Caring for palliative care patients at home: medicines management principles and considerations

Standfirst: This article outlines how and when medicine support may be required by palliative care patients and family caregivers, alongside practical steps pharmacy teams can take to deliver supportive care.

Palliative care is defined by the National Institute for Health and Care Excellence (NICE) as the active holistic care of patients with advanced, progressive illness, where the management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. With many aspects of palliative care applicable earlier in the course of illness, the main goal is achievement of the best quality of life for patients and their families [1].

Access to palliative care is highly uneven and the quality variable, even in high-income countries such as the UK [2]. Only 14% of patients deemed able to benefit from palliative care currently receive it [3,4] while the demand for palliative care is growing. For example, in England and Wales, the need for palliative care is estimated to increase by 25-47% by 2040 [3]. Policy and commissioning drives are required to support excellent care for all patients, including those being care for and dying at home [5]. This is assumed to be the preference for the majority [6], but may not be appropriate for all [7].

Patients and family caregivers require appropriate, tailored and rapid access to end of life care. An important aspect of this is support is to better manage medicines, including potent analgesics prescribed to help control pain. The needs of terminally ill patients can change quickly and be unpredictable. Responding to symptoms and advising on care involves a multi-disciplinary whole system approach. Community pharmacists have occupied a marginal role in patient care, being mainly involved in medicine supply. However, current policy promotes a greater involvement of pharmacists in direct care as a means of reducing pressure on GP services and increasing patient access to care. There is great scope for pharmacists to contribute, for example, counselling on medicine use for seriously ill patients who may be homebound, identifying key family members and carers responsible for care, and liaising with other health professionals about prescribing changes, including deprescribing and use of anticipatory medicines, close to the end of life.

This article aims to consider how pharmacists can better support terminally ill patients, and the family caregivers who support them, to manage medicines at home. Specifically, it will highlight the day-to-day challenges patients and family caregivers face and offer practical information and ways that medicines optimisation can be applied to support palliative care patients being cared in the community setting.

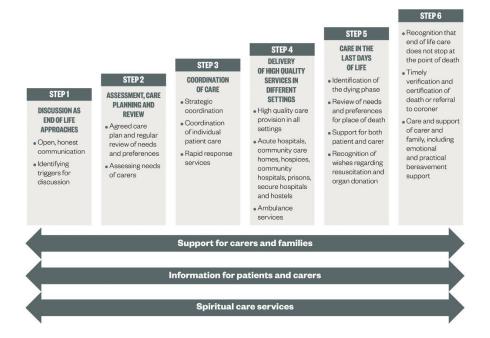
The end-of-life care pathway

The NHS Long Term Plan recommends improved proactive, personalised and well-coordinated care for all people in their final year of life [8]. Care should be patient-centered and sensitive to the physical, psychological, social and spiritual needs of the patient and family. Healthcare professionals should have the

competence and confidence to hold 'difficult conversations' with patients and family caregivers about end of life care. However, foreseeing when and how to initiate discussions, considering uncertainty around prognostication, is challenging and was covered in a previous learning article that detailed the communication and cultural competence skills required by pharmacists [9]. The government's end-of-life care strategy sets out recommendations governing the six key elements that characterise the end-of-life pathway (see Figure and Box 1) [10].

Figure 1: Department of Health: End of Life (EoL) care pathway

The six key elements of an EoL pathway. It is important that support and advice, including access to spiritual care services are provided alongside these steps to patients and family caregivers. Source: [10]



///Box 1: How pharmacists should communicate and have open discussions about end-of-life with the patient, carers and their families////

The extent to which discussions around end-of-life care are undertaken varies, but open and honest communication that is sensitive to the situation, commences early and continues through the patient's journey. The aims of these discussions include:

- Eliciting the patient's level of understanding, main problem(s) or concern(s) about their medicines
 (especially those that are anticipatory) and any impact (physical, emotional or social) that these are
 having on the patient;
- Determining how much information the patient wishes to receive and providing this to ensure medicine optimisation;
- Ascertaining whether the patient wishes more support to engage in medicines management or endof-life conversations with other family members or carers, and responding to these needs as
 necessary [9].

