

We need to talk about Palliative Care

Royal Pharmaceutical Society in Scotland

Timely access to pharmaceutical care and effective medicines are key areas of palliative care. Pharmacists from all sectors of the profession strive to provide the best care possible and ensure patients receive the appropriate medicines at the correct time to support patients, families and their carers.

In secondary care settings specialist palliative care pharmacists, many qualified as independent prescribers, work as part of the multidisciplinary team to provide expertise on all medicine related matters.

Many hospices now also rely on dedicated pharmacist input, recognising the unique contribution a pharmacist brings to their teams.

Across primary and secondary healthcare sectors there are good examples of excellent joint working with health charities such as Marie Curie and MacMillan Cancer Support. However, it is acknowledged that many more improvements could still be made. There are areas where the clinical skills of pharmacists could be better utilised and integrated into the wider palliative care team to improve patient care. This is becoming increasingly more important in the community and the care home sectors as the strategic direction of health policy indicates that all aspects of health care will be provided closer to the patient's home.

Our response is informed by the views of specialist palliative care pharmacists, specialist pharmacist prescribers working in other therapeutic areas where palliative care is sometimes required such as cardiovascular, respiratory and renal units and pharmacists working in the community as generalists with a special interest in palliative care in primary care.

Key Recommendations

- Read and write access to health records should be available with the patient's consent to all those involved in their care to ensure patient safety and timely access to medicines.
- Multidisciplinary education and training is required for prescribers to ensure they are familiar with Home Office requirements for controlled drug prescriptions to avoid unnecessary delays in patients accessing their medicines.
- Models of care need to be explored to allow community pharmacists to work to the top of their licence, as part of the multidisciplinary healthcare team to provide a more holistic package of care.
- Alignment of one GP practice, one community pharmacy and one care home to improve pharmaceutical care in care homes, which are increasingly required to deliver palliative care.

We have answered only those questions which are appropriate for a professional body and from a pharmacy perspective. We are happy to discuss in more detail any aspect of our evidence and the significant contribution pharmacy can make to palliative care.

1. What has been your experience in terms of access to palliative and end of life care?

Specialist clinical pharmacists in secondary care working in areas out-with oncology report that access to palliative care for patients with diseases other than cancer can be less than optimum with variable access across the country, depending on local policy and resources. This viewpoint accords with the findings of Audit Scotland in their report from 2008.¹

Our specialist pharmacists report that:

- Establishing patients as palliative in non-malignant disease is still more difficult than with cancer patients.
- There is still reluctance to treat non-malignant patients with agreed gold standard framework palliative care protocols.
- There are still barriers to care for certain groups of patients, e.g. people with dementia, and inequalities in access geographically and for some ethnic groups.
- There is a need for a national approach to training and raising awareness of guidelines.
- There is still room for improvement in uptake of “just in case”² prescribing to prevent unnecessary admissions to hospital.

In community, the establishment of the Community Pharmacists Palliative Care Network (CPPCN) has greatly improved access to palliative care medicines and pharmacists ‘expertise over extended hours.

These pharmacies ensure stocks of the agreed palliative care specialist medicines are available in the community at any time. Most of these pharmacies are open late in the evenings and at weekends with pharmacists available for emergency call out when the need arises. However there are still a number of challenges and gaps in this service that need to be addressed, some of which were identified by The Macmillan Pharmacist Facilitator project in Glasgow. These included “*variable communication between health care professionals, and across health care settings; a lack of concise and up-to-date palliative care resources and information for health professionals and patients; and a lack of knowledge regarding the prescription and supply of palliative care medicines*”.³

Legislative Issues

An MSc study at the University of Strathclyde⁴ has examined the challenges faced by community pharmacists in delivering pharmaceutical care to patient with palliative needs. It looked in particular at the issue of prescribing errors in controlled drugs (CDs) which can cause delays in access to treatment. It found that one in eight prescriptions submitted for dispensing in community pharmacies contained an error. A pharmacist cannot legally dispense a prescription which does not comply with stringent Home Office requirements. Scope to make even minor adjustments is extremely limited. Wherever pharmacists practice their prime concern is patient care so the current situation can pose legal and ethical dilemmas. Some pharmacists will make an ethical decision in specific circumstances to break the law in the best interests of the patient to avoid delays in accessing urgently required medication, putting themselves at risk of regulatory and criminal prosecution. Given the serious nature of any legal transgressions this should never be expected as normal practice. Some pharmacists contact the prescriber to remedy the situation as quickly as possible.

