

Palliative & End of Life Care

Pharmacy's contribution
to improved patient care



Patient quotes

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“I am shocked to learn community pharmacists do not have access to patient's full medical records”

“The time I spent chasing prescriptions, was time that should have been spent with my dying husband”

“I want to be warned about the side effects of medicines, not have to ask”

“We had longer with our dad thanks to the Total Parenteral Nutrition pharmacist”

“I feel far more comfortable going through medicines with my local pharmacist than with my GP”

“I wish we could have had a meeting with the pharmacist at the time of diagnosis so we were more prepared for all the changes in medicines and different side effects”

“My community pharmacist was the only one who answered my questions clearly and directly”

”

Introduction

People living with life-limiting conditions who are approaching the end of life must have **timely access to medicines** and clinical support from a **skilled pharmacy team**.

Patients should expect to experience **high quality, coordinated care**, approaching death in comfort, surrounded by those important to them and **in the setting of their choice**.

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Foreword

Ensuring that a person's death is as peaceful and symptom-free as possible is a key responsibility of our health and social care systems. The aim is for people to approach death in comfort, surrounded by those important to them, in the place of their choice. Achieving this aim requires a coordinated and well planned approach, with input from a range of health and social care professionals.

This policy document focuses on making sure patients who require palliative and end of life care can access the full range of pharmacy expertise, maximising safe and appropriate use of medicines. Pharmacists as members of multidisciplinary teams help patients to be cared for in their homes, if this is their wish. This is a prudent approach, making best use of NHS resources.

This policy was originally published by the Royal Pharmaceutical Society in Wales in 2018 and this refresh has been completed in the wider context of work across Great Britain (GB) and now reflects a GB approach. It considers and builds upon the strategic guidance in each country of the United Kingdom. There are different guidelines for England, Wales, Scotland and Northern Ireland, each of which recommend ways that professionals should work to provide the best care for people at the end of their lives. Most importantly, end of life care should be person-centred. This means treating the patient as an individual and considering what matters most to them.

NHS provision for palliative care is a statutory requirement of the Health and Care Act (2022). The NHS England (NHSE) Palliative and End of Life Care (PEoLC) team has produced statutory guidance for Integrated Care Boards (ICB). Co-produced by 34 organisations, the Ambitions for Palliative and End of Life Care provides a framework for each ICB to evaluate commissioning and delivery of their palliative and end of life services 2021-2026 (1). The document sets out an overarching vision together with six ambitions to be achieved, through quality improvement initiatives. In Wales, the National Palliative and End of Life care Programme provides national leadership and support and acts as a forum to drive forward change and oversee health boards' efforts to deliver the Welsh Government's vision for improving end of life care in Wales (2). This work is informed by a Quality Statement for Palliative and End of Life Care. Scottish Government published a consultation on the draft strategy "*Palliative Care Matters for All*" in October 2024, setting out eight key outcomes for delivery of this strategy (3). This five year strategy (2025-2030) builds on previous palliative care strategies, 'Living and Dying Well: A national action plan for palliative and end of life care in Scotland (2008)' and 'Palliative and end of life care: strategic framework for action (2015)'.

Recommendations in this policy are aimed at key stakeholders who have responsibility for making sure people living with life-limiting illness or approaching the end of life receive the best care. The policy also places emphasis on the professional responsibility of pharmacists and pharmacy technicians in this area of care.

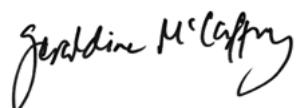
The RPS recognises the wider impact of a diagnosis on family members and people who are important to the patient. Some may have to take over decision making for their loved one. As such, it's vital that they are supported and given as much advice and information as they need, at a time that is right for them. Support for the patient, carer and family must also include dialogue between the whole multidisciplinary health team, social care and third sector organisations, to make sure the patient's needs are effectively understood and met.

The recommendations and principles of pharmaceutical care in this policy apply equally to both palliative and end of life care. Most principles also apply to both adult and paediatric care. However, some specific issues are highlighted regarding paediatric palliative care.

We would like to thank all the practitioners, third sector organisations and particularly all the patients and relatives who have been so open in sharing their experiences.



Jonathan Burton
Chair, Scotland Board



Geraldine McCaffrey
Chair, Wales Board



Tase Oputu
Chair, England Board

Royal Pharmaceutical Society

Key Recommendations

Supporting and informing patients

Patients requiring palliative or end of life care and their families must benefit from:

- 1. Regular conversations with the pharmacy team about medicines that are prescribed.**
Patients should also have access to patient focused information in a format appropriate to their needs, to make sure that they are fully informed and get the best from their medicines.
- 2. Access to a full range of health, social care and third sector support.**
The pharmacy team should signpost, and pharmacists be able to refer patients directly, to the support needed in order to streamline the patient journey.
- 3. Pharmacists who proactively support families and carers after a death with timely and considerate support.**
At present, community pharmacists are not routinely informed when a patient they have cared for has died, which can result in medicines being inadvertently delivered to a family's home following death.

Timely Access

Patients requiring palliative or end of life care and their families must benefit from:

- 4. Systems and practitioners that make sure the process of obtaining medicines, including urgent controlled medicines, is as easy and timely as possible.**
This will avoid any delay in treatment in all care settings and help to ensure patients can remain in an environment of their choice without the need to be transferred to hospital for essential medicines.
- 5. The ability to automatically share their health status when being included on a general practice palliative care register and to share advance care plans with their multidisciplinary team, including pharmacists at a community pharmacy of their choice.**
This will help the pharmacy team to proactively support the patient, taking responsibility away from the patient of having to tell each practitioner about their diagnosis.

6. A single integrated electronic health record to ensure timely communication and updating of information.

This is particularly important in the last stages of life when changes can happen rapidly. With access to the health record pharmacists can be more responsive to changes, and make informed clinical decisions, in partnership with patients and other health and social care professionals and ensure any intervention they make is recorded and available for other professionals involved in the patient's care.

7. Their wishes of dying in a care setting of their choice to be fully supported without any compromise on the level of care received.

Individuals must not be in any less comfort or feel isolated from services if they choose to die at home, and they should have access to the same high level multidisciplinary team expertise.

Workforce

8. Pharmacists must be embedded in all multidisciplinary palliative care teams to input expertise on the safe and effective use of medicines, including prescribing and deprescribing.

Pharmacists and the pharmacy team have particularly important roles following a patient's diagnosis with a progressive or life-limiting illness to ensure that the medicines regimen is optimised, as well as to coordinate the care and medicines supply for patients as they move from one care setting to another.

9. Governments in each devolved nation must have a structured approach to the development of pharmacy roles within multidisciplinary palliative care teams.

This will support workforce continuity and succession planning so that patients can access expert knowledge from pharmacists wherever and whenever they need it.

10. Integrated Care Boards or Health Boards must commission a lead paediatric palliative care pharmacist role in each country/region.

This role would provide strategic leadership and improvements in the use of medicines for children with life-limiting conditions. This role should be complemented by a support network of paediatric pharmacists with a special interest in palliative and end of life care.

Education

11. Education and training in palliative and end of life care for pharmacy teams must be strengthened to support the development of advanced roles.

Pharmacists and pharmacy technicians should keep up to date with best practice approaches and be equipped to confidently and competently discuss options about care in the end of life phase with patients.