///End Box///

How community pharmacists can support patients and families at the end-of-life

With workplace pressures and lack of remuneration, community pharmacy has had limited involvement in supporting palliative care, but there is a growing need and so great scope for greater input. Patients and family caregivers often find it hard to cope with rapidly changing symptoms and associated prescription changes. This may be particularly important in the last days of life – where pharmaceutical care needs relating to timely supply, advice on <u>anticipatory medicines</u> [11] and managing symptoms may become more pressing.

Effective communication with patients alongside effective collaboration with a range of care providers is therefore central to achieving medicines optimisation. Given their ease of access, community pharmacists and their teams could support palliative care in the community. At present most pharmacists have limited interaction, are not formally integrated into the multi-disciplinary team or are not appropriately trained to fully contribute to palliative patient-centered care [12]. A previous article provides pharmacists with simple strategies and techniques to help manage difficult conversations and situations related to palliative care and end-of-life [9]. The following sections outline how and when medicine support may be required alongside practical steps pharmacy teams can take to deliver supportive care.

Opportunities for pharmaceutical care

In accordance with National Institute for Clinical Excellence (NICE) guidelines [14], pharmacists should recognise when a person may be in the last days of life and provide advice and support both to patients / family caregivers and health care professionals. This advice should extend to the use of anticipatory medicines (i.e. 'just in case' medicines, see Box 2) [13] and that sufficient stocks of these are available. Shared-decision making is important, as will being mindful of cultural, religious or spiritual preferences. Care will need to be carefully tailored and individualized; examples of the type of advice / interventions that could be given are included in Table 1.

Table 1: Examples of pharmacological interventions at the end of life [14]

Symptom management at the end of life	Example of pharmacological intervention / considerations
Managing pain	Following discussion with the patient / family caregiver, if pain is identified, initiate discussion with the prescriber about optimal management. Ensure a match between the medicine and severity of pain. Advise patient / family caregiver to monitor breakthrough pain episodes; ensure appropriate extended-release formulations are prescribed and counsel on correct use. Consider possible non-pharmacological pain management.
Managing nausea and vomiting.	Ideally, the cause should be determined through discussion with the patient / family caregiver.

	Ensure prescribing (where necessary) and counsel on the use of a suitable
	antiemetic.
	Invite the patient / family caregiver to contact the pharmacist after 24 hours to
	measure progress. Contact the prescriber if substitution or additional anti-emetic is
	needed.
	Consider possible non-pharmacological management.
Managing anxiety, delirium	Identify and explore possible causes of anxiety or delirium.
and agitation	The dose and frequency should be reviewed according to levels of patient distress
	and response.
Managing troublesome	'The death rattle' is a distinctive sound that a person may make as they are coming
respiratory secretions	to the end of their life and may no longer be able to swallow or cough effectively
	enough to clear their saliva.
	Reassure family members / friends that, although the noise can be distressing, it is
	unlikely to cause discomfort.
	If a medicine is indicated, periodic review for efficacy and adverse effects is needed,
	whereas some non-pharmacological advice may be needed (e.g. repositioning).
Other symptoms	Invite the patient to discuss other symptoms that could arise, such as
	anorexia/cachexia (i.e. wasting of the body), fatigue, constipation, diarrhea, oral
	health issues, depression and difficulty sleeping.
	Discuss solutions with the patient and offer advice to the prescriber / appropriate
	member of the wider care team.
	Maintain hydration: Advise the family caregiver to support the dying person to drink
	if they wish to and are able to.
Rational use of medicines and	Where appropriate, and with discussion with the patient / family caregiver and
deprescribing	prescriber, suggest to the prescriber to stop any previously prescribed medicines
	that are not providing symptomatic benefit (e.g. if the patient is on a statin) or that
	may cause harm.
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Further details (for non-specialists) on how to manage end of life symptoms can be found in the NICE guideline 'Care of dying adults in the last days of life' [14].

