Palliative and End of Life Care Guidance

Anticipatory Prescribing Guidance for Dying Adult Patients

Contents

1. Introduction

1.1. Many patients nearing the end of life wish to remain in their own home, or normal social care setting, for as long as possible. However, they often experience distressing symptoms or become unable to swallow essential medicines, such as analgesics or anti-emetics.

1.2. Anticipatory prescribing seeks to minimise delay in responding to a symptom if it occurs. Although each patient has individual needs, acute events during the end-of-life period can be predicted to a certain extent with management measures put in place in advance. The decision to prescribe anticipatory medicines should be based on a risk/benefit assessment, and it is essential to discuss the need for anticipatory prescribing within the context of end-of-life care, with both the patient and their carer/s as well as other health and social care professionals involved.

1.3. Palliative care has traditionally been thought of as being a part of advanced cancer care but many life-limiting illnesses such as cardiac, neurological, respiratory diseases, and dementia, can benefit from this approach.

2. Definitions

2.1. Anticipatory prescribing is the prescribing in advance of possible needs, based on common symptoms experienced at end of life, with a focus on prescribing injectable medications (or other alternatives to oral medicines) if a patient is no longer able to swallow or absorb oral medications.

2.2. Just in case (JIC) is the previous term for anticipatory prescribing and is no longer the recommended term.

2.3. PRN refers to medication prescribed to be administered as required for symptoms already present or alongside a continuous subcutaneous infusion (CSCI or “syringe pump”) to be administered when required for breakthrough, or escalating, symptoms.

2.4. Anticipatory CSCI should only be used in exceptional circumstances and should not usually be written more than 72 hours in advance of need. The medicines and doses needed should be prescribed based on the imminent needs of the patient.

2.5. FP10 (prescription form) can refer to paper prescription or electronic prescription and includes electronic transfer of prescription (EPS).

2.6. End of Life Care Medicines Administration Record Chart (EOLC MAR chart) refers to the chart that allows medication administered to be recorded by registered nurses and paramedics. For the most up to date version of the document, please contact

cpicb.prescribingpartnership@nhs.net. It is also available in the Ardens Palliative and End of Life Care template. Medication and dose information are transcribed by a prescriber onto the MAR chart from the FP10 or hospital discharge summary. A MAR chart cannot be redeemed as a prescription at a pharmacy.

3. Purpose

3.1. This guidance aims to improve access to end of life care medicines in the community by encouraging prescribers in primary and community care, care homes, secondary care and hospice settings to anticipate common symptoms in the last few days of life (for example, pain, nausea and vomiting, respiratory secretions, agitation and anxiety) and prescribe enough of the appropriate medicines which are dispensed and kept in the patient's home or preferred care setting.

3.2. This guidance does not provide information on prescribing of regular medication or CSCI.

4. Summary

4.1. Patient's expected deterioration should be identified as early as possible, using the Gold Standards Framework (GSF) prognostic indicators or equivalent tool.

4.2. Medication for anticipated deterioration should be prescribed after careful consideration of a patient's need and their preferences.

4.3. Patients and their carer's understanding of anticipatory medication should be explored. The subject of anticipatory prescribing should be used as an opportunity to hold open and honest conversations about families' concerns and tailored information about the role of the medications in future care should be provided.

4.4. Risk assessment should be performed by the prescriber if controlled drugs and midazolam will be available in the patient's home as a part of anticipatory medication. Taking into consideration if there is a history of drug abuse by the patient, family members, carers and/or visitors to the place of care. The prescriber may wish to consider prescribing smaller quantities of controlled drugs if there is a risk of misuse of controlled drugs.

4.5. The EOLC MAR chart should be issued alongside the prescribing of anticipatory medications and should be available in the patient's home/care setting together with the dispensed medication.

4.6. Medication and the EOLC MAR chart in the patient's home/preferred care setting should be checked regularly to ensure it is still clinically appropriate, available and usable when the need arises.