A quick guide to the policy

To make it easier to get the information you need from the policy, here are a few things to look out for as you're reading through. If you're not sure of a technical term used in the policy, please see the glossary of terms on page 35.

Our recommendations

Our 11 key recommendations form the backbone of this policy, and represent our ideal vision of the ways the pharmacy team can further contribute to improved palliative and end of life care for patients. We've covered them already at the start of this document, but you'll also see each one embedded throughout, with supporting evidence and discussion of the issues that underpin them.

Professional responsibility



Many of our recommendations can only be realised with the help of pharmacy team members taking greater professional responsibility to improve patient care. Where this is a key element of a recommendation, we highlight exactly what we expect from pharmacists and the wider pharmacy team to make this improvement happen.

Quality improvement (“Daffodil”) standards for community pharmacy

The Royal Pharmaceutical Society partnered with the end-of-life charity Marie Curie to develop quality improvement (“Daffodil”) standards of palliative and end of life care for community pharmacy and these were launched in May 2023. Aligned with standards developed by the Royal College of General Practitioners and Marie Curie in 2019, the standards support engagement with community pharmacy teams in multidisciplinary improvement in the delivery of care in the community. Ongoing implementation and impact evaluation is supported through a multi-professional steering group and a range of resources are available on the RPS website.

Context for change

There is no set timescale for conditions that require palliative care. Advances in diagnosis mean that a patient's life-limiting illness can be identified decades prior to that patient's likely death.

There can be confusion between palliative and end of life, with both phrases frequently used interchangeably. For the purpose of this document, end of life care refers specifically to care provided in the last phase of life, which can be defined as approximately the last year of life (4). It has also been taken into consideration that there are often considerable changes and unpredictability during the last days and even hours of life, which will need more significant attention (5). During the last days of life, the medicines interventions and changes can be a particular focus, and access to controlled medicines and injectable medicines can be crucial.

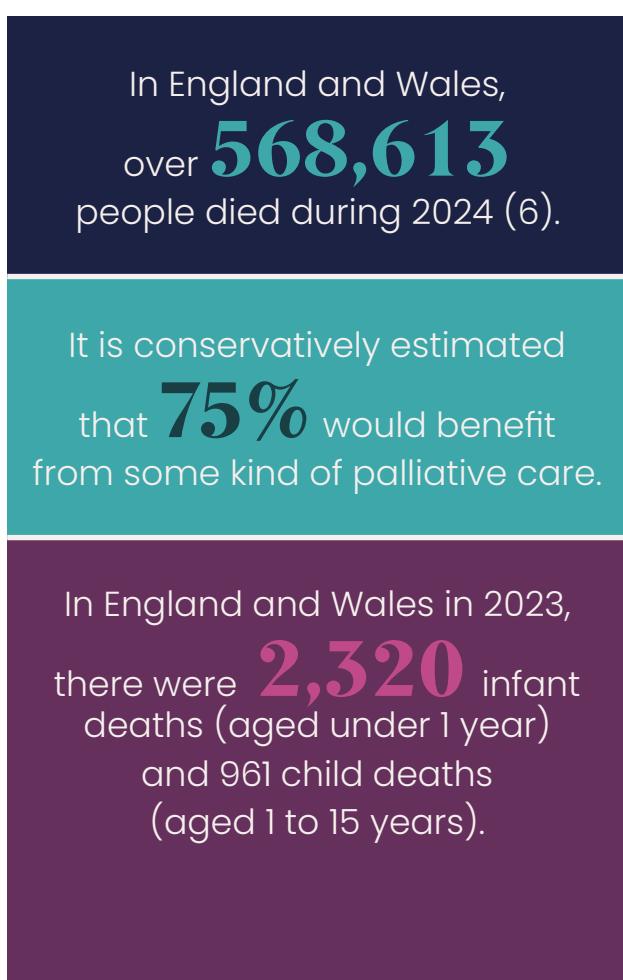


Figure 1:
Supporting statistics, adapted
from ONS data (reference 6)

Paediatric Palliative and End of Life Care

In England, the prevalence of children with life-limiting conditions rose from 32,975 in 2001/2 to 86,625 in 2017/18 (7). It is estimated that there will be between 67.0 and 84.2 per 10,000 children, and their families, living with such conditions in England by 2030. Palliative care is provided to infants, children and young people with a wide range of life-limiting or life-threatening conditions. Some will have severe disabilities and multiple complex healthcare needs related to their condition, as well as palliative care needs.

The 2015 report Palliative Care for Children and Young People in Wales states that *“much of children’s palliative care is not just about the final period of life, but about helping children, young people and families cope better with a series of conditions which may last for many years in childhood and beyond.”* (8, 9)

There are huge differences across the UK in the way children’s palliative care is planned, funded and provided. Of particular concern is children and families’ access to end of life care at home, 24 hours a day, seven days a week, provided by nurses and supported by advice from consultant paediatricians who have completed sub-specialty training in paediatric palliative medicine (also known as GRID training). This standard is met in just a third (30%) of local NHS areas (known as integrated care board, or ICB, areas) in England, with nearly a half (47%) partially meeting it and almost one quarter (23%) not meeting it at all. In England, only 6 ICBs (14%) are funding and delivering (a process known as commissioning) services to provide 24-hour access to both children’s nursing care and advice from a specialist consultant in paediatric palliative care. Two in five (41%) of ICBs do not commission this at all. The 24/7 end of life care at home standard is not met at all in Northern Ireland and only in a minority of areas in Scotland and Wales (10).

It is important to remember that children and young people are not just small adults. In caring, managing symptoms and prescribing for children and young people, whether they are in the palliative or end of life phase, complicated issues need to be explored and understood, including:

- **differing physiology and pharmacodynamics in different age groups**
- **ethical issues around autonomy and consent**
- **changes associated with development and growth**
- **family dynamics**
- **differing medical conditions, timescales and symptom presentation**
- **challenges in administering medicines and medicine adherence.**

All the above issues need to be considered when prescribing or making any changes to a child's medicines regimen. Formulation and administration of medicines is an important consideration, to ensure the medicine can be given safely by the carer and is tolerated by the child.

The **All Wales Palliative Care Standards for Children and Young People** states that *"all children identified as needing access to palliative care have access to high quality, evidence based care provided by appropriately trained multi professional teams in the most appropriate environment and with as little disruption to the child, young person and family"* (11,12) The RPS, through this policy, endorses this principle and emphasises that the clinical expertise of pharmacists is essential to achieving this.

Figure 2:
Steps to better care

To make sure that patients have access to expert medicines care and support, our recommendations are structured into key themes as outlined in the diagram.



Supporting and informing patients

People with palliative and end of life care needs must be treated with dignity and respect and supported to take part in their own decision making. When considering what good palliative and end of life care looks like, the needs and wishes of the patient must be at the forefront of any assessment. Patients should be given information, in a format that meets their needs, to help them make choices about their care. The patient's wishes and preferences should always be at the heart of the care provided by health and social care professionals.

The 2015 Welsh Government end of life care annual report emphasised that *"Encouraging more people to have open and honest conversations about their end of life preferences and final wishes with family and friends"* is a priority (13). However, in order to do this, people need to have access to professional support and advice to help inform their decision making.