///Box 2: Just in case boxes///

Many areas of the UK have implemented 'Just in case box' initiatives to support anticipatory prescribing, where dispensed medicines are stored in a readily identifiable container along with the appropriate equipment (see 'Typical contents') and the necessary documentation to facilitate prompt administration if symptoms develop [15]. Procedures should be established to minimise the risk of medicines being unlawfully diverted [16].

Typical contents

- Anticipatory medicines for subcutaneous use (including diluent);
- Needles and syringes;
- Prescribing guidance;
- Authorisation to administer medication document;
- Patient and carer information leaflet;
- Contact details for advice [11].

Best practice principles

The prescriber must accept responsibility for prescribing in anticipation of need and be mindful that the availability of medication does not replace the need for clinical assessment when the patient's clinical condition changes. They must:

- Agree the list of anticipatory medicines locally with key stakeholders;
- Reduce the risk of prescription errors by agreeing the recommended starting doses and making them readily available to prescribers on pre-printed sheets;
- Balance the quantity supplied between adequate supply and potential waste;
- Include equipment and documentation to facilitate the administration of medicines in the just in case box;
- Be self-assured that the patient and carers understand the rationale for placing medicines in the home:
- Ensure that all healthcare professionals involved in the care of the patient are aware of the clinical situation and the availability of anticipatory medicines, including those providing the out-of-hours services [15].

////End Box////

With counselling on dispensed medicines or through offering an advanced service (Medicines Use Review (MUR) / New Medicines Service (NMS)), patients along with family / carers, can be enabled to make more informed decisions about their pharmaceutical care; for guidance on how to structure these conversations, see [9]. However, most seriously ill patients will either have their medicines delivered or collected by family caregivers and this could undermine the extent to which medication review and support services are offered or for opportunities for patient-pharmacist personal contact. In these cases, the pharmacist will need to ensure family / carers feel fully supported to manage medicines. Where clinical interventions have been proactively discussed with patients / carers and are then considered to be outside the pharmacists' remit, referrals should be made to the appropriate health professionals.

Medicine optimisation

It is essential that pharmacists actively support patients to take their medicines as intended. Pharmacists should routinely initiate discussions with patients about how they are using their medicines, and any concerns and questions they may have about these. This should include offering appropriate advice on the management of multi-morbidities and polypharmacy [17, 18]. In managing the care of patients at the end-of-life clinical decision-making may become more complex as new symptoms develop and become more prevalent and even

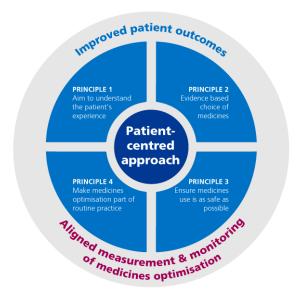
emotionally distressing for families and carers. Guidance on exercising professional judgement can be found in the 'Medicine Ethics and Practice' (MEP) [19] and through guidance issued by the RPS on ethical and professional decision making in the COVID-19 Pandemic [20]. This includes making informed decisions about the care of the patient by taking into account the law, ethical considerations relevant factors related to the surrounding circumstances (e.g. facts, relevant laws, standards and good practice guidance). The patient should remain the first concern of the pharmacist and you must ensure that you can justify your decisions. Where appropriate, make a written record of the decision-making process and your reasons leading to your particular course of action.

The principles of medicine optimisation should be employed to ensure patients get the best possible outcomes from their medicines (see Figure) [21].

