Safer anticipatory prescribing of injectables for symptom control in end of life care of adults across all care settings – recommendations of a multidisciplinary working group on behalf of the South East London Palliative & End of Life Care Work Stream

Background

Views and practice differ between providers with respect to anticipatory prescribing of syringe pumps to deliver continuous subcutaneous infusions (herein referred to as 'CSCI') for patients in the community.

The Gosport War Memorial Hospital Independent Inquiry increased public and clinician awareness about CSCI of opioids at the end of life. The inquiry highlighted the dangers for patient safety when prescribing anticipatory CSCI with large dose ranges to be started at the discretion of third parties whose clinical assessment skills are unknown to the prescriber. In an overstretched clinical climate in which clinicians are encouraged to plan ahead to optimise patient care, the Gosport inquiry reminds us of the potential risks of anticipatory prescribing in end of life care. This is balanced against the clinical risk of uncontrolled symptoms as a result of unavailability of vital medications and the significant patient, family and carer distress at the end of life this causes.

The Association of Supportive and Palliative Care Pharmacy (ASPCP) in a statement dated August 7th 2020 acknowledged the differences in provision of out-of-hours access to specialist palliative care in the UK and the difficulties this might cause, in particular rapid access to injectable medications for symptom control. However, in the opinion of the committee, the perceived benefit of prescribing CSCI in anticipation of need does not outweigh the potential risks – these being a lack of individualisation of care, no anticipation of dose/ medication changes between prescribing and initiation, and administration errors – for example, leading to double dosing when oral medicines are not stopped at the point a CSCI is commenced. The committee recommended that prescribing of CSCI should only occur after the patient has been reviewed in person by a doctor or independent prescriber. This would ensure a full assessment of the patient, including the reasons for any deterioration, and allow the safe prescribing of subsequent treatment. The Association of Palliative Medicine (APM) has not produced a position statement pertaining to this.

Scope

The working group (herein referred to as the 'group') was tasked with developing recommendations that influence safer, more consistent practice across all care settings within South East London (SEL), as well as neighbouring community providers not known to us where patients may be transferred.

The recommendations should be based upon published data and best practice at a local and national level, and be informed by incident and risk intelligence where this is available.

The intention would not be to force change, but to achieve consensus and consistency as far as possible, recognising that the balance of risks may differ in different settings.

The group's remit was to develop recommendations regarding the circumstances in which clinicians in SEL should consider anticipatory prescribing of injectables for symptom control in end of life care of adults (i.e.'who'). Decisions about which medications and at which doses should be prescribed (i.e. 'what') were out of scope.

The recommendations should be delivered to the SEL Palliative and End of Life Care (P&EOLC) Work Stream for ratification on behalf of the SEL Integrated Care System (ICS) and agreement of an action plan for implementation.

Membership

The group membership needed to be succinct to enable rapid decision making that was representative of the clinical areas where CSCI/ 'as required' (PRN) injectables are prescribed. Therefore, members were invited based upon the areas of the prescribing pathway they have a knowledge of and role within and be able to influence change, rather than the organisation they work for. Members were expected to consult the wider clinical teams they were representing, including cross-borough/ organisation to ensure variable practices were considered within the recommendations. Table 1 details the clinical areas involved and their representative staff.

Table 1.

Clinical areas where CSCI/ PRN injectables are prescribed	Representative staff
Adult community nursing providers	Charlotte Steward (Oxleas), Helen Thurkettle (GSTT)
SPC community providers	Helen Thurkettle (GSTT), Emma Hall (SCH), Nigel Dodds (SCH), Amanda Mayo (SCH), Wendy Lethem (GBCH)
Hospice inpatient	Emma Hall (SCH), Nigel Dodds (SCH), Amanda Mayo (SCH), Wendy Lethem (GBCH)
Hospital SPC Team	Polly Edmonds (KCH), Louise Exton (KCH), Irene Carey (GSTT/ joint chair), Steven Wanklyn (GSTT/ joint chair), Wendy Lethem (DVH)
CYP	Jo Laddie (GSTT/ Evelina/ Demelza), Gill Hughes (GSTT/ Evelina/ Demelza)
Other providers/ organisations	Jayne Kennedy (Primary Care GP), Emily Gibbs (Primary Care GP), Esther Appleby (Primary Care GP), Bethan Warner (Care Home Pharmacist)
Access to urgent medications/ prescriptions/ medication authorisation charts etc.	Steven Wanklyn (GSTT).