4.7. The responsibility for each part of the process should be agreed between key members of the care team, including the patient (provided they have decision-making capacity) and those identified as important to them.

5. Guidance

5.1. Anticipatory prescribing should be considered for all patients who are thought to be in the last few days or weeks of life (GSF red or amber) for the management of possible symptoms and/or when the patient becomes unable to swallow their oral medication.

5.2. Some patients and/or carers may be concerned about having anticipatory medicines. They may misinterpret anticipatory prescribing as provision for euthanasia or worry that the medicines may hasten death. However, good communication exploring their concerns and reassurance about the purpose and role of the medication in symptom control care, backed up by supplying an explanatory leaflet should help allay fears.

5.3. Care planning using the ReSPECT tool will also facilitate conversations about appropriate and timely anticipatory prescribing.

5.4. Consideration must be given to consent and appropriate application of the Mental Capacity Act 2005 for people lacking capacity to consent. Including involving the person's nominated health and welfare attorney and family in end-of-life planning decisions.

6. Setting up Anticipatory Prescribing in Primary Care

6.1. The patient's shared electronic health records should be coded to reflect that anticipatory medicines arrangements so this information is available for other healthcare professionals caring for the patient, and allow patients to be easily identified with clinical searches so their anticipatory medicines can be reviewed appropriately. Examples of codes to use include:

- Issue of palliative care anticipatory medicines box (SNOMED: 376201000000102).
- Prescription of palliative care anticipatory medication (SMOMED: 871021000000106).
- Prescription of anticipatory care medication declined (SNOMED: 719654008).
- Prescription of anticipatory care medication not appropriate (SNOMED: 723369008).

6.2. Where a relevant patient is identified by a primary and community care healthcare professional, the prescriber needs to prescribe the anticipatory medicines on an FP10 prescription based the individual needs of the patient, medication history and conditions, their preferences and the symptoms they may have in the future.

Indications to consider include pain, shortness of breath, nausea and vomiting, excessive respiratory tract secretions, agitation and restlessness.

6.3. For example:

- Morphine injections (or an alternative such as Oxycodone) for pain, based on current 24-hour oral administration if applicable.
- Water for injection or sodium chloride 0.9% injections if required to make up to volume and to flush cannula. Please check compatibilities with medicines before prescribing.
- Haloperidol injections (or alternatives such as Levomepromazine, Metoclopramide or Cyclizine) for nausea and vomiting.
- Midazolam injections (or Levomepromazine) for agitation and restlessness
- Glycopyrronium injections (or Buscopan®/Hyoscine Butylbromide injections) for respiratory tract secretions
- Oral Lorazepam tablets for sublingual use by patients with anxiety. Please note this method of administration is **unlicensed** but common practice at the end of life and an information leaflet should be provided to the patient and their carers when this has been prescribed.

Please refer to the End of Life Care MAR Chart for dose recommendations, contra-indications and prescribing information.

Usually, 5 ampoules of each medication should be issued on the FP10. However, in certain circumstances, it may be suitable to prescribe more than 5 ampules. For example, if a patient is likely to deteriorate during a weekend and/or cannot access medicines easily.

6.4. Taking into consideration where medicines may have limited availability in community pharmacies, each item should be prescribed on a separate FP10 form to enable items to be dispensed in different pharmacies/dispensaries if necessary.

6.5. A sharps bin should also be prescribed if there is not one already in use.

6.6. Include the indication and full dosage instructions, including dose and frequency on the prescription so they can be added to the dispensing label. “as required” or “as per chart” is insufficient and will result in the prescription not being dispensed.

6.7. In addition to writing the FP10 prescription, the prescriber must write each of the subcutaneous anticipatory medicines on the “As required/anticipatory medicines” section of the EOLC MAR chart with clear instructions for use, including:

- Medicine name, strength and form matching that prescribed on the FP10
- Dose (and dose range if appropriate)
- Interval between doses

- Route of administration
- Indication for use and maximum dose in 24 hours
- Each entry must be signed and dated.

