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Headline

How to manage medications for symptom control in palliative care

[original] Getting palliative medications right: what works in practice to manage medications for symptom control?

Standfirst

This article explores what the real-life challenges are of helping people to manage symptoms with medication at the end of life.

In this article...

- What is involved in medication management in palliative care
- Who is involved in medication management in palliative care
- Issues surrounding prescribing decisions and anticipatory medication

Key points

- As the population ages, the demand for palliative care services will increase
- The multi-step processes in medication management are complex and prone to risks
- It is important that all nurses understand how to select medications
- Bringing the patient and family into the palliative care team is a key aspect of managing symptoms
- Collaborative working across system boundaries leads to reduced workload and greater effectiveness

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Abstract

People receiving palliative care may experience a wide range of physical symptoms. There are many practice-based considerations to think about when medication is used to help with symptom control, as this sixth article in our series on palliative and end-of-life care explains. It is important that the right clinical decisions are made, with the least risk of harm. Understanding the real-life challenges associated with medication management can enable a collaborative and competent service that supports patients and their families at the end of life.

Quick fact

20%

Approximate number of serious safety incidents involving palliative care patients that are associated with medication

Pull quote

“The prescriber is the beginning stage, the actual taking of the medicine is the end stage, and how do you get to that in a safe and a supported way?”

[main article]

Introduction

Palliative care can provide a better quality of life for patients and families who are coping with advanced chronic conditions or life-limiting illness. It is a holistic approach that aims to meet physical, psychosocial and spiritual needs through effective care and symptom management (World Health Organization, 2023). As the population ages, it is expected that the demand for palliative care services will increase, with some estimations predicting at least a 25% rise in need by 2040 (Etkind et al, 2017). Recognition of the needs of those with non-malignant disease (such as chronic heart, kidney, respiratory, liver, or neurological disease) alongside those with malignant disease (Kendall et al, 2015; See et al, 2022) is important to inform the development of a responsive palliative care service.

People receiving palliative and end of life care may experience a wide range of physical symptoms. While different patterns of symptoms may be noted with different underlying diagnoses, pain, nausea and vomiting, anxiety, agitation, breathlessness and respiratory secretions are the most common symptoms in the final days of life (Blinderman et al, 2015). Non-pharmacological measures are important to consider, as is identifying and reversing the underlying cause of these symptoms when possible (for example, if someone is agitated – is this because they have developed urinary retention?). However, often no reversible cause can be found and treated. This means medication to alleviate symptoms regardless of cause is a vital part of palliative care.

There are a number of practice-based considerations to think about when medication is used to help with symptom control. What is involved? Who is involved? Where is care taking place and what happens when people move between care locations? In other words, what are the real-life challenges of helping people to manage symptoms with medication at the end of life?

What is involved in medication management in palliative care?

It is important that the right clinical decisions are made, such as the best choice of medication to prescribe with reference to administration routes and 'as needed' dosing choices, with the least risk of harm. However, beyond this, getting palliative medications right also requires attention to availability of medication and supply, reviewing and monitoring for effectiveness, and ensuring patients and those supporting them continue to be informed and involved. There are many possibilities in these multi-step processes for 'things to go wrong' as these complexities can pose a risk if clear processes are not followed.

The first step is assessing the person to find out about symptom control needs and whether underlying causes of the symptoms can be treated or reversed. Having a good understanding of the cause of a symptom will help professionals in choosing and administering the right medication when symptoms are not reversible. Current medications can be reviewed to determine if any medication can be optimised by reviewing the dose or dosing interval, or safely stopped (deprescribed), and if a new medication needs to be added.

When a symptom is present all or most of the time, then a regular medication is needed, with additional options for 'breakthrough' and for some people 'incident' symptoms. Breakthrough describes when the symptom recurs despite the regular medication. Some symptoms can also occur as 'incident symptoms' – here the regular medication is working, except when the person needs to undertake a specific activity. For example, if someone has good pain control except when they need to change position from sitting to standing, the 'incident' is the change in position. If they have good pain control most of the time but a few times of day their pain gets worse without an obvious reason, this is breakthrough pain.