Recommendation 1

Patients requiring palliative or end of life care and their families, must benefit from regular conversations with the pharmacy team about medicines that are prescribed. Patients should also have access to patient focused written information to make sure that they are fully informed and get the best from their medicines.

Medicines can be of significant benefit during palliative and end of life care to control symptoms and to stabilise people's conditions. It's an area where people can benefit significantly from the support and expertise of a pharmacist and the pharmacy team to help them make decisions about their medicines and health care.

People often live with a life-limiting illness for decades, and as such, need to be able to take control of their health care so they can continue to live life as they choose. A medicines regimen should be working to support this quality of life, not standing in the way of the life people want to lead. It's therefore imperative that there are open conversations about the benefits of medicines that are available, potential side effects and whether the regimen will mean being tied to monitoring routines etc. Conversations should always be supplemented by clear and easy to read information that is written with the patient in mind to help support decision making. These principles are consistent with the concept of Realistic Medicine, as promoted by NHS Scotland (14).

When diagnosed with a life-limiting condition, the amount of information to process can be overwhelming for patients and their families. Providing patients with accessible written information on medicines and a treatment regimen is important. This way, patients and their families can refer to and digest information whenever they feel comfortable and ready. This may lead to further questions for patients, therefore opportunities for follow up discussions with their pharmacists and other professionals involved in their care should be outlined.

Opportunities for consultations and written information should be available in the patient's first language, whenever possible. Being able to communicate pain and other symptoms in a patient's first language is beneficial and often essential to help communicate symptoms and ensure full understanding. We strongly believe that in line with the Welsh Government's 'active offer', patients should be offered services through the medium of Welsh rather than having the burden of asking for the service (15).

Professional responsibility



Pharmacists should always have a conversation with a patient or representative about their medicines when any changes are made to their regimen. Every effort should be made to provide supportive written information that is tailored to and of benefit to the patient.

Recommendation 2

Patients requiring palliative or end of life care and their families must benefit from access to a full range of health, social care and third sector support. The pharmacy team should signpost and pharmacists be able to refer patients directly to the support needed, in order to streamline the patient journey.

A STATEMENT OF SUPPORT FROM MARIE CURIE CYMRU

“ Marie Curie welcomes this report which addresses some very important issues impacting on the care and support for people who are near the end of their lives. For many people end of life care is not something they like to think about yet we know that telling other people about your fears and wishes have a big impact on your experiences at the end of your life. People approaching end of life will have some basic expectations and timely access to medicines is one of them, but as this report shows more needs to be done to make that expectation a reality. Too much time is wasted at the end of life in assessments and reassessments by teams looking after patients. Sharing medical records will allow pharmacists to be more responsive to patient's needs. Many individuals also state a desire to die at home yet it is often not possible to obtain essential medicines outside of a hospital environment which all too often leads to a stressful and unnecessary admission to hospital which is in the best interests of no one.

There are many simple steps outlined in this report which can make a huge difference to the quality and experience of care for people who are at their most vulnerable. We hope that all, Government, the NHS and health professionals, who have it in their power to make these changes will do so and do so quickly.”

Community pharmacies and their teams, being the most accessible healthcare setting, are ideally positioned to highlight support resources for patients and families. They can also appropriately signpost to other sources of health and social care support that are open to their patients. Additionally, many third sector organisations including Tenovus, Macmillan and Marie Curie have telephone lines and digital solutions such as online chat functionalities that patients and their families can access for support. Information about local and out of hours support, such as telephone helplines (e.g. NHS Highland hospice), should also be available through community pharmacies and NHS support platforms and phonelines e.g. NHS 24, NHS Inform, NHS111.

Pharmacists, pharmacy technicians and their wider teams are ideally placed to provide support to families after a bereavement. Every bereavement is different, and its impact on family and friends can vary according to the age or circumstances of the person who died (16). A sensitive approach is needed and the pharmacy team can play an important role in signposting people to bereavement support services, making use of information portals such as CRUSE Bereavement support, DEWIS Cymru or NHS Inform Coping with Grief pages in Scotland (17, 18). This approach can help direct people to relevant support which may be wider than health and wellbeing, including access to advice on financial and legal issues.

Professional responsibility



Pharmacists should keep up to date on the various services available to patients in their local areas to actively signpost to appropriate resources and organisations that are likely to benefit their patients.

Recommendation 3

Patients requiring palliative or end of life care and their families, must benefit from access to pharmacists who proactively support families and carers after a death with timely and considerate support. At present, community pharmacists aren't routinely informed when their patient has died, which can result in medicines being inadvertently delivered to a family's home following the death.

The pharmacy team also has an important role in helping to ease the process for the disposal of unused medicines for families. When a relative or carer brings any medicines back to a pharmacy for disposal, regardless of the original source, this should be supported sensitively and made as easy as possible for the individual. Broader support and discussions should take place in the private consultation area. Access to appropriate training and a private area to support more sensitive discussions may be a challenge as clinical services in community pharmacy expand.

Professional responsibility



Every member of the pharmacy team should be made aware when a regular patient has passed away, in order to proactively support families that may seek advice or further services from them.

Timely access

Pharmacy has a particular role to play in making sure patients can access the medicines they need. Patients need up to date advice about medication and how it may affect their symptoms. To fully contribute expertise to the multidisciplinary team and directly to patients, the pharmacy team must be fully integrated into the models of care that are established for patients with palliative and end of life care needs.

Recommendation 4

Patients requiring palliative or end of life care and their families must benefit from systems and practitioners that make sure the process of obtaining medicines, including urgent controlled medicines, is as easy and timely as possible. This will avoid any delay in treatment in all care settings and also help to ensure patients can stay in their own homes, in comfort, without needing to be transferred to hospital for essential medicines.

Access to medicines in the out of hours period can be particularly challenging. Anticipatory prescribing and supply should be considered and local arrangements for urgent medicines supply should be established. The Just in Case (JIC) service, which is available in many community pharmacies, provides improved access to key medicines for rapid control of breakthrough symptoms in palliative care. In those ICBs or Health Boards that have commissioned this service, a JIC should be considered for any patient with a terminal diagnosis and a prognosis of 3 months or less. The decision to supply should be based on a discussion between the patient and the prescriber (19)

The JIC service uses a sealed bag, often orange, or a box. The box or bag will contain medicines, product information and sundry items to support administration of medicines to relieve symptoms at the end of life. Once opened, any unused medicines can be added to other supplies in the patient's home, and any that are no longer required can be returned to the pharmacy. A starting dose for each medicine must be included to satisfy controlled drugs regulations and also to facilitate administration. A Medication Record Chart or Medicines Authorisation and Administration Record (MAAR) Chart can be partially completed by the GP (or other prescriber) at the same time as the prescription. For practitioners such as paramedics who may be called to the aid of a dying patient, the availability of a medication chart can be crucial to help keep patients in their own home and in as much comfort as possible.

There can be difficulty in obtaining certain medicines for end of life in a community setting, as they can be medicines that are not regularly dispensed from a community pharmacy. In some areas, often as part of a network arrangement, there are agreements in place with certain community pharmacies to keep specific medicines in stock that are commonly used at end of life. The medication is still provided in conjunction with a prescription from a prescriber as with other medicines (19, 20).

