Leicestershire Medicines Strategy Group

Anticipatory Prescribing for Patients on the Palliative Care Register for Non-Malignant Conditions
Primary Care Guidance

Contents

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Anticipatory Prescribing for Patients on the Palliative Care Register for Non-Malignant Conditions in Primary Care

The LMSG website hosts a range of palliative care documents and a link to the LOROS website under the title 'Palliative care,' to aid prescribing in this group which clinicians must familiarise.
http://www.lmsg.nhs.uk/guidelines/health-community/palliative-care-2/

Up to 12 months to live or may live for years

- Medication review to rationalise oral drugs with the aid of STOPP START tool kit http://267lv2ve190med3l1mgc3ys8.wpengine.netdna-cdn.com/wp-content/uploads/2016/04/STOPP_START_Tool.pdf
- Discuss predictable complications (e.g. bleed, seizure or infection) with patient/family and plan for its management.
- Document medication changes and plan for choice of drugs for anticipated symptom control in the advance care plan of the patient.
- Regular review and update of medication depending on patient's condition.
- 'Deciding right medication review of current drugs template' must be completed and the Personalised Care Plan – Deciding Right (previously called EHCP) should be placed in a plastic wallet before handing over to the patient/carer to store in the Green Medication bag, which the patient may already have or can be requested from patient's local chemist

Few months to live (2 months or more)

All aspects of review as above to be followed. In addition, these patients may require reviews more frequently based on clinical conditions and symptoms, as there is a likelihood of rapid deterioration

Last few weeks (6 weeks or less) /days of life

- Anticipatory prescribing as per care plan.
- Anticipatory prescribing even if patient is symptom free at this stage for the four symptom categories based on the 'Deciding Right - anticipatory prescribing template'. Update Personalised care plan with this information.
- Complete LLR authorisation for palliative care anticipatory medications and print out for storing with patients medications.
- The **Personalised Care Plan** – Deciding Right (previously called EHCP), **anticipatory medications** and the signed **LLR authorisation form** should be placed in a plastic wallet before handing over to the patient/carer to store in the Green Medication bag, which the patient may already have or can be requested from patient's local chemist. Out of Hours Service, and others involved in the care of the patient must be made aware of the clinical situation and the availability of drugs.
- Patients and carers would not be expected to take the anticipatory EOL medications prescribed into hospital if the patient needs to go in for investigation, attend clinic or if being admitted for any reason

Background

Patients in the last stage of their life (last 12 months of life) are identified through the use of a predictive tool and recorded on the GP practice palliative care register. The service provision is then for an advance care plan called the **Personalised Care Plan – Deciding Right,** (previously called the Emergency Health Care Plan {EHCP}), to be completed after discussing with the patient and/or their carer's[1].

The process is divided into 4 key stages:

1. Stage 1 involves patient assessment with the assistance of SPICT tool to be entered on to the palliative care register. This also includes completion of key documentation in patient clinical records.
2. Stage 2 involves MDT assessment and care planning discussions for individual patients
3. Stage 3 involves anticipatory prescribing
4. Stage 4 involves completion of the After Death Audit (ADA)

The demographic of death is changing with the ageing population and includes death from cancer as well as life-limiting illnesses such as cardiac, neurological, renal and respiratory diseases. Symptoms and medication needs can vary between patients with malignant and non-malignant conditions and between those in the last few weeks/days of life and those with a longer prognosis.
An independent review More Care Less Pathway [2] identified that there was a lack of clarity currently over the dying process and meaning of the term 'end of life.'

The words 'End of life' cover a wide range of timeframes from the last year of life of a person with a chronic and progressive disease to the last months, the last weeks or for the end of life subcutaneous medications the last hours or days of life in any settings (hospitals or the community). A doctor's statement about the patient being now at the 'end of life' may be misinterpreted for certain medications to be initiated inappropriately. The review recommends clear timeframes are to be taken into account for various treatment considerations and suggests the following as a model.

END OF LIFE → **THE DYING PHASE**				
At risk of dying in 6 – 12 months, but may live for years	**MONTHS** 2 – 9 months	**SHORT WEEKS** 1 – 8 weeks	**LAST DAYS** 2 – 14 days	**LAST HOURS** 0 – 48 hours
DISEASE(S) RELENTLESS Progression is less reversible Treatment benefits are waning	**CHANGE UNDERWAY** Benefit of treatment less evident. Harms of treatment less tolerable	**RECOVERY LESS LIKELY** The risk of death is rising	**DYING BEGINS** Deterioration is weekly/daily	**ACTIVELY DYING** The body is shutting down The person is letting go.

Individualized care plans supporting care in accordance with "The Priorities of Care for the Dying" and NICE Guidance on Care for Dying are used as a models of good practice in the last hours and days of life and are not a treatment in itself. They are a framework for managing treatment aimed to support, but do not replace, clinical judgment[3]. It requires senior clinical decision-making, communication, a management plan and regular reassessment.