6.8. The EOLC MAR chart may be:

- Filled in electronically in MS Word via the clinical system.
- Automatically populated by the tools in the clinical system.
- Printed and completed by hand.
- Signed electronically with the initials of the prescriber/authoriser. It must be sent from the nhs.net email of the prescriber or downloaded and printed from the clinical system. For safety, it is essential that all 4 pages are printed, numbered, and stapled together.
- It is essential that the EOLC MAR chart is kept in the patient's home/ care home and the patient and/or their carers are aware where it is kept.

6.9. An electronic version of the EOLC MAR chart is available via the Ardens Palliative and End of Life Care template, which needs to be filled in and printed by the prescriber.

6.10. Prescribers should note that nursing teams do not have regular access to printers. If an EOLC MAR chart is completed, it needs to be conveyed to the patient's home. Suitable methods of conveyance should be discussed with the patient and/or their carers and followed up to ensure the chart and medicines are available in the home in a timely way.

6.11. Nurses/prescriber may choose to place the completed, printed EOL MAR chart in a coloured wallet for ease of identification.

6.12. The prescriber, in conjunction with the patient and/or carer, will also need to review the patient's routine medication for continued clinical efficacy and acceptability.

6.13. Assessment of patients and provision of medication should, when possible, take place during routine surgery/community pharmacy hours so not to generate unnecessary delays during out of hour periods.

6.14. The prescriber should inform the community nursing team / nursing home that anticipatory medicines have been requested/supplied and the agreed method of conveying the EOLC MAR Chart to the patient's care setting.

6.15. The Out of Hours (OOH) service should also be made aware via the EOLC template and patients should be encouraged to allow sharing of their GP medical records.

6.16. The CSCI (Syringe pump) prescription should not normally be completed at this stage, as it is not usually possible or appropriate to anticipate an individual patient's requirements for CSCI medicines in advance of need.

6.17. Patients on the palliative care register should be reviewed regularly with multi-disciplinary input for appropriateness of anticipatory medicines. This should be done at least every six months and after any changes in the patient's circumstances. Searches available in the clinical system may be used to identify the patients.

7. Patient and Carer Education

7.1. The prescriber must explain the purpose of anticipatory medications and how possible symptoms can be managed to the patient and/or carer. This includes exploring their understanding, preferences and concerns in an open, tailored way. The prescriber should back up conversations by ensuring the patient and carer have a copy of the ICS anticipatory prescribing patient information leaflet and know how to access urgent medical advice.

7.2. The prescriber should ensure that patients and/or carers know when and who to contact both in-hours and out of hours should any symptoms or problems arise. This should be recorded for the patient/carers, preferably on the information leaflet. This should normally be either the community nursing team or the Palliative Care Hub telephone service at 111, option 4.

7.3. The prescriber must explain that the injectable medicines are for administration by a healthcare professional only, except for Lorazepam tablets.

7.4. The prescriber must explain that Lorazepam tablets can be self-administered by the patient or administered by the carer in accordance with the instructions on the label, including when and how to do this. This verbal advice should be backed up with supplying the ICS patient information leaflet for Lorazepam tablets.

8. Obtaining Supplies of Palliative Care Medication in the Community

8.1. The prescriber should establish who will be responsible for collecting supplies for each patient, based on their individual circumstances and support networks. This may be a friend or a relative of the patient or in exceptional circumstances, may need to be a health or social care professional, depending on the organisation's medicines management policy. This should be discussed and agreed with all parties at the outset and documented in the patient's notes. Health and social care professionals will need to follow their organisational Standard Operating Procedures (SOP) and risk assessments.

8.2. Community pharmacies and GP dispensaries (for dispensing patients only) can obtain information on supplies availability from wholesalers at least twice daily, Monday to

Friday. Some pharmacies are open on Saturdays and Sundays. Opening hours can be obtained from NHS Find a pharmacy service.