Regardless of the services set in place by the ICB or local Health Board, it's important that both health care professionals and patients are aware of the processes that are in place to aid medicines supply in the community to avoid delays in treatment. This could be through extending existing services that are deemed to be best practice, or through improving communication regarding current systems of obtaining medicines that are in place.

All prescribers issuing emergency prescriptions for end of life care should also take responsibility for making sure that the pharmacy they refer a patient to does have stock of those prescribed medicines. At an emotional and difficult time for patients and their families, sourcing important end of life medicines shouldn't be an additional worry.

A STATEMENT OF SUPPORT FROM COMMUNITY PHARMACY WALES (CPW)



The community pharmacy network in Wales is the most accessible part of NHS Wales and provides a quick, safe and convenient supply of medicines together with valued advice on how the people of Wales can get the most out of the medicines they have been prescribed.

CPW supports the recommendation of the development of a single integrated health record for patients to ensure timely communication and updating of information which is particularly important in the last stages of life; as many patients choose to spend their remaining days in their home environment it is important that community pharmacists should be granted the same level of access as that of pharmacists working in other sectors.

Timely access to medicines together with clinical support is essential for people living with life-shortening or terminal conditions and CPW would encourage all Health Boards to put in place one of the community pharmacy enhanced services designed to guarantee a supply of palliative care medicines, together with clinical advice, when it is most needed and to ensure that these services are available to the patient or their carer at their home if requested.



Professional responsibility



Patients requiring palliative or end of life care and their families must benefit from the ability to automatically share their health status when being included on a general practice palliative care register and to share advance care plans with their multidisciplinary team, including pharmacists at a community pharmacy of their choice. This will help the pharmacy team to proactively support the patient, taking responsibility away from the patient of having to tell each practitioner about their diagnosis.

Recommendation 5

Patients requiring palliative or end of life care and their families, must benefit from the ability to automatically share their health status when being included on a palliative care register, and to share advance care plans with their multidisciplinary team, including pharmacists, at a community pharmacy of their choice. This will help the pharmacy team to proactively support the patient, taking responsibility away from the patient of having to tell each practitioner about their diagnosis.

The report by a National Assembly for Wales Cross Party Group (CPG) looking into inequalities in access to hospice and palliative care highlighted that *"for people with life-limiting conditions other than cancer, little is known of the effectiveness of Palliative Care Registers in enabling access to appropriate palliative care and delivering good outcomes"* While we are pleased to see an increase in the number of patients who are captured on the GP held palliative care register (21) we share the concern made by the CPG. We would advocate for the register to open more doors to support for patients from other health care professionals, including pharmacists. This would give pharmacists an opportunity to proactively support their patients who are recently diagnosed with a palliative condition.

Every week, millions of people across Great Britain visit a community pharmacy (23). People will often have a relationship with their pharmacy team prior to a diagnosis of a palliative illness, yet the information about a patient's inclusion on a GP palliative register is very rarely communicated to pharmacists, especially those in community pharmacies. When asked in an online survey to support the initial drafting of this policy, 63 per cent of RPS members surveyed reported that they are 'never' made aware if a patient that they care for is on a palliative care register. Only 11 per cent of respondents stated that they are 'always' made aware, whilst 26 per cent noted that they are 'sometimes' informed. Without the information being communicated, community pharmacists depend on patients actively sharing their health status or will have to see a significant change in the patient's medicines regimen to become aware that the patient is receiving palliative care.

Patients will often have additional questions and want advice from the pharmacist about their diagnosis. They should be able to request that their health status is automatically shared so that the onus is no longer on the patient to communicate their illness. Subsequently the pharmacist can be ready to proactively support the patient and (with permission) their loved ones when they next see the patient.

When an advance (or anticipatory) care plan is in place, sharing this with the pharmacy team could help to ensure that patients and their families have increased access to support from the pharmacy team and that decisions about their medicines can be discussed. The pharmacist would also be in a more informed position to assist colleagues such as paramedics who may require more information to enable them to treat the patient in their own home. Our survey of RPS members indicated that details of advance care plans are seldom communicated to pharmacists. When asked if they had ever seen any advance care plans for their patients, 81 per cent of respondents stated that they had not.

It's important to identify patients with changing care needs towards the end of life at an early stage, through the use of palliative care registers and regular multidisciplinary team meetings involving primary and social care. Coordination and communication across the multidisciplinary team is critical to delivering high quality and responsive palliative and end of life care.

Professional responsibility



When a pharmacist is aware that a patient is on a GP palliative care register and has had sight of their advance care plan, they should make every effort to proactively support the patient with decisions about their medicines and make every effort keep up to date with any changes in health status via communication with relevant members of the multidisciplinary health and social care team.

Recommendation 6

Patients requiring palliative or end of life care and their families, must benefit from a single integrated electronic health record to ensure timely communication and updating of information. This is particularly important in the last stages of life when changes can happen rapidly. With access to the health record, pharmacists can be more responsive to changes and make informed clinical decisions, in partnership with patients and other health and social care professionals.

Without access to the patient's records, community pharmacists do not have access to an accurate diagnosis and are 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 identifying patients receiving palliative care, making sensitive conversations with families and carers even more difficult. Patients frequently expect the pharmacist to already have access to their records and to be informed of their health and medicines history. Therefore, the present situation can often undermine patient confidence in the care they are receiving.

Ensuring that community pharmacists gain full read and write access to the patient health record has been a long-standing call of the RPS. Information is key to delivering more effective pharmaceutical care to patients, improving medicines adherence and reducing the medication related errors which contribute to unplanned admissions to hospital. Access to the electronic patient health record allows pharmacists to make more informed clinical decisions, in partnership with patients and other health and social care professionals, about the pharmaceutical care that patients receive and underpins the ability for patients to access appropriate advice and medicines from their community pharmacy.

It must also be noted that both prescribing and ensuring safe supply during end of life care can sometimes be challenging and there are inherent legal, ethical and patient safety issues in dispensing high risk medicines. Access to the patient record can, for example, help to clarify a prescriber's intentions with the prescribing of high doses of licensed medicines, off-label prescribing or unlicensed medicines, ensuring better communication between practitioners and no time delays in supply to the patient due to the need to query prescriptions.

There has been significant progress with IT connectivity for community pharmacy in each country over recent years. For example, with the rollout of the Choose Pharmacy IT platform in Wales. The platform enables interoperability between pharmacist and general practices. Pharmacists can gain limited access to GP held patient records for specific services such as the Emergency Medicines Supply Service. The Digital Front Door is a key commitment in the Digital health and care strategy in Scotland (25). We advocate that routine access to records would be beneficial for patient safety and to help ensure timely advice and support. The vital role that medicines play in managing pain and other symptoms in palliative and end of life care, would mean that these patients would be among those who would benefit most from sharing their records with community pharmacists.

There are currently some services such as the Discharge Medication Review (DMR) Service in Wales, and the Discharge Medicines Service in England, that will be of particular benefit to patients with palliative care needs, supporting the transfer of care from one setting to another. This service ensures that the person's medicines are maintained accurately (reconciled) during transfer of care and that no unintentional changes are made to the medication regimen. As part of this service, the pharmacist or pharmacy technician will also check that the patient is getting the best use of their medicines. Services like this could be further built upon. Together with appropriate access to the GP held patient record, patients could further benefit from specific advice and support for palliative and end of life care following the transfer of care from one setting to another.

