NHS Borders
Planning & Performance

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Freedom of Information request 284-19

Request

I would like to request the following information under the Freedom of Information (Scotland) Act 2002:

1. A copy of all health board policies and guidance regarding the certification of death when a patient has had a terminal or life-shortening condition.

2. If the health board makes use of expected or anticipated death forms? If so,

   a. The circumstances in which such a form should be used.
   b. The timescales within which such a form can be used.
   c. A copy of the form.

3. A copy of all guidance given to staff and GP services on what paperwork and forms are to be completed when a patient has a life-shortening condition and death is imminently expected.

Response

1. The Palliative Care Team has developed a document called the CREOL to improve the quality of end of life care.

   The Liverpool Care pathway (LCP) was withdrawn from use within Scotland by the Scottish Government in 2014 and subsequently NHS Borders withdrew their Integrated Care Pathway for the dying patient. Later in 2014 the Scottish Government published guidance on end of life care “Caring for people in the last hours and days of life”, but no care plan to replace the LCP was introduced. Following consultation with major Palliative Care groups across Scotland, a Strategic Framework for Action on Palliative and End of Life Care was published by the Scottish Government in early 2016 which stated their commitment to work with partners to ensure that high quality palliative and end of life care is available to all who can benefit from it.

   In response to this assertion within NHS Borders a short life working group was formed in regard to the new challenges to delivering end of life care, namely acknowledgement of the difficulty in diagnosing the dying phase and lack of documentation to support the delivery of appropriate care. After wider consultation the end of life vision document was created which set out our mission, aims and objectives which would help achieve the aim of high quality palliative and end of life care available to all in any and all settings.

   This document the Care Record for End of Life (CREOL) was developed to help achieve high quality accessible end of life care across NHS Borders.

2. a) The circumstances in which the form should be used are documented below:

   The CREOL is a record of care delivered to patients at end of life and is not a tick box exercise or rigid process or procedure to be followed. It can be used to promote discussion of diagnosis of dying between clinicians and the wider MDT, and clear, concise communication between clinicians, patient and family or carers.

It is flexible and allows the MDT to focus on relevant issues at end of life with clearly defined areas for daily assessment of symptoms so these issues can be reviewed and addressed quickly. The patient's wishes and goals of care are clearly documented so future care can be planned in accordance with this, ensuring all clinicians including out of hours are informed and aware of care needs at end of life. The CREOL has also been designed so it is flexible in use and can be used in any and all settings – acute, community and care home. Clinicians, carers and the wider MDT across the board will be familiar with one document with a common goal which should ease communication and understanding. The document travels with the patient and stays with them if they are discharged from acute setting to home for end of life care or admittance to a hospital setting following an acute episode at home when end of life care at home is no longer an option. It replaces the unitary patient notes used in the acute setting and the nursing notes held by the patient in a community setting so reducing duplication of effort and enhancing communication.

b) The timescales within which the form can be used can vary and depends on when the diagnosis of dying has been made

Areas for initial discussion and assessment include:

- Diagnosis and signs present that the patient is now dying.
- Discussion of the deterioration with the patient and or family.
- Confirmation that contact details are available and up to date.
- Review and rationalisation of medicines.
- Regular review of nutrition and hydration.
- Resuscitation status and goals of care clearly documented.
- Preferred place of care clearly documented.
- Spiritual care and wellbeing issues addressed.
- Welfare benefits
- Bereavement support
- Post mortem issues including organ donation.

The document continues with space for documentation of daily assessment of particular symptoms such as pain, agitation and distress but also wider areas of concern such as spiritual and social issues of the patient and the family or carers. A blank page is also provided for notation of any changes to the patient's condition or further input from the wider MDT for each day. The trend in management of symptom control, deterioration of patient and ability to address wider issues such as spiritual or social concerns can be clearly reviewed and addressed as each new day starts with a new page.

The CREOL meets the NHS Borders corporate objectives by helping deliver a safe and effective high quality service. A health promotion approach is taken with the early discussion around death and dying and what matters to the patient and their families and training and use of the CREOL will help promote a culture within the organisation which supports good quality end of life care. A copy of the CREOL is attached.

c) Copy of form attached:

CREOL form.doc

3. Guidance and training is delivered to teams of small numbers by our Palliative and End of Life Care Facilitators. One to one training and coaching can also be delivered throughout the course of care delivery to patients approaching end of life. The document contains notes on guidance around care delivery and support both in and out of hours. The following is an extract from the document.

   Initial Assessment and Regular Planned Review and Documentation Is Essential

   The following pages will provide a way of documenting discussions clearly and concisely and enhance care provision out of hours.

   - The initial assessment should be completed at the time that it is decided that a patient is diagnosed as in the last days of life.
   - Phase of illness should be noted in relation to the patient's holistic management.

- Daily assessments should be recorded on the daily assessment sheet preferably following the morning ward round (in acute settings) or after assessment in other areas.
- Assessments when the patient's condition changes and overnight entries should be recorded in the blank page opposite the daily assessment sheet. If more than one page is required for free text then following day assessment sheet scored out and continue on the next blank page.
- Each day should be recorded on a new daily assessment sheet and starts at the start of the morning shift and ends at the end of the night shift. There are a total of 7 days worth of assessments.
- A continuation document can be used after day 7 if required however after day 7 patients should be assessed by MDT to consider reverting to standard Unitary Patient Notes documentation.
- It should be remembered that the process may be fluid and decisions should be reviewed regularly, including the diagnosis that the patient is in the last days of life.
- If Medical Certificate for Cause of Death can be issued out of hours ensure page 28 of CREOL completed by certifying doctor.

If you are not satisfied with the way your request has been handled or the decision given, you may ask NHS Borders to review its actions and the decision. If you would like to request a review please apply in writing to, Freedom of Information Review, NHS Borders, Room 2EC3, Education Centre, Borders General Hospital, Melrose, TD6 9BS or foi.enquiries@borders.scot.nhs.uk.

The request for a review should include your name and address for correspondence, the request for information to which the request relates and the issue which you wish to be reviewed. Please state the reference number **284-19** on this request. Your request should be made within 40 working days from receipt of this letter.

If following this review, you remain dissatisfied with the outcome, you may appeal to the Scottish Information Commissioner and request an investigation of your complaint. Your request to the Scottish Information Commissioner should be in writing (or other permanent form), stating your name and an address for correspondence. You should provide the details of the request and your reasons for dissatisfaction with both the original response by NHS Borders and your reasons for dissatisfaction with the outcome of the internal review. Your application for an investigation by the Scottish Information Commissioner must be made within six months of your receipt of the response with which you are dissatisfied. The address for the Office of the Scottish Information Commissioner is, Office of the Scottish Information Commissioner, Kinburn Castle, Doubledykes Road, St Andrews, Fife.