

Identifying patients with life-limiting illness and planning supportive and palliative care in Leeds

(Adapted from Macmillan Cancer Support, NHS Camden and Islington guide to identifying patients for supportive / palliative care)

People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected to die within a few days or hours) and those with:

- Advanced, progressive, incurable conditions
 - General frailty and coexisting conditions that mean they are expected to die within 12 months
 - Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
 - Life-threatening acute conditions caused by sudden catastrophic events
- GMC, 2010; NICE, 2011**

The aim of this guidance is to support healthcare professionals in identifying patients who are approaching end of life. Patients identified as approaching the end of life, with patient consent could be included on the Palliative Care Register (EPaCCS) giving them the opportunity for better planned and coordinated care in line with their preferences and priorities. Access to palliative care services is also an option.

What is the Electronic Palliative Care Coordination System (EPaCCS)?

EPaCCS is a shared electronic summary of up-to-date patient information to inform end-of-life decision-making and care delivery at the point of care, across service boundaries, for patients in the last months / year of life who have consented to inclusion.

The benefits for patients

- Earlier identification gives patients the opportunity to express their preferences about future care and have these documented
- Their healthcare information can be shared to support provision of co-ordinated care delivered by staff aware of their medical condition, care plan and preferences
- They have timely access to services that provide supportive and palliative care

The benefits for healthcare teams

- Sharing of patient information improves co-ordination and planning of care and anticipation of crises
- Increased knowledge of patients' needs and preferences supports clinical decision making
- Sharing of patient information supports effective GSF meetings by highlighting information gaps and potential PC patients
- Links to useful websites and documentation save time and support decision-making

The benefits for carers

- Carers own needs are fully assessed and they are offered support to help them cope
- Access to emotional, spiritual and bereavement support is available if required.

The EPaCCS approach

Identify

General and disease specific prognostic indicators (see overleaf) can help to support clinical judgement

Communicate

Consider how to approach conversations about end of life care

Establish patient consent to share their information on EPaCCS

Open shares with healthcare professionals involved in the patient's care, including OOHs

Add to Palliative Care Register

Include patients you have identified as approaching end of life on your Palliative Care Register (EPaCCS)

Record patient information on EPaCCS and review at GSF meetings

Information about patient's end of life care preferences and care plan is recorded and shared e.g. preferred place of care, DNACPR status and review of fast track status

Discuss preferences: Offer patients the opportunity to discuss their preferences about their future care and record
Assess needs: Develop care plans reflecting these needs and preferences

Supportive and Palliative Care Indicators Tool (SPICT)

Adapted from NHS Lothian 2011 v2 April 2013

1. Look for two or more general clinical indicators

- Two or more unplanned hospital admissions in the past 6 months.
- Performance status deteriorating (needs help with personal care, in bed or chair for 50% or more of the day).
- Unplanned weight loss (5 - 10%) over the past 3 - 6 months and / or body mass index < 20.
- A new event or diagnosis that is likely to reduce life expectancy to less than a year.
- Persistent symptoms despite optimal treatment of advanced illness.
- Lives in a nursing care home or NHS continuing care unit; or needs a care package at home.

2. Now look for two or more clinical indicators of advanced, progressive illness

Advanced heart / vascular disease

- NYHA Class IV heart failure, or coronary artery disease:
 - Breathless or chest pain at rest or on minimal exertion
- Severe, inoperable peripheral vascular disease

Advanced respiratory disease

- Severe chronic obstructive pulmonary disease (FEV1<30%) or severe pulmonary fibrosis:
 - Breathless at rest or on minimal exertion between exacerbations
- Has needed ventilation for respiratory failure

Advanced kidney disease

- Stage 5 chronic kidney disease (eGFR < 15ml/min)
- Kidney failure as a recent complication of another condition or treatment
- Stopping dialysis

Advanced liver disease

- Advanced cirrhosis with one or more complications in past year:
 - Diuretic resistant ascites
 - Hepatic encephalopathy
 - Hepatorenal syndrome
 - Bacterial peritonitis
 - Recurrent variceal bleeds
- Serum albumin < 25g/l, INR prolonged (INR > 2)
- Liver transplant is contraindicated

Advanced cancer

- Performance status deteriorating due to metastatic cancer and / or co-morbidities
- Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment

Advanced neurological disease

- Progressive deterioration in physical and / or cognitive function despite optimal therapy
- Speech problems with increasing difficulty communicating and/or progressive dysphagia
- Recurrent aspiration pneumonia; breathless or respiratory failure

Advanced dementia / frailty

- Unable to dress, walk or eat without help; unable to communicate meaningfully
- Needing assistance with feeding maintaining nutrition
- Recurrent febrile episodes or infections; aspiration pneumonia
- Urinary and faecal incontinence
- Fractured neck of femur

3. Is this patient at risk of dying in the next 6-12 months, or less? YES

4. Consider how to approach conversations about end of life care

5. Discuss inclusion of the patient on the Palliative Care Register with GP / members of the MDT

6. Assess needs and plan care:

- Which services should be involved?
- Who is best placed to be the Key Worker?