Professional responsibility



Until full read and write access is in place, pharmacists shouldn't let a lack of technological communication systems be a barrier to good communication and involvement in their patients' care. Where possible, pharmacists should endeavour to be a part of multidisciplinary discussions in whichever care setting they work in.

Recommendation 7

Patients requiring palliative or end of life care and their families, must benefit from the patients wishes of dying in a care setting of their choice to be fully supported without any compromise on the level of care received. Individuals shouldn't be in any less comfort or feel isolated from services if they choose to die at home, and they should have access to the same high level multidisciplinary team expertise.

The stated wish of many palliative and end of life patients is to die at home. If a patient is to truly have the power to choose their care setting for end of life, there should be no compromise in terms of the care and support they should expect to receive whether it's at home, in a hospice or hospital setting.

Whilst recognising financial constraints on the NHS, innovation in technology and more effective use of the whole multidisciplinary team should enable access to care and around the clock support. Evidence currently suggests that home-based care can reduce hospital use at the end of life and lead to a cost saving for the NHS, even when taking into account professional contracts, local authority funded social care and hospices (24).

With the likelihood of an increase in the number of people receiving care at home during the end of life, the skills of pharmacists and pharmacy technicians must be better harnessed in the community. Achieving this will be further explored in the workforce section of this policy.

Many community pharmacy services require the patient to be present at the pharmacy to receive that service, for example, a medicines use review. Some local health boards will commission a proportion of these services to be undertaken in a patient's home, but it's not something that is routinely in place. Many of the patients who receive palliative and end of life medicines will also request home delivery of their medicines, giving fewer opportunities for pharmacists to have face to face conversations.

Professional responsibility



Regardless of the patient's ability to visit their community pharmacy, pharmacists must still take responsibility for making sure that patients or their carers have the same opportunity and access to support and consultation about their medicines as well as the services available to them.

A STATEMENT OF SUPPORT FROM HOSPICE UK



Enabling people with terminal and life-limiting conditions to make a real and equitable choice about their preferred place of care and death means ensuring that people being cared for in their own homes have the same access to expert care as those who die in hospitals or hospice settings.

Community pharmacists have a key role in making this a reality and, where this is happening, play an essential part of the multi-disciplinary team working with hospices and primary care practitioners to support people dying at home, particularly when urgent medicines are needed in the last days of life or during out of hours periods. Rapid access to medicines and the expertise of a pharmacist can make the difference between a person remaining in their own home, in line with their wishes, or an urgent admission to hospital.

While there are pockets of good practice across GB, often driven by the determination of individuals, greater leadership is needed to consistently embed pharmacist involvement in the MDTs delivering palliative care in the community. Hospice UK recognises that it is vital that we help increase capacity in the caring profession beyond the hospice walls. This must include working in partnership with pharmacists as part of MDTs to see more people supported to die closer to home.



A STATEMENT OF SUPPORT FROM WELSH AMBULANCE SERVICE NHS TRUST (WAST)

“ For situations when Just in Case medications are present but the drug chart is not, a paramedic can still legally administer these if required in an emergency situation. In order for the drugs to have left pharmacy, they will have to have been prescribed by a doctor and are now owned by the patient. The Human medications regulations allow for anyone to parenterally administer a prescription only medicine as long as they are acting in accordance with the directions of an appropriate practitioner.(reg 214(2)). To meet Home Office requirements, there has to be a quantity attached to the directions of a controlled drug eg: ‘one’ as directed’ is acceptable but ‘as directed’ is not. If 2.5mg as directed is written by the doctor on the prescription then the box of medication should say exactly the same. Nurses require a direction to administer and therefore require a chart to be written, however these are NMC guidelines and are not applicable to paramedics.

Good practice for the paramedic to follow in instances of no drug chart being present dictates the paramedic should make contact with the patients doctor (e.g. GP, out of hours GP, Palliative Care Doctor) to discuss administration, the doctor may then advise the paramedic of a suitable dose to be administered. The paramedic should leave a copy of their paperwork, indicating the drug and dose that has been administered and the time it was given. Wherever possible, a drug chart should be with the JIC drugs. This allows the paramedic to record medication administration in the same place that other HCPs are likely to record future doses.



Ymddiriedolaeth GIG
Gwasanaethau Ambiwlans Cymru
Welsh Ambulance Services
NHS Trust

”

Workforce

It is apparent from the numerous interviews and focus groups conducted to inform the first iteration of this policy, from within the pharmacy profession and externally, that the field of palliative care is served by very dedicated individuals, some employed by the NHS but many funded by the independent and voluntary sectors. **Throughout this section, all roles described as palliative care roles would also include a remit within end of life care.**

Recommendation 8

Pharmacists must be embedded in all multidisciplinary palliative care teams to input expertise on the safe and effective use of medicines, including prescribing and deprescribing. Pharmacists and the pharmacy team have particularly important roles following a patient's diagnosis with a progressive or life-limiting illness to ensure that the medicines regimen is optimised, as well as to coordinate the care and medicines supply for patients as they move from one care setting to another.

The direction of travel set out for the pharmacy workforce in palliative and end of life care over the coming years must put patients at the centre. The profession should promote active, compassionate pharmaceutical care and encourage all health care professionals, services and organisations to work together. Pharmacy teams should be accessible in each sector and across sectors to support safe transfer of care, with clear cover arrangements in place for leave etc.

RPS is supportive of each country's Palliative and end of life delivery plan which promote an integrated end of life care service. For example, *"local health boards must build and lead coalitions with NHS Trusts, locality networks, GPs, nursing homes, pharmacists, dentists, opticians, social services, prison services and the Third Sector voluntary bodies. Palliative care charities and independent hospices are essential in meeting the needs of people approaching the end of life."* (1, 2, 3)

In order to sustain and maximise the essential pharmacy contribution to patients and health care colleagues to the safe and effective use of medicines, the development of pharmacy palliative care teams is required. Patients should be able to access expert knowledge from pharmacists wherever they need their care, be it in community, primary or secondary care.

Both patients and health care professionals need access to specialist advice. For many health care practitioners who are generalists, the specific complexity of each palliative or end of life patient may require additional information from specialist colleagues who deal with similar conditions on a more regular basis. In addition, community pharmacy teams should have access to specialist practitioners for information and advice. Local arrangements should be in place to facilitate this.

Professional responsibility



Pharmacists embedded in palliative care teams should take responsibility to ensure the optimisation of the medicines regimen. They should also work with pharmacy colleagues in other care settings to ensure the coordination of medicines supply for patients as they move from one care setting to another.

Recommendation 9

Governments in each devolved nation must have a structured approach to the development of pharmacy roles within multidisciplinary palliative care teams. This will support workforce continuity and succession planning so that patients can access expert knowledge from pharmacists wherever and whenever they need it.

The RPS has developed a roadmap which outlines career pathways for pharmacists (26). The roadmap takes into consideration the changing landscape of health care to address the needs and expectations of patients and the public. This roadmap will support the creation of the suggested structure (below).