8.3. Where an urgent palliative care medicine is required and the usual pharmacy/dispensary is unable to supply, a list of community pharmacies commissioned by the ICS to hold a defined list of emergency drug supply is available on the ICS website.

8.4. This information should be available at every community pharmacy and practice dispensary. If you have any questions about the locally commissioned service or require guidance, please contact the Medicines Optimisation Team at cpicb.prescribingpartnership@nhs.net .

9. Setting up Anticipatory Prescribing on Discharge from Hospital or Hospice

9.1. Healthcare professionals, in primary care, secondary care and hospice settings should identify patients likely to need anticipatory medications. People who are likely to die within the next few days should have medicines prescribed in anticipation of common symptoms such as pain, nausea, respiratory secretions and agitation. This will enable prompt treatment to be administered if and when symptoms arise. Anticipatory medicines should be personalised to each patient, depending on their preferences, current treatment, underlining conditions and symptomatic needs. Please refer to organisation policies and specialist palliative care advice for appropriate dosages.

9.2. If the patient is at risk of sudden catastrophic events such as terminal haemorrhage or an irreversible airway obstruction, seek advice from the specialist palliative care team in order to create a management plan with the appropriate anticipatory medicines required.

9.3. Where a patient is identified as needing anticipatory medications upon discharge by a healthcare professional in hospital or hospice settings, it is the responsibility of the hospital or hospice prescriber to liaise with a GP and Community Nurse in the patient's practice team to join up care. Where a patient is expected to die with days of discharge, it is essential to inform the GP before the patient is discharged about the situation and care planned.

9.4. The prescriber should prescribe injectable anticipatory medications in full pack quantities, with a minimum of five days' supply (with the exception of bank holidays/long weekend, where more than 5 days' supply may be required). Discharge prescription should be sent to the inpatient pharmacy 24 hours prior to discharge if possible or according to the organisation's prescription process.

9.5. If the dispensary cannot fulfil the full quantity of medicines prescribed, a partial supply should be considered to avoid delays in discharge. This information should be communicated to the patient's GP and the community nursing team.

9.6. The hospital or hospice prescriber should inform the community nursing team or nursing home team that anticipatory medicines have been requested or supplied. A fast-track process may be used to ensure the continuation of care for the patient.

9.7. Communications with the GP and community nursing team should include:

- Diagnosis
- Prognosis
- Anticipated care needs
- Current and anticipated medications
- Changes made to medication taken by patient prior to admission
- If a C&P EOLC MAR Chart has been completed for the patient

9.8. The hospital or hospice prescriber should also clarify if patient has been sent home with the medicines, whether they include anticipatory medicines or if the GP will need to consider prescribing anticipatory medicines following discharge.

9.9. If anticipatory medicines have been prescribed and dispensed at discharge from the hospital or hospice, a completed C&P ICS EOLC MAR chart needs to be supplied with the medicines for patients from Cambridgeshire and Peterborough.

9.10. If a completed EOLC MAR chart cannot be supplied at discharge, a duplicate inpatient chart or an after-visit summary/discharge summary should be provided with the discharge prescription and labelled medication for community nurses to use. This is for use if the medicines are needed before a EOLC MAR chart can be completed by the patient's GP or non-medical prescriber. The patient's GP or non-medical Prescriber needs to be informed of the request to complete the EOLC MAR chart as early as possible before the patient is discharged.

9.11. The medication information should be transferred onto the EOLC MAR chart by the GP or non-medical prescriber as soon as possible and within one working day of discharge from hospital or hospice.

9.12. After receiving the notification from the hospital or hospice, the GP or non-medical prescriber should update the shared EOLC template to ensure OOH services will be able to access the information.