Choice of prescription medication is informed by understanding the therapeutic action of each drug and how they act on symptoms. It is relatively common in palliative care for more than one medication to be used to treat one symptom. Also, some medications can be used effectively to treat more than one symptom and different combinations can be grouped to optimise symptom management.

Choice of drug dose (including accurate dose calculations), preparing medication (where necessary) and selecting the most appropriate route, are all essential components of safe medication administration. It is particularly important that all nurses, not just those with prescribing qualifications, understand how to select medications, and doses (when a range of doses is prescribed). Maintaining accurate records whilst monitoring and documenting the effects of medication inform clinical decision-making that can result in changes to prescribed drug therapy (Nursing and Midwifery Council, 2018).

Other influential factors may include type of symptoms, severity of symptoms, patient preferences, allergies, urgency of need, care setting and whether a person can self-administer medication or requires assistance. A more recent issue in the UK is knowing about the availability of a medication, with shortages of some medications or formulations requiring the prescriber to make alternative prescribing decisions (Dayan et al, 2024).

Special requirements will need to be met if prescribing controlled drugs – drugs that have been identified as potentially addictive and/or harmful are subject to strict legal controls and legislation to minimise harm to patients and staff from any misuse. For example, there are specific prescribing, storage and destruction requirements (Joint Formulary Committee, 2024). Drugs are sometimes prescribed as an unlicensed medication or for 'off-label' use. Off-label is when a medication is being used in a way that is different to that described in its licence, for example, at a higher dose than is stated in the licence. In palliative care, there is general acceptance supporting unlicensed and off-label medication use in the management of symptoms. Healthcare professionals wishing to prescribe an unlicensed medication, or an off-label medication, will have professional guidance to follow.

Anticipatory prescribing of injectable medications is undertaken to aid with the control of distressing symptoms during the last days of life (also known as 'just in case' medications). Prescribing is based on the needs of an individual person. Table 1 provides examples of types of anticipatory medications and the symptoms they treat.

Table 1: An example guide to anticipatory prescribed medications and the symptoms they treat (Marie Curie, 2023)

Common symptoms	Examples of symptom control medication (the exact choice of medication is often determined by local formularies)
Pain	Opioid medication such as morphine, diamorphine, oxycodone or alfentanil
Nausea and vomiting	Cyclizine, metoclopramide, haloperidol or levomepromazine
Anxiety	Midazolam
Delirium or agitation	Haloperidol, levomepromazine, midazolam or phenobarbital
Breathlessness	Midazolam or an opioid
Noisy chest secretions	Hyoscine hydrobromide or glycopyrronium

Note: This is not intended to be prescribing advice on its own – see Table 2 for resources for prescribing guidance.

By prescribing medication for symptoms that may occur in the future, it is intended to ensure that medication is available when and where it may be needed at short notice and so avoid delay. However, previous research has shown that the act of prescribing anticipatory medications is a significant event for patients and their families, and more time should be spent explaining and checking understanding of the role of anticipatory medication for helping with symptoms (Bowers et al, 2023).

When administering anticipatory medications, a study of nurses' experiences indicated that nurses' confidence to take the complex decision to administer the first dose of anticipatory medication was underpinned by their education, training and clinical experience (Wilson et al, 2015). When working independently in out-of-hours community palliative care, trust and access to expertise are necessary components to be able to deliver care that meets a patient's needs and achieve good outcomes (Yardley et al, 2022).

The safe storage, transportation and disposal of medication that is no longer needed are essential aspects of safe medication management and can vary according to care location. Family carers often report feeling concerned about what to do with palliative medications after someone has died, and in many places systems for this do not work as well as needed (Pollock et al, 2021; Lau et al, 2023; Francis et al, 2024).