Through meetings and the use of a questionnaire, the group fed back on baseline activity and what 'good looked like' for their representative constituencies. This included, but was not limited to, considering:

- The published data pertaining to risk (Appendix 1).
- Any variations in current practice.
- Any relevant local provider data.
- Under what circumstances anticipatory prescribing of CSCI/ PRN is and is not supported.
- What might mitigate against risk such as dose ranges, quantity of medications dispensed at discharge, mechanisms for rapid access to medications in and out-of-hours.
- Any differences for local community providers versus community providers not known to us, and how this is overcome.
- Any differences between community and hospital team practice, and how this is overcome.
- Workforce impact / logistics e.g., access to urgent prescriptions/ medication authorisation and administration record ('MAAR') charts; access to prescribing training.

Published data

A review of the papers detailed in Appendix 1 and related discussions offered the following considerations:

- No data to quantify risk/ benefit. Conclusions are more pragmatic than evidence-based.
- Helpful if developing recommendations based on best practice/ specialist opinion in the absence of data.
- Note: no position statement from the APM.
- The papers may not provide an answer to what practice should be, but they do err on the side of there being a risk for which recommendations can be developed based upon best practice/ specialist opinion.
- Changes to policy, through the influence of recommendations provides a good platform for improving safety e.g., detailed information in guidelines and authorisation charts and educational resources, which align with the overarching principle that '*anticipatory prescribing of a syringe pump is undertaken as close to the time of need as possible to ensure that the medications and doses are appropriate for the individual needs of the patient, and that this is reviewed on a regular basis after initiation'*

Recommendations

1. Anticipatory prescribing of PRN +/- CSCI injectables based on individual clinical need should be considered for patients who are imminently dying (days/ 1 – 2 weeks):
    - With symptoms and currently taking oral medications (for control of symptoms commonly seen in the dying or control of critical underlying conditions e.g., anticonvulsants), which are likely to be switched to the CSCI route.

- Without symptoms but in whom there is a high risk of developing symptoms or anticipated problems due to an underlying condition e.g., heart failure, malignant bowel obstruction.

  Switching medications from the PO to subcutaneous route will take into account an inability to swallow or high likelihood that PO absorption is compromised, and there remains a high risk of need for the medication.