- Principle 1 "Aim to understand the patient's experience"
 - o It is paramount to understand patients' perspectives for any given intervention or treatment. Pharmacists can encourage palliative care patients and their carers to express their views in an open dialogue about their experience and any concerns. This needs to be an ongoing two-way process to elicit patients' choices as they progress through different phases of their illness. An important part of this process will be active listening to understand the patient/family experience of specific medicines i.e. concerns about side effects, dislike of certain medicines/formulations and respond constructively. These discussions will help ensure the patients' preferences are understood and promote an environment of shared decision;
- Principle 2 "Evidence based choice of medicines"
 - Medicines regimens should be regularly reviewed to ensure they remain clinically appropriate and cost effective while meeting the needs of the patient. Such reviews can help identify medicines which are no longer necessary and can be stopped as symptomatic treatment progressively takes precedence.
- Principle 3 "Ensure medicines use is as safe as possible"
 - All aspects of safety should be considered, for example side effects, interactions and safe processes for handling. Medicines in palliative care carry significant potential for harm if mishandled or not used as advised.
 Pharmacists can engage patients and carers in improving their health literacy.

This can ensure that unnecessary incidents of harm do not occur and the patient feels confident using their prescribed medicine;

- Principle 4 "Make medicines optimisation part of routine practice"
 - Pharmacists should routinely initiate conversations with patients or their carers about their medicines. If they are homebound, a considerate telephone call to enquire how the patient is would be welcome. Additionally, effective medicines optimisation strategies require routine discussion and collaboration across professional boundaries. Patient permission for information sharing between services should be obtained.



Insights and lessons from the 'Managing medicines for patients with serious illness being cared for at home' study

The 'Managing medicines at home' study was a three-year qualitative investigation examining how patients and family givers cope with managing medicines at home, how they felt about doing this and the manner in which they were supported by different health care professionals and services involved in providing their care. [22]. Three main themes emerged and their application to medicines optimisation is described below. These themes can act as further areas where recommendations for community pharmacists can be considered.

1. Help required to enable patients to manage their medicines at home

Patients were being asked to manage complex medicines regimes at home with little support or guidance on their use [22]. A range of simple recommendations were identified to improve the support and management of medicines in the home, including:

- Encouraging greater awareness that people can approach the pharmacist for help and advice about medicines; the pharmacist was an untapped and under-used resource.
- Provide patients with accessible written and verbal information about what medicines are for and how to take them especially in relation to pain relief;

- Suggest alternative routes of administration where appropriate (e.g. move to liquid formulations);
- When applicable, provide dose administration aids, such as using multi-compartment compliance
 aids, to help reduce confusion about what tablets a patient should take and when; review their use on
 refill to ensure medicine adherence;
- Whenever possible, inform patients and carers when a tablet changes in size, shape or colour; these small changes were seen to be the cause of much confusion and anxiety;
- Keep adequate stocks of palliative care medicines in the pharmacy (as appropriate), for example
 medicines to relieve pain (e.g. various formulations of fentanyl and morphine) and manage confusion
 or restlessness (e.g. midazolam);
- Rationalise the use of or deprescribing of medicines where appropriate [23-25].

Prescribing changes often become more frequent during end-of-life, family caregivers may become anxious or confused if they are not properly informed and supported thereby resulting in potential non-adherence and medicine waste. This may be partly mitigated using dosette boxes, however advice on how to manage liquids, creams, patches and 'when required' doses will need to be discussed with the patient and carefully monitored by the pharmacist to ensure medicines are used appropriately [26].

2. Diversity and Disadvantage

Emerging evidence suggests that patients from marginalised groups may have greater un-met palliative and end-of-life care needs [27]. The study outlined how community pharmacy can improve the care delivered to people from diverse backgrounds (e.g. people who are unable to speak English may require support through a translator or a bilingual member of pharmacy staff) [28, 29]. It is crucial that patients and family caregivers feel supported to ensure optimum use of their medicines and avoidance of adverse effects. A range of disadvantaged patient groups who may require additional support include:

- Those with disability, including people with physical disability; visual impairment; hearing impairments or learning impairment;
- Those from Black, Asian and Minority Ethnic (BAME) communities and whose first language is not English;
- Those from Gypsy, Roma and Traveller communities;
- The homeless or those with no fixed address;
- Refugees or those seeking asylum;
- Those with mental health and stigmatised medical conditions (e.g. HIV);
- Those from rural communities;
- Those with alcohol/drug dependency;
- Those with poor literacy [30].