Table 2 summarises a range of resources that may be used to inform prescribing decisions in palliative care. National and local treatment guidelines will provide contemporary evidence-based recommendations regarding selection of prescription medication and dosing schedules

Table 2: Example resources for prescribing guidance in palliative care

Palliative Care Adult Network Guidelines (PANG) (Back et al, 2024) https://book.pallcare.info/
Palliative Care Formulary (Wilcock et al, 2022) https://www.pharmaceuticalpress.com/products/palliative-care-formulary/
British National Formulary Palliative Care guidance (Joint Formulary Committee, 2024) https://bnf.nice.org.uk/medicines-guidance/prescribing-in-palliative-care/
Healthcare Improvement Scotland. (2024) Right Decisions Service. Scottish Palliative Care Guidelines. https://rightdecisions.scot.nhs.uk/scottish-palliative-care-guidelines/
National Institute for Health and Care Excellence (NICE). (2015) Care of dying adults in the last days of life. NICE guideline [NG31]. https://www.nice.org.uk/guidance/ng31/chapter/Recommendations#pharmacological-interventions

Who is involved in medication management in palliative care?

Patients together with informal carers (such as family and friends) are often crucial to link together all steps in the processes of medication management, and maintain continuous supplies, especially at home. The contribution and influence of carers' assessments of care-recipients' symptoms (when they can no longer self-advocate) need to be incorporated in decisions regarding prescribing and medication administration (Bowers et al, 2022). Attention must be paid to lack of knowledge, health literacy, beliefs about medication and medication hesitancy amongst patients and carers (Lin et al, 2000; Lo et al, 2022) – and when preferences and beliefs may differ between patients and carers (Mulcahy Symmons et al, 2023) – taking the opportunity where possible to educate, clarify and correct mistaken beliefs about medication and end of life care.

A feasibility trial was conducted in the UK to examine carer administration of as needed subcutaneous medication for breakthrough symptoms in people dying at home (Poolman et al, 2020). The practice was found to be acceptable, possible and safe. However, as only a small number of carers (n=22) completed the study, it provided insufficient evidence to proceed to a full trial. During the Covid-19 pandemic and the limited access to community nurses and doctors, the role of family carers administering anticipatory medications at the end of life was considered, but it was acknowledged that to do this safely, training, support and careful prescribing were needed, in addition to recognising the potential tension between family carers' emotional involvement whilst undertaking a clinical-based task (Bowers et al, 2020). In the UK, some places have established systems for carer administration of injectable medication, but this is not currently widespread.

A wide range of health and social care professionals can be involved with patients receiving palliative care and their carers including nursing, medical, pharmacy, palliative social work, speech and language therapy, dietetics as well as other allied health professionals. Knowing who is involved and being proactive in identifying contributions and limitations to roles can be beneficial. Not making assumptions but speaking directly to carers and healthcare professional colleagues about their roles

can help to build effective working relationships and streamline medication management processes. Providing both verbal and written information is helpful.

Consideration needs to be given to the roles of generalists and specialists, as well as in and out-of-hours care (Offen, 2015; Sekse et al, 2018; Latter et al, 2020; Latter et al, 2023). When symptoms are difficult to control, involving specialist palliative care colleagues early is important. In community settings, challenges can arise when there are multiple professionals involved or if care is limited to a single professional. For example, when the prescriber of medication may not be the same professional visiting the person at home, clear systems need to be in place to lead on responsibility for medication, coordinate medication review and maintain consistent advice to patients and carers (Francis et al, 2022). Conversely, situations can arise (for example, out-of-hours practice in the community) where a single professional is present and solely undertaking all activity regarding prescribing, accessing supplies (if no-one is available to collect medication from a community pharmacy) and administering medication, with no opportunity for checks.

Thinking forward and planning for what may be helpful for medication provision and timely access to care when a patient is discharged to another care setting or while moving between settings or outside normal working hours are important elements of continuing care and highly valued by patients and their carers. For example, following established protocols, maintaining confidence and skills, and being able to effectively support patients at home when medication is delivered via a syringe driver have all been identified as important factors in the safe delivery of palliative care out of normal working hours (Williams et al, 2019).

Where does palliative and end of life care take place?

Most often, people are receiving palliative and end of life care in one of four locations: in hospital, at home, in a care home or a hospice. Different care environments will have specific expectations (local advice should be sought when someone is in another setting e.g. prison, mental healthcare hospital, homeless hostel), but key to effective person-centred care is helping to coordinate and manage the transitions between settings when required, as well as good care within each.