Initiating conversations about end of life care

It is good practice to offer patients approaching the end of life the opportunity to discuss their preferences about future care, so that care and services can be appropriately planned. This should be a voluntary process of discussion with which some patients may not wish to engage at this time or in the future.

Conversation triggers can include diagnosis of a life limiting condition or recurrence, a marked deterioration in condition or declining performance status, and recent admission to hospital or a nursing home. Alternatively the patient may ask a question about the future, death or dying, or as a result of uncontrolled symptoms such as pain or anxiety.

Getting communication right can help patients feel supported when approaching end of life and it is important to think about whom the right person is, when the right time is and where the right place is to have these discussions. Below are some tips for effective communication:

- Use active listening and open ended questions
- Respond to cues
- Acknowledge, empathise, reflect and summarise

- Use non verbal communication e.g. maintaining eye contact
- Check understanding

What someone approaching end of life might be thinking about and want to discuss with someone:

- The type of care they would like towards end of life
- Where they'd like to die
- How long they want doctors to treat them
- Their funeral arrangements
- Care of any dependents
- How they'd like to be remembered
- Worries about being ill and dying
- What they'd like people to know before they die
- How they feel about people
- Organ donation

(Taken from *Dying Matters* leaflet 'To do list')

A wide range of resources to help people start conversations about dying, death and bereavement are available on the Dying Matters website. The Yorkshire Cancer Network has a summary of patient and carer information (see 'websites and further information' section below).

Approaching conversations about electronic record sharing on EPaCCS

Below are some suggested phrases to support conversations about electronic record sharing:

"We have a new way of electronically recording information..."

The information we record will be accessible by the out of hours GP service and the night nursing service and also the ambulance service, as well as the community nursing service and local hospices...

This is designed to give you an opportunity to make decisions and express your views and wishes about your medical care...

If you need any emergency medical care in the future, the healthcare professionals will be able to access your information to ensure they give you the best and most appropriate care which is in line with your wishes...

We need your consent to share your record and therefore this will not be done without you knowing."

Advance care planning

As a result of these discussions some patients may want to document their preferences about end of life care and links to national tools and further information are available within the Advance Care Planning sections of the EPaCCS template.

Assessing needs and planning care

Assess needs

- Assess patient and family needs
- Develop care plans reflecting these needs and patient preferences. Review regularly

Coordinate care

- Identify a key worker
- Share patient information and review at GSF meetings
- Ensure timely referral to appropriate services
- Agree and share emergency care plans for patients at risk of rapid deterioration
- Ensure resuscitation status and preferred place of care / death is shared with consent
- Complete OOHs handover forms

Palliative care services in Leeds

The District Nursing (DN) service can provide support at home seven days a week for patients identified as approaching end of life. Typically this includes access to equipment, symptom control and psychological, social and spiritual support. As patients' needs increase DNs work closely with **Specialist Social Workers** and **Joint Care Managers** to access additional care when needed.

Community Matrons and **specialist community nursing teams**, such as the Heart Failure and Respiratory Teams, may be involved with patients who have long term conditions and can also provide support.

Specialist Palliative Care services are available in hospice, hospital and community settings to support patients with complex palliative care needs.

Yorkshire Ambulance Scheme (YAS) Hospital avoidance scheme: paramedics will consider referral of palliative care patients to DNs if admission would not be of medical benefit or is against the patient's wishes.

Dedicated Palliative Care Ambulance supports patients wishing to be transferred to their preferred place of care or requiring urgent palliative treatment or investigations.

NHS Direct OOHs Palliative Care Line is available for patients approaching end of life who may need access to GP or DN support OOHs.

Websites and further information

In 2009, the National Council for Palliative Care (NCPC) set up the **Dying Matters Coalition** to promote public awareness of dying, death and bereavement and provide resources for the public and professionals at <http://www.dyingmatters.org/overview/resources>

Yorkshire Cancer Network Information Pathway outlines end of life information resources to support patients and their families <http://www.ycn.nhs.uk/html/publications/information.php>

National end of life care programme provides a wide range of information and resources to support health and social care staff <http://www.endoflifecareforadults.nhs.uk/>

Leeds Palliative Care website provides many more resources (including information on those listed above) and links to other websites for both professionals and patients www.leedspalliativecare.co.uk