Some of the results are shown in the tables below.

Analysis of the Nature of Errors

Nature of Errors	Total	% of Total
Total Errors	106	12.5%
Legal Errors	91	86%
Clinical Errors	15	14%

This illustrates that although clinical intervention was frequently required the majority of errors were due to non-compliance with Home Office regulations. Current legislation combined with no access to patient records means that despite the pharmacist's clinical expertise they are unable to dispense safely without contacting the prescriber for adjustments or clarification of intent.

Analysis of Types of Prescribers

The study also looked at when errors occurred and found a much higher percentage in the out of hour's period. Out of hours prescriptions are by nature usually urgent but errors often resulted in longer delays in getting medicines to the patient than in the in hours period.

	Total	NSH GPs	OOH GPs	Probability
Total Prescriptions	850	804	46	p =
Reported Errors	106	87	19	<0.05
% Error Rate	12.5%	11%	41%	3.8

Findings

The study concluded that there is a need for continuing education of GPs and pharmacists, including tools to aid GPs with the legal requirements for prescribing controlled drugs. In addition it highlighted that further improvements in the provision of community based palliative care would only be possible if the current CD legislation is adapted to meet the modern clinical needs of patient's, prescribers and pharmacists in today's NHS. While we recognise that Home Office Legislation is a reserved matter it is important that the committee is aware that changes would be required at UK level to improve this aspect of patient care.

2 How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?

The Macmillan Rural Palliative Care Pharmacist Practitioner Project in Skye has highlighted gaps in service provision and demonstrated the potential to *“develop community pharmacy capacity to effectively, efficiently and safely support the needs of those in this rural community with palliative care needs regardless of care setting”*⁵

The principles of multidisciplinary team working and learning from this project could easily be applied to other settings to improve patient access to palliative care.

Anecdotally we hear that hospice beds are not always available for everyone who wants them and extra resourcing is required in this area to build capacity and ensure equity of access.

3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?

Access to patient health records

Access to patient records is one of the most important areas which must be addressed. Communication between secondary and primary care needs to be greatly improved and between community pharmacy and other health care sectors. Community pharmacy is the patient facing end point in primary care where timely access to palliative care medicines can be critical to patient care and to both prevention and relief of suffering.

Currently community pharmacists do not have access to patient records. For palliative care patients this can result in delays in accessing medicines and

carries a significant risk to patient safety. This can be particularly challenging in the out of hours period.

To ensure patient safety we advocate that full access to a patient's health record, with the express consent of the patient, should be made available to everyone involved in patient care as part of normal daily practice. The ability to record the pharmacist's contribution to a patient's care, for example, Minor Ailment Service consultations, Chronic Medication Service interventions or when urgent supplies of repeat medication ensure continuity of care, would give a more comprehensive and fuller awareness of all health and social care input.

There are numerous examples of instances where access to patient records would have improved patient care. Clarifying prescribers' intentions in palliative care can sometimes be challenging and there are inherent legal, ethical and patient safety issues in dispensing these high risk medicines. Although the establishment of the CPPCN and "just in case" boxes has improved access to the specialist medicines required in palliative care, particularly on the out of hours situations, there are still challenges in that the network pharmacy will have no record of the medicines previously prescribed and dispensed at the patients' regular pharmacy. An awareness of this medication history is crucial to managing risk of adverse drug reactions, and even prevention of potentially fatal overdose situations.

Without access to the patient records community pharmacy do not have access to an accurate diagnosis and is not notified routinely when someone is at the palliative stage of treatment. Pharmacists rely on their communication skills and expertise in medicines to establish what a probable diagnosis might be but some medicines can be used for more than one therapeutic area. This can cause problems in identification of palliative care/urgent prescriptions, making sensitive conversations with families and carers even more difficult. Patients frequently expect the pharmacist to already have access to their records and be informed of their situation and so the situation can undermine patient confidence in the care they are receiving.

In the out of hours period access to the Emergency and Palliative Care Summaries (ECS, PCS), even for pharmacists, is via NHS24. Scottish Government pledged access to the ECS for community pharmacists by 2014 but there has been no roll out of this programme yet.

