline NG42 – Motor neurone disease: assessment and management

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

Summary of Contents: This guideline updates and replaces NICE
guideline CG105 and includes new recommendations on assessing
and managing MND. It covers assessing and managing motor
neurone disease (MND). It aims to improve care from the time of
diagnosis, covers information and support, organisation of care,
managing symptoms and preparing for end of life care.

Enquiries:
Any enquiries about the content of this Circular should be addressed
to:
Quality Regulation and Improvement Unit
DHSSPS
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Castle Buildings
Stormont Estate
BELFAST
BT4 3SQ

SGU-NICEGuidance@dhsspsni.gov.uk

Circular Reference: HSC (SQSD) (NICE NG42) 28/16

Date of Issue: 19 April 2016

Related documents:
HSC (SQSD) 3/13
TA20 - Riluzole (Rilutek) for the treatment of Motor Neurone Disease

Superseded documents
CG105 - The use of non-invasive ventilation in the management of
motor neurone disease

Status of Contents:
Action

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

Additional copies:
Available to download from
Dear Colleagues

NICE Clinical Guideline NG42 - Motor neurone disease: assessment and management

https://www.nice.org.uk/guidance/ng42

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.dhsspsni.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 DHSSPS 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
# Endorsed NICE guidance - Details from Departmental review

| Reference Number | NICE Clinical Guideline – NG42  
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<tr>
<td>Title</td>
<td>Motor neurone disease: assessment and management</td>
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| Summary of guidance | This guideline updates and replaces NICE guideline CG105 (Endorsed by DHSSPS in May 2012) and includes new recommendations on assessing and managing MND.  
It covers assessing and managing motor neurone disease (MND). It aims to improve care from the time of diagnosis, and covers information and support, organisation of care, managing symptoms and preparing for end of life care.  
The guideline includes recommendations on:  
- recognition and referral  
- information and support at diagnosis  
- cognitive assessments  
- prognostic factors  
- organisation of care  
- planning for end of life  
- managing symptoms |
| Related strategically relevant DHSSPS / HSC policies | None |
| 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. 
The Mental Capacity Act 2005 and the Department of Health document ‘Reference Guide to Consent for Treatment or Examination’ do not apply in NI, but work is under way to bring forward similar legislation |
for NI, incorporating mental capacity and mental health provisions. The DHSSPS guidance ‘Reference Guide to Consent for Examination, Treatment or Care (2003)’, which is available on the DHSSPS website, gives advice on determining whether a person has capacity and on what action may be taken where the person lacks capacity. Available from: https://www.dhsspsni.gov.uk/articles/consent-examination-treatment-or-care

Where the guidance indicates that informed consent should be obtained and documented, the DHSSPS guidance ‘Reference Guide to Consent for Examination, Treatment or Care (2003)’, which is available on the DHSSPS website, gives advice on the law concerning consent to intervention. Available from: https://www.dhsspsni.gov.uk/articles/consent-examination-treatment-or-care

Reference to Lasting Power of Attorney is also not applicable to Northern Ireland where the Enduring Powers of Attorney (Northern Ireland) Order 1987 allows instead for the appointment of an Enduring Power of Attorney.

Each Health and Social Care Trust currently has its own policy for making and recording Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions. Work is ongoing to develop a regional operational policy on DNACPR for use in both community and hospital settings and across organisations.

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