Anticipatory prescribing for symptoms of pain, respiratory tract secretions, agitation, nausea and vomiting, dyspnoea is just one of the ten key elements of best care for the dying patient. The other elements are:

- Recognition that the patient is dying;
- Communication with the patient (where possible) and always with family and loved ones;
- Spiritual care;
- Review of clinical interventions, (in the patient's best interests);
- Hydration review, including the need for commencement or cessation;
- Nutritional review, including commencement or cessation;
- Full discussion of the care plan with the patient and relative or carer;
- Regular reassessment of the patient;
- Dignified and respectful care after death.

The above element of best care is irrespective of the place of care and is considered in both the GMC and NICE guidance.

The General Practitioners Committee (GPC) guidance, 'Focus on anticipatory prescribing for end of life care[4]**,** discuss some issues and concerns raised about anticipatory prescribing. These issues can be exaggerated especially if it is many months in advance:

- Drugs remaining in the community for extended periods of time: Many, if not most, anticipatory drugs will not be required. Consequently, there is the danger that drugs may end up discarded in the community with very little supervision of their use or disposal.
- Prescribing for the future: usually good medical practice has the provision for a prescription as one of the last elements of consultation, following and not preceding clinical assessment. Anticipatory prescribing inevitably involves uncertainty and risk concerning the drug's correct use, and prescribers are properly wary of providing drugs with less control over their use than is normal.
- Inappropriate administration: Doctors who prescribe drugs in this way have very little control over what will happen when the drug is actually administered, and some have expressed concerns about their responsibilities should such a drug be administered inappropriately. There has been a concern that the availability of such drugs might encourage their administration without proper assessment (for example, midazolam supplied for terminal restlessness might be authorised for administration over the phone, when a visit and examination might have revealed a distended bladder as the cause of the patient's distress).

Hence, there is a need for clarity on stage 3 of the local service provision.

I. Twelve months to live or may live for years

There is prognostic uncertainty in this group and the options of care in these patients include a holistic approach and anticipatory prescribing based on the approach of Amber care bundle[5]. GMC guidance states that the benefits of a treatment that may prolong life improve a patient's condition or manage their symptoms must be weighed against the burdens and risks for that patient, before reaching a view about its overall benefit[6].
NICE guidelines NG 31 recommends that when deciding which anticipatory medicines to offer, take into account:

- the likelihood of specific symptoms occurring
- the benefits and harms of prescribing or administering medicines
- the benefits and harms of not prescribing or administering medicines
- the possible risk of the person suddenly deteriorating (for example, catastrophic haemorrhage or seizures) for which urgent symptom control may be needed, the place of care and the time it would take to obtain medicines

The following good practice can be used as guide.

1) Medication review needs to be conducted to rationalise oral drugs. This should be tailored based on individual patient's clinical review after discussion and agreement with the patient and those important to them (as appropriate) so as to stop any previously prescribed medicines that are not providing symptomatic benefit or that may cause harm. In the case of non-malignant patients and elderly this could be conducted with the aid of the **STOPP START tool kit**[7] and other approaches tailored to individual need e.g. stop statins (LMSG guidance), stop ferrous sulphate/iron preparations if causing constipation or gastric side effects. If a patient is unwell and losing weight then BP monitoring and blood glucose, monitoring should help guide reducing/stopping antihypertensive and hypoglycaemic drugs. Link to the STOPP START tool is also available on End of Life Personalised Care Plan-Deciding Right template on SystmOne or on the LMSG website link http://267lv2ve190med3l1mgc3ys8.wpengine.netdna-cdn.com/wp-content/uploads/2016/04/STOPP_START_Tool.pdf
2) Involve the patient and those important to them in making decisions about predictable complications (e.g. bleed, seizure or infection) and symptom control in the last days of life. Use the person's individualised care plan to help decide which medicines are clinically appropriate. Discuss the benefits and harms of any medicines offered and document this in the End of Life –Personalised Care Plan - Deciding Right template.
3) Conduct regular multidisciplinary meetings, (ideally every other month or at the least every six monthly), to review symptom control and prescribe based on individual symptoms in line with care plan. Medication changes and planning for choice of drugs in anticipated symptom control need be documented in the clinical record and updated in the **Personalised Care Plan – Deciding Right** (previously called EHCP). This can then be reviewed and updated depending on the situation of the patient. **Do not automatically prescribe anticipatory medications at this stage if patient is not symptomatic[2].**

4) The EOL - Deciding Right medication review of current drugs template, which forms the Personalised Care Plan – Deciding Right (previously called EHCP) must be completed and should be placed in a plastic wallet before handing over to the patient/carer to store in the Green Medication bag, which the patient may already have or can be requested from patient's local chemist. Green bag is supplied via community pharmacies to any patients on more than four drugs and frequent admissions to hospital.