Care Home Provision

Care homes are now essentially operating in the same way as many geriatric hospitals were twenty years ago with residents much closer to the end of their lives. They are therefore now delivering palliative care and need much greater pharmaceutical input for clinical and medicines related activities as well as staff training in this specialist area. It is important that staff are aware of the palliative nature of treatment and the services available through the CPPCN to access urgently required medication. These should not be processed by the normal routes which can delay medication reaching the patient. Equally

with more patients being cared for at home – care at home staff and lay carers require training similar to that provided to care home staff.

Our report, “Improving Pharmaceutical Care in Care Homes”⁶ published in March 2012⁶ contained sixteen recommendations, including the need for greater involvement of the CPPCN as a resource for care home staff. Currently any contractual pharmacy involvement in care homes is focused on a supply function rather than pharmaceutical care. Many health boards are now deploying pharmacists to work with care homes as part of the national polypharmacy work⁷ but greater use should also be made of existing community resources and different models of care need to be explored to facilitate person centred, rather than system led approaches, appropriate for local needs. Community pharmacists, frequently know the patients and their families and are extremely well placed to provide a holistic package of care to their patients. Several health boards have deployed pharmacy technicians to provide support to care homes to help improve ordering systems and stock control thereby reducing waste.⁸ Properly resourced this model could be expanded to include the local community pharmacy teams.

4. When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?

The pharmacist facilitators report that diagnosis and discussions around palliative care should take place much earlier in the patient journey than is common practice currently.

We recommend that pharmacists are included as part of the multidisciplinary team and must be informed whenever palliative care is initiated and that pharmacists are included in care planning meetings.

5. What works well in discussing palliative and end of life care and how is good practice communicated? Where do the challenges remain?

For the clinical teams transfer of information between settings⁹ can be challenging and there is a need for similar language and formats of information to be used in primary and secondary care to facilitate a common understanding throughout the patient journey. There are recognised assessment tools for cancer patients to help with sharing of diagnostic and prognostic information but such tools have not been developed for other therapeutic areas. There are challenges in ensuring everyone involved is trained in the difficult discussions around palliative care and informed of a patient’s wishes at end of life.

6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?

Pharmacists have been instrumental in developing anticipatory care prescribing and “just in case” boxes which are now being rolled out across most health boards. These plans have encouraged forward planning and helped alleviate crisis situations in the out of hours period. Further training of

care home staff in the protocols around “just in case” boxes and wider team working with primary care teams would encourage prescribers to use these more in the care home setting.

7. How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?

With reference specifically to medicines any patient information leaflets should include signposting to encourage patients and the families to ask their pharmacist if they have any queries about their medicines. This will free up GP appointments and relieve pressure on out of hours services. Research looking at palliative care from a patient’s perspective has identified that poor communication between patients and health professionals is the most common cause of misunderstanding around medicines¹⁰. This would indicate that more needs to be done around health literacy in general and keeping patients informed on where to go for advice.

In rural areas where no pharmacist is available e.g. in some dispensing doctor practices, consideration should be given to the use of tele-pharmaceutical care provision – especially for reassurance and advice about medicines e.g. how to alleviate any side effects.

8. What training and support is provided to Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement

Training for pharmacists and support staff needs a greater focus on the communication skills required to have “difficult “ conversations , allowing the patient and/or their family to express their feelings and obtain assistance with understanding of what is to come. Pharmacists are not routinely trained in these specialist soft consultation skills and without access to patient records, diagnosis or notification of a patient on the palliative care register can render discussion and support difficult.

The MacMillan Facilitator project in Glasgow aimed at improving services through improving knowledge and skills, communication, information and anticipating needs. It identified a wide variation in levels of skill in communicating with patients or their families and carers which needs to be addressed. It also recognised a need to provide training for community pharmacy support staff who interface directly with the public, to give them a broad awareness of palliative care and improve their ability to identify and support patient and carer needs. There are now resources available through National Health Education Scotland (NES) and we must ensure that these and the learning from the MacMillan project are used and disseminated widely. The wide ranging situations faced by community pharmacists supporting palliative care patients, and the challenges of managing these within the community pharmacy environment, are described in a study by O’Connor et al (2011).¹¹

9. How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?

N/A

10. What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?

The biggest challenge to any communication between health and care providers is not having one shared patient record. There is currently no way of recording a person's personal wishes and priorities in any one place, accessible to everyone involved in their care to ensure continuity of care in a person centred way.