2. Anticipatory prescribing of PRN injectables should be considered for patients with a longer prognosis (e.g., those meeting the criteria for CHC fast track funding), with an expressed wish to avoid acute admission at the end of life. An appraisal of any PRN drug use would then determine the appropriateness of any subsequent CSCI prescription and initiation at the time of need.
3. Patients with a longer prognosis (e.g., those meeting the criteria for CHC fast track funding), without an expressed wish to avoid acute admission at the end of life, may benefit from a supply of PRN injectables for administration in case of future need. This should be considered based on individual clinical need.
4. Anticipatory prescribing of CSCI/ PRN injectables based on individual clinical need for patients residing in care homes (to include nursing homes, residential homes and other sheltered accommodation) or other community settings e.g., hostels should be considered. However, bear in mind the following:
   - Nursing homes generally have a trained nurse on site at all times who should be able to administer PRN subcutaneous injectables and, with appropriate oversight, set up a CSCI. However, it is worth double-checking this is the case beforehand with the individual setting as external support and additional training may be required.
   - Residential homes, sheltered accommodation and hostels generally do not have trained nurses on site, so the help of a district nurse is generally needed. As a result, a CSCI may be preferable as a means of symptom control if multiple PRNs are required given the time delay in awaiting district nurse attendance.
   - Individual community settings will have unit-specific rules for the storage of anticipatory injectables (i.e., controlled drugs to be stored in a locked box), which will need to be established and adhered to.
5. When patients are discharged outside of SEL and are felt to require PRN/ CSCI anticipatory injectables, discuss their clinical requirements with the receiving community provider, to address potential differences in practice. Support transition through liaison with the Community Palliative Care Team, GP +/- Marie Curie nursing.
6. For advice regarding which medications should be prescribed under these circumstances – and at which doses – clinicians should refer to their local specialist palliative care / symptom control / end of life care guidance.
7. The Pan- London Symptom Control Medication Authorisation and Administration Record (MAAR) chart should be utilised to authorise and record administration of these injectable medicines, including PRN, CSCI, crisis / emergency and regular dose SC injections.
8. Establish an ongoing approach to formulating ‘steps-for-safety’ that ensure advance-prescribed medications are initiated/ administered in ways that minimise the potential for harm; base these on local examples of good practice, underpinned by incident surveillance and observations of concern.

Examples should be shared with local improvement groups such as the SEL Palliative Care Medicines Improvement Group who can influence policy and practice e.g., through feedback to the pan-London Steering Group responsible for the MAAR chart and related procedure.

Examples of good practice discussed by this group, included:

- Guidance that states a clinical review is undertaken as close as possible to the time of need so that drugs and doses remain appropriate based on individual circumstances and with a flexible approach to review taking into account the skills of the healthcare professionals involved e.g., not everyone will need a F2F review, as DNs can liaise with the specialist team.
- When large CSCI dose ranges are clinically indicated, consider prescribing the range in smaller increments and do this with specialist support.

Appendix 1 – Published data

Paper
The Association of Supportive and Palliative Care Pharmacy (ASPCP) statement (07.08.20).
Key messages/ what it adds

- Acknowledged the differences in provision of out-of-hours access to specialist palliative care in the UK and the challenges this may cause, in particular rapid access to injectable medications for symptom control.
- However, in the opinion of the committee the perceived benefit of prescribing syringe pumps in anticipation of need does not outweigh the potential risks. Risks include:
  - A lack of individualisation.
  - No anticipation of dose/ drug changes between prescribing and initiation.
  - Administration errors leading to double dosing when oral medicines are not stopped when the pump is commenced.

Paper
Anticipatory syringe pumps: benefits and risks (letter) Bowers B, et al. BMJ Supportive & Palliative Care 2021; 11: 303–304.
Key messages/ what it adds

- Provides cross-reference to suite of papers from Ben Bowers & David Barclay at the Palliative & End of Life Care Group in Cambridge – PELiCam.
- Supports ASPCP position statement.
- Despite risks anticipatory syringe pump prescribing remains common in some areas of the UK and is increasing during the COVID-19 pandemic. Sites ongoing research subsequently published September 2021 in Palliative Medicine.
- Poor evidence for robust anticipatory prescribing guidance/ authorisation charts (12/28 areas only) to govern the risks identified by the ASPCP.
- Danger of specialist palliative care for complex needs is being followed in general practice for less complex needs.
- Concurring with the ASPCP, syringe pumps should only be prescribed after a face-to-face review by a skilled prescriber to consider causes of deterioration and associated symptoms, evaluate reversibility, establish a dying diagnosis and appraise the effectiveness of previously administered oral and PRN drug injections.

- In the relatively unusual circumstances in which an anticipatory syringe pump is appropriate, it is important to ensure that prescribers regularly reassess the patient's needs and review the prescription accordingly.

Paper

Bowers B, Ryan R, Hoare S, et al. Anticipatory syringe drivers: a step too far. BMJ Support Palliat Care 2019; 9:149–50.