Good end of life care is sometimes defined by enabling a person to die in their preferred place. Most people prefer to receive palliative and end of life care outside of hospitals, in the community (National Palliative and End of Life Care Partnership, 2021). Availability of, and access to, medication to assist effective symptom control, are key factors to support this outcome and avoid (re)admission to hospital.

Proactively contacting colleagues in other care settings to forewarn of discharges, admissions or specific needs of patients can be widely valued by patients, carers and healthcare professionals.

Hospitals

Within hospital settings, challenges can arise with some hospital wards not used to caring for patients at the end of life and others being unable to use syringe drivers. The use of generic, unlicensed and off-label medication and associated risks need to be understood. When moving between hospital and hospice settings, seek local

advice regarding the need for discharge medication as some hospices will be able to supply commonly prescribed palliative medications and so there will be no requirement to travel with medication. Creating relationships between hospital and hospice staff and understanding local needs can help with seamless and quick transfers.

Discharges

While discharging patients to their own homes, patients need to be prepared in advance and informed about their medication. Consideration should be given to medication that may still be at home, and clear instructions provided about whether this should be continued or stopped. Patients' understanding of their medication needs to be checked. Patients should be informed about what symptoms an individual medication has been prescribed to treat. If the opportunity arises, invite medication questions on more than one occasion, and include written information. Ask patients to involve carers if they wish them to be part of this conversation.

Think about whether the patient will be able to manage the medication if they live alone. If the person will be relying on carers for medication administration, are the carers able to administer medication at the right time; alternative formulations such as modified release or longer acting could be helpful. If the district nursing team needs to be involved, discuss in advance about what is possible and how this may impact on discharge medication plans. Consider any risks that may exist with regards to keeping medication at home, such as concerns about medications going missing and whether it would be helpful to supply a locked box.

General practitioners

The general practitioner (GP) may not be routinely informed that a person for whom they care has been admitted to an inpatient setting. It can take time for discharge summaries to arrive at the GP surgery and for prescribing to be continued. Empowering patients to take their own copy of the discharge summary to the GP surgery can help to speed up the process of prescribing continuous supplies (Francis et al, 2024). Also, prompt patients and carers to tell their community pharmacist that they are receiving palliative or end of life care and to ask what help the pharmacy can offer such as ordering medication early to enable continuous supplies, information about extended opening hours, or a service for delivery of palliative medications to a patient's home.

Home management

Proactive medication management at home is a priority. This means making sure the necessary supplies of the right medication are at home with the person, together with any required equipment (such as a syringe driver) and any essential documentation such as a Medication Authorisation and Administration Record (MAAR) chart. People living in their own homes, and their family/those important to them, will often undertake medication management activities themselves; their roles and responsibilities include ordering medication, obtaining supplies of medication and bringing them home, organising medication to adhere to a complex schedule, administering medication, monitoring symptoms and adverse effects, sharing

experiences of medications with healthcare professionals such as effectiveness of symptom control, questioning the necessity of different medication and discussing future treatment plans. This can be difficult for patients and carers when the caring role in itself can be exhausting. Carers can view medication-related tasks as taking time away from being a family member or friend, and thus changing the dynamics of the relationship. Support needs to be given to informal carers with time made available for proactive conversations about their activities and challenges. Asking patients and families about their experiences with medication will reveal information about their beliefs about medication, what and how medication is used, and how they are coping. These conversations provide opportunities for evidence-based person-centred nursing care, to enhance people's understanding about their medication and correct any mistaken beliefs about medication that can adversely influence medication-taking behaviour. The burden of medication management can be significant for patients and carers. Support with medication education and management should be offered where possible.

If needs become more complex, greater healthcare professional input will be required with a district nursing team and/or a community palliative care team. Contributions to care may extend to responding to the need for rapid and timely access to medication and equipment, including syringe drivers (for symptom management during an illness or at end of life), and the addition of anticipatory prescribing of medication.

Summary: what are the real-life challenges of helping to manage symptoms at end of life?

“... the prescriber is the beginning stage, the actual taking of the medicine is the end stage, and how do you get to that in a safe and a supported way?” (Quote from a Community Clinical Nurse Specialist, Francis et al, 2024).