II. Few months to live (2 months or more)

All aspects of review based on **section I** need to be followed and in addition these patients may require reviews more frequently compared to the above group based on clinical conditions and symptoms as there is a likelihood of rapid deterioration.

III. Last few weeks/days of life (6 weeks or less)

The aim of anticipatory prescribing at this stage is to provide prompt relief from symptoms like pain, agitation, secretions or nausea. This is based on the premise that although each patient is an individual, many acute events during the last days/weeks can be predicted and management measures put in place in advance. This includes prescribing and availability of medication for end of life symptom control at home/care home so that these medicines can be given, if required, without unnecessary delay. The health professional authorising administration of a pre-supplied anticipatory drug has to accept responsibility for that decision. The LMSG website hosts a range of palliative care documents and a link to the LOROS website under the title 'Palliative care' to aid prescribing in this group, which clinicians must familiarise.
http://www.lmsg.nhs.uk/guidelines/health-community/palliative-care-2/
UHL/LPT guidance document to support staff "The Care of Adult Patients in the last days of Life" with the prompt sheet is a useful resource.
http://www.leicspart.nhs.uk/Library/CareintheLastDaysofLifeadoctosupportstaffVersion1July2014.pdf
Advice or second opinion can be sought if unsure about effective symptom control from specialist (palliative care, LOROS, experts in other specialities) or colleagues/EOL mentors with more experience with prescribing in the area. Once prescribed these drugs belong to the patient and have the same legal status as other prescribed controlled drugs. The decision to prescribe medication for use in the future should always be based on a risk/benefit analysis. Reasons for not providing anticipatory medicines include risk of drug diversion or misuse.

The availability of such medication in the patient's home is in no way a substitute for proper clinical evaluation at the time of a change in the patient's condition:

1) When considering medicines for symptom control, NICE NG 31 recommends using an individualised approach to prescribing anticipatory medicines for people who are

likely to need symptom control in the last days of life. Specify the indications for use and the dosage of any medicines prescribed taking into account

- the likely cause of the symptom
- the dying person's preferences alongside the benefits and harms of the medicine
- any individual or cultural views that might affect their choice
- any other medicines being taken to manage symptoms
- any risks of the medicine that could affect prescribing decisions, for example prescribing cyclizine to manage nausea and vomiting may exacerbate heart failure.

2) Along with prescribing for symptom control effort must be taken
    - to treat any reversible causes of pain, such as urinary retention.
    - to treat any reversible causes of breathlessness in the dying person, for example pulmonary oedema or pleural effusion
    - assess for likely causes of nausea or vomiting in the dying person. These may include: certain medicines that can cause or contribute to nausea and vomiting, biochemical causes, for example hypercalcaemia, raised intracranial pressure, gastrointestinal motility disorder, ileus or bowel obstruction.
    - be aware that agitation in isolation is sometimes associated with other unrelieved symptoms or bodily needs for example, unrelieved pain or a full bladder or rectum.
3) Decide on the most effective route for administering medicines in the last days of life tailored to the dying person's condition, their ability to swallow safely and their preferences.
4) Regularly reassess, at least daily, the dying person's symptoms during treatment to inform appropriate titration of medicine.
5) Consider changing or stopping medicines if the patient does not respond to treatment or treatment causes unacceptable side effects, such as dry mouth, urinary retention, delirium, agitation and unwanted levels of sedation.
6) Be aware that not all people in the last days of life experience pain or other symptoms. However, patients who are symptom free at this stage can be prescribed a minimum quantity from the following four symptom category in line with CD guidance and based on the '**Deciding Right - anticipatory prescribing template'**. The Personalised Care Plan – Deciding Right (previously called EHCP) needs to be updated with this information:

    - Pain - Morphine TEN (10) x 10mg/ml Ampoules;
    - Agitation and restlessness - Midazolam TEN(10) x 10mg/2ml Ampoules;
    - Secretions - Glycopyrronium FIVE x 200microgm/ml Ampoules;
    - Nausea and vomiting - Haloperidol FIVE x 5mg/ml Ampoules **OR** Levomepromazine FIVE X 25mg/ml Ampoules (if haloperidol supply shortage)
    - Diluent - Water for injection TEN x 10ml ampoules.