Key messages/ what it adds

- Focus on the Gosport findings and the importance of 'safe hands'.
- In an overstretched clinical climate in which clinicians are encouraged to plan ahead to optimise patient care, Gosport is a timely warning of the potential dangers of 'anticipatory syringe pumps' prescribed in anticipation.
- Anticipatory prescribing highly anomalous and not reflective of palliative care practice; most people were in hospital for rehabilitation, not terminal care.
- Practices highlight the risks of prescribing anticipatory syringe pumps with excessive starting doses or wide dose ranges to be started by third parties whose clinical assessment skills are unknown to the prescriber. This can result in syringe drivers being started, or doses increased, without skilled assessment and consideration of potentially reversible causes of symptoms and clinical deterioration.
- Anticipatory prescribing is regarded as best practice for the dying in the UK ensuring that drugs are available in the home 'Just in Case' they are needed for PRN administration. There is a danger that this may be conflated with anticipatory syringe pump prescribing. The two should be regarded as distinct interventions.
- Commencing a syringe pump marks a more significant change in patient care. In the absence of appropriate guidelines, syringe pumps should only be prescribed after an experienced doctor or nurse prescriber has reviewed the patient in person in order to consider the causes of deterioration and associated symptoms, evaluate reversibility, establish a dying diagnosis and appraise the effectiveness of previously administered prn drug injections.
- Before starting a syringe pump, it is vital to explore patient and family understanding and wishes, to discuss the goals of treatment, including the possible effects of administered drugs and to advise that drugs given in doses appropriate for symptom control will not hasten death. These conversations require the skills of a compassionate, knowledgeable and experienced doctor or nurse.
- NICE guidance simply advises ensuring suitable anticipatory medicines and routes are prescribed as early as possible.

Paper

Howard P, Curtin J, Behmer B, et al. Response to "anticipatory syringe drivers: a step too far". BMJ Support Palliat Care 2019;8.

Key messages/ what it adds

- Individual circumstances where anticipatory syringe pump is more appropriate i.e. patient has unambiguous and pre-existing symptom control needs. Criteria to consider:
  1. Patient circumstances are foreseeable and unambiguous even for those without specialist experience.
  2. Medication choices and doses are unlikely to change.
  3. Initiation of the syringe pump is reliably followed by a timely review by a skilled clinician.

Paper

Ben Bowers, Kristian Pollock and Stephen Barclay, Unwelcome memento mori or best clinical practice? Community end of life anticipatory medication prescribing practice: A mixed methods observational study. Palliative Medicine. 8 September 2021

Key messages/ what it adds

- High frequency and standardised prescribing of anticipatory medication prescriptions for terminally ill patients in generalist community palliative care.
  329 deceased patients registered with 11 GP practices, treated at home or care home.
- Half the patients were prescribed anticipatory medications, often standardised drugs and doses.
  Variations in prescribing rates, depending on the GP practice (23% vs 93%, median 47%) and condition (nearly 70% cancer vs 39% non-cancer). Prescribing was higher for patients who had expressed a preferred place of death or had the involvement of a specialist palliative care team, and often as part of ACP.
- The range of timing of prescribing, at times many months before death, emphasises that it is difficult to predict the timing of death.
  The timing of prescriptions varied substantially, occurring at a point between 0 and 1212 days before death. Patients who died from cancer were prescribed medications a median of 21.5 days before death; for those who died from non-cancer illnesses, medications were prescribed a median of 12 days before death. But seven patients in the study were prescribed anticipatory medications a year or more before death, of which six had a non-cancer diagnosis.
- The presence of anticipatory medications for long periods of time, or when situations are uncertain, may compromise patient safety unless robust systems are in place to review their continued appropriateness and safe use.
- Patient and family views and experiences of anticipatory medication care, and their preferences for involvement in prescribing decision-making, warrant urgent investigation.