Ensuring patient safety and optimum treatment in a timely manner is challenging for community pharmacists who cannot access either hospital or GP records from the pharmacy. Currently the multiple IT systems in use in different healthcare settings means that sharing of information between different secondary care sites is not always possible and there is a disconnect also between primary and secondary care.

In particular, there is no routine ready access to discharge letters and information. Patients are sometime given a letter to hand to their GP or letters are sent. Community pharmacists are not routinely included in this communication chain. This can pose serious problems in accessing information on changes in medication when it is required ensuring patient safety. Palliative care patients are frequently prescribed high risk medications and access to the full information on their medication history is of critical importance.

Some pilot projects are now underway with electronic discharge information being shared with community pharmacies as well as the patient's GP. We are currently unaware of any timelines to make this information available on national basis.

About us

The Royal Pharmaceutical Society (RPS) is the professional body for pharmacists in Great Britain. We represent all sectors of pharmacy and we lead and support the development of the pharmacy profession including the advancement of science, practice, education and knowledge in pharmacy. In addition, we promote the profession's policies and views to a range of external stakeholders in a number of different forums.

Royal Pharmaceutical Society in Scotland

¹ Audit Scotland 2008. "Review of palliative care services in Scotland". Available from: www.audit-scotland.gov.uk, accessed 4 August 2015.

² “Just in Case”boxes seek to avoid distress caused by poor access to medications in the Out of Hours (OOHs) period, by anticipating symptom control needs and enabling availability of key medications in the patient’s home. Gold Standards Framework. Examples of good practice. Resource Guide. <http://www.goldstandardsframework.org.uk/cd-content/uploads/files/Library%2C%20Tools%20%26%20resources/ExamplesOfGoodPracticeResourceGuideJustInCaseBoxes.pdf>, accessed 12 August 2015.

³ NHS Greater Glasgow & Clyde. Macmillan Pharmacist Facilitator Project. Final Evaluation Report – 2012. <http://www.palliativecareggc.org.uk/uploads/file/guidelines/Macmillan%20Full%20Report%2031012012%20FINAL.pdf>, accessed 12 August 2015.

⁴ Stuart, Jane 2013. “Investigating the Prevalence and Nature of Controlled Drug Prescribing Errors identified in Community Pharmacies”, MSc Project, University of Strathclyde.

⁵ Macmillan Rural Palliative Care Pharmacist Practitioner Project in Skye. <http://www.palliativecarescotland.org.uk/content/publications/19.-Macmillan-Rural-Palliative-Care-Pharmacist-Practitioner-Project.pdf>, accessed 12 August 2015.

⁶ Royal Pharmaceutical Society in Scotland, 2012, “Improving Pharmaceutical Care in Care Homes”: <http://www.rpharms.com/promoting-pharmacy-pdfs/rpscarehomereportfinalmarch2012.pdf>, accessed on 12 August 2015.

⁷ Scottish Government 2015, “Polypharmacy Guidance”, <http://www.sehd.scot.nhs.uk/publications/DC20150415polypharmacy.pdf>, accessed on 12 August 2015.

⁸ Royal Pharmaceutical Society in Scotland, 2012, “Improving Pharmaceutical Care in Care Homes”: <http://www.rpharms.com/promoting-pharmacy-pdfs/rpscarehomereportfinalmarch2012.pdf>, accessed on 12 August 2015.

⁹ Royal Pharmaceutical Society 2012, “Keeping patients safe when they transfer between care providers – getting the medicines right”: <http://www.rpharms.com/current-campaigns-pdfs/rps-transfer-of-care-final-report.pdf>, accessed on 12 August 2015.

¹⁰ MacRobbie, A., Brearley, S. G. & Payne, S. “Palliative Care Patient Perceptions and Experiences of Medicines Information in a Community Pharmacy: A Grounded Theory Approach”, <http://www.palliativecarescotland.org.uk/content/publications/19.-Macmillan-Rural-Palliative-Care-Pharmacist-Practitioner-Project.pdf>, accessed 12 August 2015.

¹¹ O’Connor M, Fisher C, French L, Halkett G, Jiwa M, Hughes J. 2011. “Exploring the community pharmacist’s role in palliative care: Focusing on the person not just the prescription”. *Patient Education and Counselling* 2011; 83:458-464.