Figure 3:
Suggested structure
for pharmacist roles
for palliative and
end of life care



The RPS post-registration assessment and credentialling curricula describe the expectation in terms of knowledge, skills and behaviours of entry-level advanced pharmacists, bridging the gap between the post-registration foundation curriculum and the consultant pharmacist curriculum. Building on the RPS post-registration foundation curriculum, the RPS core advanced curriculum articulates the requirements for an advanced pharmacist to be able to deliver holistic care autonomously to people with complex needs. It also describes the leadership and management, education, and research capabilities expected of advanced pharmacists to be able to drive service change and improve outcomes for cohorts of people. It will support pharmacists to develop the skillset to progress towards RPS consultant pharmacist credentialing.

Consultant Pharmacist

'A consultant pharmacist is a clinical expert working at a senior level, delivering care for patients and driving change across the health care system' (27). Consultant pharmacist roles have now existed within the NHS for over 15 years. The **Department of Health Guidance for the Development of Consultant Pharmacists Posts** (28) describes an aspiration to increase the number of consultant pharmacists working in the NHS. Consultant pharmacists have four main priorities: clinical practice, leadership, education and research. The need for, and area of practice of, a consultant pharmacist is currently decided at a local level (29).

The consultant pharmacist provides leadership at a country/regional level, working with senior colleagues from other disciplines and must be enabled to make positive changes for patient care. Direct clinical, expert care would continue to be a core part of the consultant's role, providing care to patients with the most complex needs. The post holder would lead a network of specialist pharmacists in palliative and end of life care and contribute to service planning within a Health/Integrated Care Board.

Specialist Pharmacist

Health/Integrated Care Boards should employ or have access to specialist palliative care pharmacists. Depending on the geographical landscape and population, there is a likelihood that there could be a need for a number of specialists per locality. Specialist pharmacists should be available to actively participate in the multidisciplinary palliative care teams. They should provide direct clinical expertise and be accessible for patients within every hospital as well as in community and primary care settings to ensure consistency in patient support and care.

The development of a specialist palliative care pharmacist network has helped to share best practice and provide continuity in the care patients can expect to receive wherever they live. A structured approach to specialist pharmacists in palliative care will support a sustainable consultant pharmacist workforce, providing a career pathway, succession planning and workforce continuity.

Advanced Generalist Pharmacist

A generalist pharmacist with a special interest in palliative care who is taking increased responsibility for providing services and advice to patients at a local level would be ideally placed to take on this role. The current cluster approach provides an ideal structure for this role, either within the GP practice or in a community pharmacy. They could help to coordinate any local support that is needed, working with third sector and social care organisations. These post holders should link in with the advanced specialist pharmacists on a regular basis to keep up to date with current processes and guidance used in the local Health Board (LHB) as well as to help ensure further continuity of care for patients.

RPS advocate for all pharmacists in the aforementioned structure being independent prescribers and using this skill working within the multidisciplinary team. Ensuring coordinated care for the patient is crucial, so prescribing decisions should be made in collaboration with other members of the multidisciplinary team. By being in communication with the palliative multidisciplinary team, the pharmacist can make decisions according to the pre-determined advance care plan. This would be particularly important in the last few days of life to help keep patients in their homes, should this be their wish.

Pharmacists could be working with other professionals such as paramedics and nurses to facilitate access to medicines in the home to help keep the patient out of hospital.

Palliative Care Pharmacy Technicians

Pharmacy technician roles in palliative care should be developed and maximised. These roles would be particularly beneficial within hospices as well as supporting patients at home. Pharmacy technicians can lead on all operational and technical aspects of medicines including; procurement, stock management, medicines administration and medicines destruction (30).

Pharmacy technicians will also have a crucial patient facing role and can educate patients and their carers on how medicines are used and stored which is particularly important in end of life when many new and complex formulations and combinations of medicines are often prescribed. This role could be extremely beneficial to support patients and social care workers with medicines in the home and should be further explored under new and emerging structures.

Recommendation 10

Integrated Care Boards or Health Boards must commission a lead paediatric palliative care pharmacist role in each country/region. This role would provide strategic leadership and improvements in the use of medicines for children with life-limiting conditions. This role should be complemented by a support network of paediatric pharmacists with a special interest in palliative and end of life care.

Paediatric Specialist Pharmacist

Currently, not all areas of Great Britain employ a specialist paediatric palliative care pharmacist. We believe that the Paediatric Palliative Medicine team would benefit from the medicines expertise this pharmacist role would bring. Paediatric palliative teams manage children through changes which will affect how medicines work, are metabolised and their potential for harm. Providing specialist knowledge, the paediatric specialist palliative care pharmacist would ensure that medicines are tailored for each individual child's needs to provide maximum benefit and reducing adverse effects. The safe and appropriate prescribing and administration of medicines is essential to support children to be cared for in their own home. A specialist paediatric palliative care pharmacist would work with the primary care team, children and families to ensure this support and advice is provided. They would also provide support if a patient is identified as suitable to transition to adult services.

A STATEMENT OF SUPPORT FROM COMMUNITY PHARMACY SCOTLAND (CPS)



Community pharmacies play a vital role in delivering palliative care. Due to their contact with patients and their representatives, they are uniquely placed to provide access to the best possible pharmaceutical care through a hugely difficult time for patients and their families – from diagnosis through to care around dying and bereavement support.

Community Pharmacy Scotland welcomes this policy and the recommendation of shared care plans and access to health records between professionals involved in the care of the patient. This will support a whole system approach, enable seamless transfer of care between services and ultimately support the patients' needs and wishes in their palliative journey.

Implementation in Scotland of Just In Case boxes and locally agreed services to support participating community pharmacies to hold stock of essential palliative care medicines aids with timely access to medicines. Providing more education around these medicines upon supply and greater visibility of these sites would allow for greater care around dying. Having a palliative care specialist pharmacist contact in each Health Board to support community pharmacy teams with training, materials advice and support will help ensure all staff delivering palliative care have the necessary skills to do so.

A clearly defined process, with each stakeholder understanding and supporting each other's roles, is key to delivering these recommendations and providing optimal palliative care.



Education and training

Recommendation 11

Education and training in palliative and end of life care for pharmacists should be strengthened to support the development of advanced roles. Pharmacists in all care settings should keep up to date with best practice approaches and be equipped to confidently discuss options about care in the end of life phase with patients.

The establishment of specific bodies to support the development of our health workforce in each country offers new opportunities for multidisciplinary workforce planning as well as education and training. It was recommended in an inquiry report from the Cross Party Group on Hospices and Palliative Care in Wales that '*the Welsh Government should work with Health Education and Improvement Wales and external partners, such as the Royal Colleges, to incorporate annual mandatory training in palliative care for all hospital-based clinical staff as part of their Continuous Professional Development*' (21). We are supportive of this statement but would also take it further to incorporate all frontline health and social care workers if we are to help shift more care into community settings. We would envisage levels of education & training to deliver the appropriate competencies and knowledge required for the different levels of specialism within palliative care.

In 2025 Health Education and Improvement Wales published an Adult Competency Framework for Palliative and End of Life Care (37)

Undergraduate teaching and placements

Effective consultation skills are an essential part of the pharmacist's role, ensuring important and often complex information is communicated appropriately, whether you're speaking to colleagues or patients. Developing the skills and competencies for effective communication should begin from the first year of a pharmacy student's undergraduate studies.