10. Managing the Anticipatory Medicines in the Patient's Residence

10.1. Once the anticipatory medicines have been dispensed, the patient/carer should be advised to store them safely and securely in their home, out of reach of children and pets, in accordance with the ICS anticipatory prescribing patient information leaflet issued by the prescriber.

10.2. To ensure the anticipatory medicines remain available for use at a time of need, the patient/carer should be advised to regularly check the medicines to ensure they have not expired.

10.3. If the patient is in a care home, the care home's own procedures relating to controlled drugs and medication security should be followed.

10.4. If the patient is on the community nursing service caseload, the registered nurse should ensure the patient and their family / carers have:

- The opportunity to discuss what the medications are for, when they might be used and how to access help.
- The ICS information leaflet explaining the purpose of anticipatory medicines.
- The ICS leaflet explaining how and when Lorazepam tablets should be used (If applicable).
- Adequate supplies of equipment, including needles, cannulas, syringes and a sharp bin if appropriate.

10.5. For patients on the community nursing service caseload the registered nurse should:

- Record the anticipatory medicines in the patient's notes, detail where these are kept, and complete the contact details for the patient and carers.
- Record the strength and quantity of injectable schedule 2 and 3 controlled drugs (Opioid analgesia and Midazolam) on the Controlled Drug Balance Record Form.
- Risk assess and document the frequency of checks required to ensure the anticipatory medicines remain available for use at a time of need. It is recommended to check them at least once every four weeks to ensure that nothing has been removed, expired or is unaccounted for.
- Review the patient at least monthly, and after any changes in the patient's circumstances, to ensure the anticipatory medicines and the EOLC MAR Chart are still appropriate in terms of the medicines and dosages prescribed as the patient's requirements/symptoms may change. It is also important to check the medications remain appropriate and understood by the patient and their family. The review should be documented in the patient's record and any changes should be communicated to all individuals involved in the patient's care.
- Count the quantity of the controlled drugs each time they are used and/or each time the contents of the bag or container is checked. It is not necessary

to record the quantity of other anticipatory medicines, but it is important to ensure the patient has adequate supplies going into a weekend or public holiday.

- If any of the medicines cannot be accounted for after an enquiry with the family and healthcare team, an organisational incident report should be completed as soon as possible, and an investigation should take place. If the medicine is a controlled drug the regional Controlled Drugs Accountable Officer should also be informed via www.cdreporting.co.uk. Lockable boxes for storage should be considered if appropriate.
- If the patient is discharged from the community nursing service caseload, this should be clearly documented and communicated to the patient/carer and the GP, and other individuals involved in the patient's care.

10.6. There is no expiry date for the EOLC MAR Chart. However, a prescriber should review the prescriptions at least every six months and after any changes in the patient's circumstances to ensure the anticipatory medicines and EOLC MAR chart are appropriate in terms of medicines, dosages and forms prescribed, as requirements may change. It is also important to check the medications remain acceptable for, and understood by, the patient and their family. The review should be documented in the patient's record and any changes should be communicated to all individuals involved in the patient's care and may result in a new EOLC MAR chart being issued.

11. Administration of Anticipatory Medicines

11.1. When a subcutaneous anticipatory medicine is administered, the administering healthcare professional must:

- Record the medicine and the dose given on the EOLC MAR chart and update the balance record of any controlled drugs used. It is not compulsory to record the administration of oral Lorazepam on the chart, but a record should be made in the patient's notes to state the amount given, reason for use and its effectiveness.
- Update the clinical record and notify the responsible clinician that medicines have been used.
- Monitor the patient for benefits and any adverse effects at least daily and give feedback to the responsible clinician (usually the patient's GP).
- Regularly review the patient's symptoms and record the effectiveness of previously administered doses of anticipatory medicines. The responsible clinician should be informed if there is a need to review or change the route, dose or medicines prescribed. Any changes made should be recorded on the EOLC MAR chart and updated on the ICS shared electronic End of Life template.
- Replace the medicines administered to meet the patient's needs, taking into consideration upcoming weekends or bank holidays to prevent unnecessary pressures on out of hour services.