7) In case of drug shortage please refer to the LOROS website for alternate choices and discuss with palliative care consultant in case of any doubt http://www.loros.co.uk/media/uploads/files/healthcare/symptom_management_a4_poster_final_june_2013.pdf
8) Clinicians need to ensure that the LLR authorisation for palliative care medications is completed and printed out and handed to patient/family /carer to be placed along with the Personalised Care Plan –Deciding Right (previously called EHCP).
9) The anticipatory medications along with the Personalised Care Plan –Deciding Right (previously called EHCP) and signed authorisation form must be placed in the wallet provided before handing over to patient/carer for storing in the **Green Medication Bag**, which the patient may already have or can be requested from their local chemist. Green bags are supplied via community pharmacies to any patients on more than four drugs and frequent admissions to hospital.
10) Patients should be prescribed medication for symptom control on an as and when required basis in the first 48 hours and a syringe driver should be offered to deliver a continuous infusion over 24 hours if the patient:
    a. Requires more than two doses of injections within 24 hours;
    b. Has a prescription of essential drugs, which can no longer be given orally (antiepileptics, analgesics etc.).
11) Medicines for symptom control should only be given when needed in response to a symptom, at the right time and just enough and no more than is needed to help with the symptom.
12) Patient and carers must be advised of the sedating side effects of the opioid analgesics and medication used to treat anxiety so that they are given a choice to remain conscious or not during the time of death.
13) It is vital that patients and carers make informed choices in respect of the medication prescribed. In this respect every effort should be made to ensure that community language or British Sign Language (BSL) interpreters are employed where a patient's first language is not English or if the patient is unable to hear. The use of a patient's children to interpret should be avoided. If patients or carers require information in their own language or in an accessible format this should be considered and provided where resources allow. Effort needs to be made for patients with dementia or learning disabilities to use a validated behavioural pain assessment to inform their pain management
14) A patients nutritional and hydration status need to be reviewed when prescribing medications with sedating side effects so that they do not remain semiconscious with a feeling of thirst and unable to request a drink.
15) Quantities supplied needs to be balanced between adequate supply and waste e.g. as a minimum, sufficient quantities should be provided for a patient over a bank holiday weekend.
16) The Out of Hours service, and all others involved in the care of the patient, must be made aware of the clinical situation and of the availability of drugs.

17) Patients and carers would not be expected to take the anticipatory EOL medications prescribed into hospital if the patient needs to go in for investigation, attend clinic or if being admitted for any reason

Access to Palliative Care Drugs from Community Pharmacy

- List of community pharmacies who stock hold palliative care drugs in Leicester, Leicestershire and Rutland (covering all three CCG's) along with their extended hours of opening can be accessed via the following LMSG link Palliative Care Drugs and Emergency Antibiotics – Pharmacies and Stock
- List of medications and minimum quantities to be stocked by participating community pharmacies as agreed for palliative care immediate access can be accessed via the following LMSG link Palliative Care Drugs and Emergency Antibiotics – Pharmacies and Stock
- Community pharmacies in **West CCG** and **East CCG** have an extended hours service provision along with minimum stock holding provision of end of life medication (see LMSG links to both as above)
- Community pharmacists in **Leicester City CCG only** have a service provision where by certain participating community pharmacist are on-call for timely access to palliative care medicines and pharmaceutical advice out of hours. As per this service, agreement out of hours can be defined as the period from 18.30 to 8.00 am between Monday to Friday and 24 hours over weekends and bank holidays. Community pharmacists will be on-call for a period of one calendar week at a time. It is recognised that there are pharmacies partaking in this service that are normally open late, early and over the weekends, therefore there will be a period of overlap Single Point of Access (SPA) has access to the on-call pharmacist rota and personal numbers. SPA will receive calls from nurses in the out of hour's period, consider the appropriateness of the request and communicate this information to the on-call pharmacist.
  During the on-call period, community pharmacists will be available to reach the designated pharmacy within 1 hour of being contacted.
  These pharmacies would accept used CD denaturing kits from nurses and deal with them appropriately. Nurses returning used CD denaturing kits to pharmacies must also furnish the appropriate Controlled Drug Record Cards to the pharmacist.

References:

1. Local Enhanced Service NHS Commissioning Board Appendix 18

2. Independent review of the Liverpool Care Pathway –More Care Less Pathway July 2013.
3. http://www.mcpcil.org.uk/media/livacuk/mcpcil/documents/Statement,-,LCP,review,15,July,2013
4. Focus on anticipatory prescribing for end of life care GPC guidance, April 2012. http://bma.org.uk/practical-support-at-work/gp-practices/prescribing
5. The Amber Care Bundle. http://www.ambercarebundle.org/homepage.aspx
6. Treatment and care towards the end of life : good practice in decision making GMC Guidance for doctors http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf
7. LMSG STOPP START toolkit http://267lv2ve190med3l1mgc3ys8.wpengine.netdna-cdn.com/wp-content/uploads/2016/04/STOPP_START_Tool.pdf
8. NICE Quality Standard 13:Quality standards for end of life care for adults August 2011
9. DOH - End of life care strategy: quality markers and measures for end of life care, June 2009
10. Care of dying adults in the last days of life. NICE guidelines [NG31] Published date: December 2015