It is essential that during the undergraduate degree, students have the opportunity to learn from expert practitioners in palliative and end of life care with scenario based learning and a focus on the decision making processes regarding medicines use. Students should experience real care environments to better understand the patient perspective and how practitioners support them. Opportunities for students to undertake placements within a hospice or care home environment would be beneficial.

Foundation Trainee Pharmacists

Foundation trainee pharmacist training is a mandatory step in the journey to become a registered pharmacist. Foundation pharmacist training involves a placement under the supervision of an assigned tutor, spending at least 52 weeks in an approved training site or across multiple sites, where they will be developing their practice to meet a range of performance standards that are specified by the pharmacy regulator, The General Pharmaceutical Council (GPhC) (31).

During foundation trainee pharmacist training and subsequent post-registration foundation training, pharmacists will build upon their undergraduate consultation skills training and knowledge, starting to hone these skills in practice. Effective consultation skills are particularly crucial in palliative and end of life care, where consultations can be more complex and require a higher degree of sensitivity. It is important that pre- registration and foundation pharmacists have opportunities for placements in more complex areas of care as well as generalist, in order to further develop their consultation skills.

Continuing Professional Development (CPD)

All pharmacists and pharmacy technicians in patient facing roles should ensure that they continue to keep up to date with clinical guidelines and best practice approaches for palliative and end of life medicines use to support their day-to-day practice. Undertaking CPD activities to support learning and having access to the latest references and tools available will ensure that pharmacists can give the patients the best care and advice.

Health care professionals, including pharmacists must constantly develop their consultation skills throughout their career to ensure they can give the best care to patients, providing advice at a time that the patient is ready, and importantly, constantly listening to the individual's needs. There are eLearning programmes available to support generalist learning in both consultation skills and palliative care for generalist use.

Specialist pharmacy practitioners should be working at an advanced level with ongoing development of their knowledge and skills within palliative care. The RPS has taken steps to help ensure that all practitioners can gain access to a specialist Palliative Care Formulary by its inclusion into MedicinesComplete, which is an online resource that brings together the world's leading resources, providing health professionals with expert and unbiased knowledge to make the best clinical decisions on the use and administration of drugs and medicines. MedicinesComplete is published by the Pharmaceutical Press, which is the publishing arm of the Royal Pharmaceutical Society.

Postgraduate education and training

Pharmacist independent prescribing aims to provide patients with more efficient access to medicines and to make the best use of the skills of pharmacists (32). All new pharmacist registrants from 2026 will be annotated as independent prescribers. Existing pharmacists who are not already prescribers, must complete a GPhC accredited course available throughout the UK. Pharmacists can undertake this training as a part time course alongside their existing practice and will take around six-seven months to complete. Currently as a part of the training, pharmacists are asked to specify a scope of practice. Some may choose palliative care to be their scope of practice from the outset but for those that have qualified with a different specialism, it would be appropriate to support these practitioners with a transition programme. Pharmacist independent prescribers with specialism in palliative and end of life care would be able to use these skills, working within the multidisciplinary palliative care team.

Palliative and end of life care is a clear opportunity to use prescribing in a range of situations. Examples of these include prescribing alternatives due to the unavailability of medicines, protocol-based pain management in opioid-naïve individuals and out of hours access to medicines. The RPS Extended scope of practice guidance provides a structure to support prescribers to identify and meet their development needs to ensure competency. Outside the context of specialist team-based or GP practice-based pharmacist prescribing it is unlikely that others would get sufficient experience to be able to demonstrate and assure that they are maintaining their competence.

Giving pharmacists an opportunity to undertake a module in palliative and end of life care as a part of relevant post-graduate qualifications e.g. MSc Clinical Pharmacy or other forms of post-registration education and training would be beneficial. This would enable post-registration pharmacists at any stage in their career to explore and learn about the expert management of medicines in palliative and end of life care.

To support pharmacists in becoming palliative care specialists and potentially consultant level practitioners, opportunities to undertake more in-depth learning such as a full MSc in Palliative Medicine would be beneficial. As well as exploring in-depth clinical issues, courses such as the MSc in Palliative care encourages multidisciplinary learning which is particularly valuable to create supportive working relationships outside of your own professional groups. Multidisciplinary learning can also help to foster appreciation of how the expertise of the different professions can complement the care provided for a patient. At the core of an MSc is the desire to improve patient outcomes wherever palliative care is practiced by its students and to enhance the quality of palliative care through research and quality improvement (33).

We would expect pharmacists and pharmacy technicians working within palliative care to have completed a more advanced level of post-registration consultation skills training to effectively support patients and families in this area of care which can be more complex and require a higher degree of sensitivity. Consultant pharmacists could work with higher education institutions (HEIs) to develop and deliver educational sessions on palliative and end of life pharmaceutical care, as well as gaining professional recognition through the RPS assessment and credentialling process.

Linking with other team members as well as the patient and their carers and access to a current update on clinical condition and treatment plan are all essential for safe prescribing. Good practice also requires effective communication with the patient/ carer so that there is good understanding of how to get the best outcomes.

Improving integration, communication and sharing of patient records with community pharmacies is necessary for community pharmacist prescribers to build confidence and competence to prescribe in this area. Current service specifications for the provision of pharmacist prescribing services through community pharmacies do not currently include palliative and end of life within the clinical context.

An understanding of administration policies and local procedures is needed so that timely symptom management (following prescribing and supply) can occur.

Professional responsibility



Pharmacy professionals should make sure they use their professional judgement and have completed appropriate training to support the level of service provision that they provide for patients and families dealing with palliative and end of life care.

Next steps

This policy has been developed to instigate action at national and local levels to ensure people with palliative care needs can benefit from greater access to the expertise of pharmacists and support from the pharmacy team.

The implementation of these recommendations will drive quality improvements in the delivery of palliative and end of life care across GB.

The Royal Pharmaceutical Society is committed to supporting pharmacists and working with the NHS and its other partners to take this important agenda forward.

Additional resources to support professional practice will be available and updated on the RPS website.

Glossary of terms

Advance care planning – The process of discussing the type of treatment and care that a patient would or would not wish to receive. Particularly important in the event that they become unable to decide or express their wishes. A record of a patient's wishes and values, known as an advanced care plan will be created (34).

Capacity – The ability to make a decision. An adult is deemed to have capacity unless, having been given all appropriate help and support, it is clear that they cannot understand or communicate their wishes. (from GMC website) (35).

End of Life – Generally considered to be a period up to the last year of life, but this timeframe can be difficult to predict.

Multidisciplinary Team – A group of health care workers who are members of different disciplines or professions, each inputting their expertise for patient benefit.

Paediatric palliative care – Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement (36).

Palliative care – This policy adopts the World Health Organization definition of palliative care. This is '*an approach that improves the quality of life of patients and their families facing the problems associated with life limiting illness, through the prevention of, and relief of, suffering, by means of early identification and impeccable assessment and treatment of pain and other problems, physical and spiritual*' (36).

Pharmaceutical Care – The use of drug therapy to achieve definite outcomes that improve a patient's quality of life

Pharmacy Team – This includes pharmacists across all sectors including community, cluster, primary care and hospital as well as registered pharmacy technicians.

Pharmacy Technician – Undertakes the technical aspects of medicines management e.g. check inhaler technique, synchronise medications, reviews repeat prescribing and dispensing processes. These roles are developing rapidly and in some areas pharmacy technicians are taking on prescribing data analysis roles but would not undertake clinical reviews.