- Consider a regular prescription for administration by CSCI via syringe pump for symptom control if the patient has required two or more injections in 24-hour period, or if they are no longer able to take any regular background medications orally.

11.2. If the healthcare professional is unsure about the appropriate management of the patient's symptoms, they should seek advice from the responsible clinician (usually the GP), Palliative Care Hub (111 Option 4 or if unable to reach the hub via the option, 07919877241), or specialist palliative care team. This may be especially needed if there are new unexplained symptoms, an unexpected change in the patient's condition, a potentially reversible condition which requires assessment, or a failure to adequately control the patient's symptoms with the current medication.

12. Disposal of medication

12.1. When an episode of care finishes, the patient's family member/carer should be advised to return all medicines to a community pharmacy or practice dispensary for disposal as soon as possible, especially controlled drugs.

12.2. In exceptional circumstances, for example where a high risk of diversion or misuse has been identified, the visiting clinician may return the medicines to the community pharmacy or practice dispensary in accordance with their local policy relating to the management of controlled drugs in patient's homes.

12.3. All medicines are prescribed for the named patient only and are their property. If the patient lives at home or in a care home, their medicines must never be used for any other patient or returned to stock.

13. Risk Management

13.1. The subcutaneous route is recommended for all injections. Many medicines administered via the subcutaneous route are not licensed for subcutaneous administration, and therefore their use is "off label". However, the effective use of medicines via the subcutaneous route is well documented and widespread practice in the UK and the prescriber should be conversant with such evidence and follow unlicensed medicines prescribing guidance.

13.2. Caution should be taken when prescribing parenteral opioids for patients who had not previously received doses of opioids or received only low doses of opioids.

13.3. Caution is required when calculating doses of parenteral opioids. Adequate checks should be carried out on previous doses of opioids to prevent a mismatch between patient needs and prescribed dose. **Every member of the healthcare team** has a responsibility to check that the intended dose of an opioid is safe for the individual patient. When opioids are prescribed, dispensed or administered, the healthcare professionals involved should be familiar with the usual starting dose, frequency of administration, standard dosing increments, symptoms of overdose and common adverse effects.

13.4. Any incidents or near-misses concerning anticipatory prescribing, and remedial action taken must be reported through the organisation's incident report system, such as Datix or www.cdreporting.co.uk if controlled drugs are involved.

14. Specialist Advice and Information

14.1. The Palliative Care Hub is a free phone service operated by Arthur Rank Hospice Charity for patients, relatives, friends, and all health and social care professionals caring for patients in the community within Cambridgeshire and Peterborough Integrated Care System. The service provides specialist palliative care advice and support to those with life limiting illnesses and is available 24 hours a day, 7 days a week. To contact the Palliative Care Hub, call 111 Option 4.

14.2. For further prescribing information, refer to Palliative Care Adult Network Guidelines Plus.

14.3. Specialist advice is also available from your local hospice or specialist palliative care team:

- Arthur Rank Hospice, Cambridge:
  - Telephone: 01223 675 777
  - Email: reception@arhc.org.uk
- Thorpe Hall Hospice, Peterborough:
  - Telephone: 01733 225 900
  - Email: thorpehall@sueryder.org
- St. John's Hospice, Moggerhanger:
  - Telephone: 01767 642 410
  - Email: contact.stjohns@sueryder.org
- East Anglia's Children's Hospice (Symptom Management Team):
  - Telephone: 0808 196 9495
  - Email: each.each.smns@nhs.net
- Palliative Care Team, Woodlands Centre, Hinchingbrooke Hospital, Huntingdon
  - Telephone: 01480 416 283
  - Email: hch-tr.palliative-care@nhs.net
- Alan Hudson Centre, North Cambs Hospital, The Park, Wisbech:
  - Telephone: 01945 669 620
  - Email: nee.alanhudson@nhs.net

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