Prescribed medication and doses can change rapidly for patients receiving end of life care. Patient and family education is a key aspect of managing symptoms – recognising in the first instance that there can be barriers to whether or not treatment is accepted. The 24-48 hour period post-discharge from an inpatient setting can be critical. Patients and carers need access to advice to resolve medication-related questions and problems including a call-back telephone number with hours of availability, what to do outside of these hours and avoiding duplicity of numbers, which can be confusing.

Making it easier for patients to nominate a carer to act on their behalf when organising the practicalities and logistic around medication management, including carers in conversations about symptom management and what matters most, can help to achieve a patient's goals and priorities, especially when trying to find the right balance between good symptom control and medication side effects.

Sufficient time needs to be allowed for handover and exchange of information when a person is moving between care settings (e.g. hospital discharge) and ensuring complex care needs are recognised and plans are in place. Where possible, build relationships with colleagues who work in other care settings such as hospice,

hospital, and community, to develop awareness of how the whole system works for people receiving palliative or end-of-life care. For example, the Royal Pharmaceutical Society (RPS) (2024) has partnered with Marie Curie to develop the Daffodil Standards, which encourage the development of community pharmacy palliative care provision.

Technology

Technology can assist coordination of services through the use of Electronic Palliative Care Coordinating Systems (EPaCCS) although issues can occur due to challenges in maintaining the currency, accuracy and comprehensiveness of these records. Access to live drug charts such as the Medication Authorisation and Administration Record (MAAR) Charts on an electronic system in the community that all prescribers could access would be a positive development, ensuring that it holds the most up-to-date record of prescribed and administered medication. Although reliance on electronic records can be problematic in different geographical areas where internet connections can vary. Any portable documents (PDFs) sent to community staff should be sent as small individual files rather than combined into a single larger file as these can be difficult to download while at patients' homes.

Teamwork

When a patient is at home, if the prescriber of medication and the colleague visiting the patient are different, there can be differences in opinion about what is the most appropriate prescription. Creating time for a two-way discussion (in real time if urgent) can save time overall and make care more effective. Fostering joint visits between GP services, district nursing and community palliative care teams, can improve continuity of care and information.

It is important to agree preferred ways to communicate, for example text or email, and to have a backup mode if you do not get a response or are unsure if messages are getting through. Increasing non-clinical staff's awareness (e.g. administrative staff) of the needs of patients receiving palliative or end of life care through training can improve response times and ensure input from the right person can be as efficient as possible.

Support

Patients and carers need support at home regarding the micro-decisions about managing medication (for example, deciding when to administer 'when required' medication when responding to symptoms), monitoring effectiveness and side effects, adapting to changes in prescribed medication, and carer-led administration of medication, as these can be a great source of concern and worry (Payne et al, 2015). A patient's or carer's interest and ability to administer medication should be checked at each visit, giving support if needed. Relieving carers of logistical and technical responsibilities when possible and providing clear written information about support systems, including documented contact numbers, are all helpful (Pollock et al, 2021; Francis et al, 2024).

Access to 24/7 supplies of palliative medications may need to be considered. Be aware of the local out-of-hours palliative care services that can deliver care and/or medication using appropriately trained and experienced healthcare professionals. Create mechanisms for staff to be flexible around a patient's needs when dealing with a patient who is alone or only has one carer (for example, enabling a lone carer to stay with a dying person rather than them needing to leave to collect supplies of medications).

Conclusions

Palliative care pioneer Dame Cicely Saunders' legacy is still evident in hospital wards, homes, care homes and hospices around the world, and can best be summarised by one of her most famous quotes: "You matter because you are you, and you matter to the end of your life. We will do all we can, not only to help you die peacefully, but also to live until you die." Taking a relational approach when caring for patients and carers and collaborating with colleagues (getting to know each other, working as a team across organisational boundaries, dialogue, and discussion) can lead to reduced overall workload and greater whole system effectiveness. The contribution of nurses is critical in this. Through personal and professional competence in organisation, education, support, assessment, communication, administration and documentation, nurses have a pivotal role in palliative care.

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