Polypharmacy – The concurrent use of multiple medications by one individual.

References

1. Ambitions for Palliative and End of Life Care: A national framework for local action 2021–2026. National Palliative and End of Life Care Partnership May 2021. <https://www.england.nhs.uk/publication/ambitions-for-palliative-and-end-of-life-care-a-national-framework-for-local-action-2021-2026/>
2. Welsh Government & NHS Wales. 2016. *Palliative and End of Life Care Delivery Plan*. Available at: <https://performanceandimprovement.nhs.wales/functions/networks-and-planning/peolc/>
3. Palliative Care Matters for All. Scottish Government October 2024. <https://www.gov.scot/publications/palliative-care-strategy-palliative-care-matters/>
4. NHS. 2018. What end of life care involves. Available at: <https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/>
5. Dixon, J, and King, D, and Matosevic, T and Clark, M and Knapp, M. 2015. *Equality in the Provision of Palliative Care in the UK: Review of Evidence*. Marie Curie & London School of Economics. Available at: <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>
6. Office for National Statistics (ONS), released 9 October 2025, ONS website, statistical bulletin, <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2024>
7. Fraser et al (2020) 'Make Every Child Count' Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom. Together for Short Lives Report. <https://www.york.ac.uk/media/healthsciences/documents/research/public-health/mhrc/Prevalence%20reportFinal.pdf>
8. Marie Curie Cancer Care and the Bevan Foundation. 20014. *Death and dying in Wales*. Available at: <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/december-2014/death-dying-wales-exec-summary.pdf>
9. <http://mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/december-2014/death-dying-wales-full-report.pdf>
10. <https://www.togetherforshortlives.org.uk/app/uploads/2024/06/Short-Lives-Cant-Wait-Full-Report-Updated-19-June.pdf>
11. Skone, J and Longley, M and Rogers, C. 2015. *Palliative Care for Children and Young People in Wales*. Welsh Institute for Health and Social Care. Available at: <https://www.gov.wales/sites/default/files/publications/2024-11/atisn22076.pdf>
12. Together for Short Lives (2022) Care Planning in Advance – Together for Short Lives

13. Welsh Government (2022) Quality Statement for palliative and End of Lifecare for Wales. <https://gov.wales/quality-statement-palliative-and-end-lifecare-wales-html> (accessed 23/07/25)
14. <https://realisticmedicine.scot/>
15. Follow-on Strategic Framework for Welsh Language Services in Health, Social Services and Social Care 2016-2019. Available at <https://www.gov.wales/new-plan-boost-welsh-language-health-and-social-care>
16. Care for the Family. 2018. *Types of bereavement*. Available at: <https://www.careforthefamily.org.uk/family-life/bereavementsupport/supporting-bereaved-people>
17. <https://www.dewis.wales/home>
18. <https://www.cruse.org.uk>
19. NHS Wales. 2018. *Just In Case (JIC) Bags*. Available at: <https://cpwales.org.uk/clinical-services-2/additional-clinical-services/national-just-in-case-pack-service-d10/>
20. Community Health Council North Wales. 2017. *New palliative care medication service launched by health board*. Available at: <http://www.wales.nhs.uk/sitesplus/900/news/44157>
21. The National Assembly for Wales's Cross-Party Group on Hospices and Palliative Care. 2018. *Inequalities in access to hospice and palliative care*. Available at: <http://www.senedd.assembly.wales/documents/s77444/Inquiry%20Report%20July%202018.pdf>
22. Welsh Government. 2013. *Together for Health – Delivering End of Life Care*. Available at: <https://www.gov.wales/sites/default/files/publications/2023-12/atsn19339doc1.pdf>
23. Royal Pharmaceutical Society. 2016. *Improving Care for Patients with Long Term Conditions*. <https://www.rpharms.com/Portals/0/RPS%20document%20library/Open%20access/Policy/LTC%20-%20England.pdf>
24. Welsh Government. 2016. *Together for Health End of Life Care Annual Report 2016*. <https://www.gov.wales/sites/default/files/publications/2023-12/atsn19339doc1.pdf>
25. <https://www.digihealthcare.scot/our-work/digital-front-door>
26. Royal Pharmaceutical Society. 2016. *The RPS Roadmap to Advanced Practice*. Available at: <https://www.rpharms.com/Portals/0/RPS%20document%20library/Open%20access/Development/Roadmap%20to%20Advanced%20Practice/the-rps-roadmap-to-advanced-practice.pdf>
27. The NHS Specialist Pharmacy Service. 2018. *Draft Consultant Pharmacist Guidance*. Available at: <https://www.sps.nhs.uk/wp-content/uploads/2018/08/Draft-Consultant-Pharmacist-Guidance-for-consultation.pdf>
28. Department for Health. 2005. *Guidance for the Development of Consultant Pharmacist Posts*. Available at: <https://www.hee.nhs.uk/our-work/pharmacy/consultant-pharmacist-guidance>
29. Smith, L. 2018. *A day in the life of a paediatric palliative care pharmacy technician*. Available at: <https://pharmaceutical-journal.com/article/news/a-day-in-the-life-of-a-paediatric-palliative-care-pharmacy-technician>
30. General Pharmaceutical Council. 2018. *Pharmacist pre-registration training scheme*. Available at: <https://www.pharmacyregulation.org/students-and-trainees/pharmacist-education-and-training/foundation-training>
31. Cardiff University. 2018. *Pharmacist Independent Prescribing*. Available at: <https://www.cardiff.ac.uk/study/postgraduate/taught/standalone-modules/pharmacist-independent-prescribing>
32. Cardiff University. 2018. *Palliative Medicine for Health Care Professionals (MSc)*. Available at: <https://www.cardiff.ac.uk/study/postgraduate/taught/courses/course/palliative-medicine-for-health-care-professionals-msc-part-time>
33. General Medical Council. 2018. *Advance care planning*. Available at: <https://www.gmc-uk.org/professional-standards/the-professional-standards/treatment-and-care-towards-the-end-of-life/working-with-the-principles-and-decision-making-models---cont>
34. General Medical Council. 2018. *Capacity issues*. Available at: <https://www.gmc-uk.org/professional-standards/the-professional-standards/decision-making-and-consent/circumstances-that-affect-the-decision-making-process-continued-2>
35. Together for Short Lives. 2018. *Introduction to children's palliative care*. <https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/>
36. World Health Organisation. 2018. *WHO Definition of Palliative Care*. Available at: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>
37. <https://heiw.nhs.wales/our-work/national-programmes/all-wales-competency-framework-for-palliative-and-end-of-life-care/>

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About the Royal Pharmaceutical Society

The Royal Pharmaceutical Society is the dedicated professional body for pharmacists and pharmacy in England, Scotland and Wales. We are the only body which represents all sectors of pharmacy in Great Britain. We lead and support the development of the pharmacy profession including the advancement of science, practice, education and knowledge in pharmacy.

We make sure the voice of the profession is heard and actively promoted in the development and delivery of health care policy and work to raise the profile of the profession.

We put pharmacy at the forefront of patient care and we aim to be the world leader in the safe and effective use of medicines. We are committed to supporting and empowering our members to make a real difference to improving patient care.

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