3. System complexity for patients

Complexity, especially when patient care involves a large number of professionals from different services is challenging to co-ordinate and manage. Patients sometimes felt frustration with a complex system that was experienced as fragmented and bureaucratic [22]. Pharmacists should facilitate and offer navigational support to sign-post to appropriate healthcare professionals or care agencies, particularly in a crisis.

As patients' health deteriorates, they gradually relinquish responsibility for medicines management, even to the point of requiring physical assistance with administration. Pharmacists should work closely with key family caregivers to maintain quality of care and safety of medicines and be mindful that sometimes family caregivers can themselves be in poor health.

Better communication, such as regular phone calls, between healthcare professionals and with families, especially GPs and pharmacists, is important to enable effective continuity of care. Patients may welcome pharmacists as the 'go to' professional whenever difficulties arise to proactively fix issues related to symptom management and medicines use. For example, pharmacists can carry out early palliative care discussions with patients and their family caregivers. It is important for pharmacists to develop a relationship so they have a good rapport with them that is useful in facilitating potential future difficult discussions. However, currently there is a lack of awareness of the pharmacist as a potential resource. In this case, the pharmacist should be proactive and can periodically check the wellbeing of palliative patients and their family members by organising routine review appointments, either in person or remotely.

Conducting medication reviews could be particularly valuable during end-of-life care, where achieving medicine optimisation may be more imperative. Pharmacists could consider conducting audits / research to build this evidence base.

Improving awareness of pharmacy support

Patients and families are often unaware of the help and support the pharmacy team is able to provide. A simple and effective way of alerting patients /family caregivers about what the pharmacy can offer could be made possible through a poster displayed in the pharmacy or local GP surgery. This could encourage patients and family caregivers to take the first step to seek help (Figure).

For example, when a patient asks the following questions, you could respond as follows:

- "Why have I been given this medicine?"
 - You should ask them what conversations they had with the prescriber and check their understanding of why this has been prescribed. If applicable, you can reinforce what the medicine is used for, explaining to the patient how the medicine works and why it is needed can help ensure patients feel comfortable with the prescribing decision.
- "Why have my medicines been changed?"
 - You can discuss their condition and how they feel it has been managed. If a medicine
 has been changed, explore the reasons why this change has occurred and
 communicate this to the patient. Has there been a GP practice formulary change?
 Did the patient report a side-effect, certain medicines are more or less appropriate
 for any given patient.
- "What if I miss a dose?"
 - Explain what the patient should do in this circumstance. This may be taking one as soon as they remember, or skipping a single dose. Advising the patient or their carer to check the patient information leaflet that typically has information relating to missed doses. Remind them that you or the pharmacist on duty for questions, and they may see you or ring you during opening times.
- "Do I have to take them all?"
 - Questions like this will depend on the medicine being taken. Explaining the rationale behind dosage regime can alleviate concerns. Where available, consider offering a Medicine Use Review (MUR) where more detailed discussions are warranted.
- "I'm finding my medicines difficult to take?"
 - Try to understand the reason it is difficult to take, consider whether it is mechanical (e.g. are they unable to open the packaging), a scheduling issue (i.e. are they struggling to access their medicines at night) or physical (e.g. is the medicine simply too large to swallow). Explore intentional non-adherence issues too i.e. aversion to taking medicines. Once this is understood the pharmacist can make recommendations on how to best manage the individual issues.
- "Where should I keep my medicines?"

 Advise the patient on the appropriate location to store their medicine and add that the patient can read the PIL for directions of a particular medicine.

Display the poster in your pharmacy – this can be freely downloaded. Consider printing an A5 flyer to be inserted in dispensed medicine bags. Be especially mindful of people from marginalised groups who find navigating health services challenging and may experience additional barriers to access the pharmacy for support.

///INSERT POSTER HERE (SEE ATTACHED FILE)///

Figure: Example of a poster that could be displayed in pharmacies and GP surgeries to facilitate access to care. This poster was co-produced by patient-professionals from the 'managing medicines at home' study. It can be downloaded and displayed in your pharmacy.

Multidisciplinary collaboration

The current involvement of community pharmacists in palliative and end-of-life care is predominantly with their role in medicine supply. As this learning article demonstrates, the pharmacist could significantly contribute and support dying patients and their families. Common barriers that contribute towards effective inter-professional collaboration include:

- limited access to medical care records;
- lack of remunerations for extended services;
- limited integration within the multidisciplinary team [31].

However, newer roles have promoted the potential for greater integration, for example, the 'Macmillan Pharmacist Project', 'Macmillan Pharmacy Service', the 'Community Macmillan Pharmacist Project' and 'Macmillan Rural Palliative Care Pharmacist Practitioner Project' [32-36]. These projects demonstrate that clinic-based, hospice and home medicine support is feasible and can help patients with complex palliative care needs. The following approaches can help towards improved pharmacy inclusion in palliative care services:

- Engage with Quality Improvement audits and review and action outcomes. For care pathways, the aim will be to enable more efficient information exchanges between different health care professionals engaged in patient care;
- Delegate more routine work to other pharmacy team members to allow for greater clinical input for patients with palliative care needs
- Promote your pharmacy as a 'medicines information hub' for other healthcare professionals, patients, and family carergivers;
- Invest in wider staff training to enable them to engage more effectively with palliative care patients and their families
- Explore the role of independent prescriber pharmacists in palliative care. This could be tailored for the appropriate and timely supply of anticipatory medicines.

For a summary of best practice principles for community pharmacists in relation to palliative care, see Box 3.

///Box 3: Best practice///

Community pharmacists should undertake certain responsibilities in order to ensure the best possible care for palliative patients:

- Act as a central point of contact and information about medicines for patients and their carers;
- Provide adherence aids (i.e. reminder charts) and patient information sheets about medicines that are used in palliative care;
- Provide advice to patients receiving palliative care and their carers post-discharge from hospital. This
 could be a useful trigger to ensure patients are aware of the pharmacist and are able to ask for advice
 to manage any changes that may have been made;
- Recommend the discontinuation of long-term medicines that are not needed during palliative care;
- Support the MDT about changes to medicines, providing prescribing advice and medicines information on complex medication issues (e.g. medicines compatibility with syringe drivers).

///End box///

Response to COVID-19

This article illustrates the significant opportunities (including new avenues for remuneration) for pharmacist involvement in palliative and end-of-life care. It highlights that pharmacists can play a key role in reducing the burden of medicines management for patients and their families. This learning article is written at a time when the world is struggling to overcome the effects of the COVID-19 pandemic. Rapid guidance from NICE has already been issued, prompting changes in how anticipatory medicines are prescribed and used. To cope with the pressures of rising demand for end-of-life care medicines and on professional time, it is suggested that prescribers should consider the use of long acting formulations which can be administered by subcutaneous injection, buccally, sublingually or rectally [37] and that these may need to be administered by family members. This proposal will likely result in extending the role and responsibility of FCGs in administering end of life care medicines in relation to the type of drug and method of delivery. It is the pharmacist's responsibility to advise on the correct use of these medicines and to adopt strategies that ensure effective counselling can be undertaken where people are in isolation (i.e. via remote consultations) and to those who are from marginalized groups who may find accessing pharmacy service more challenging [38].

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