

**ROYAL
PHARMACEUTICAL
SOCIETY**
Wales Cymru



Palliative & End of Life Care

**Pharmacy's contribution to
improved patient care**

**R
P
S**



Patient quotes



"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"



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.

The policy takes into account and builds upon the Welsh Government and NHS Wales' Palliative and End of Life Care Delivery Plan, published in March 2017.¹ 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 emphasises the professional responsibility of pharmacists in this area of care.

The policy 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 in Wales.

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.



Suzanne Scott-Thomas FFRPS MRPharmS
Chair, Welsh Pharmacy Board
Royal Pharmaceutical Society Wales

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 written information 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 their patient 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 also help to ensure patients can stay in their own homes in comfort without needing to be transferred to hospital for essential medicines.

5. 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.

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.

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 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.

Workforce

8. Pharmacists should be embedded in all multidisciplinary palliative care teams to input expertise on prescribing, deprescribing and use of medicines.

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

9. A national structured approach to the development of pharmacy 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. An All Wales lead paediatric palliative care pharmacist role.

This role would provide strategic leadership and improvements in the use of medicines for children with life-limiting conditions across Wales. 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 32.

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.



DELIVERY PLAN PRIORITY

Our policy takes into account the Welsh Government's Palliative and End of Life Care Delivery Plan. Where our recommendations relate to a specific objective in the delivery plan, we have included a direct quote from the delivery plan.



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.

Context for Change

There is no set timescale for conditions that require palliative care. Advances in diagnosing mean that a patient's terminal illness can be identified decades prior to that patient's likely death. It can be applied in any circumstance where a patient is diagnosed with an illness where there is no expectation of recovery or a cure.

There can often be confusion between palliative and end of life, with both phrases often used interchangeably. For the purpose of this document, end of life care refers specifically to care provided in the last phase of life, which is often defined as approximately the last year of life.² It has also 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.³ 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.

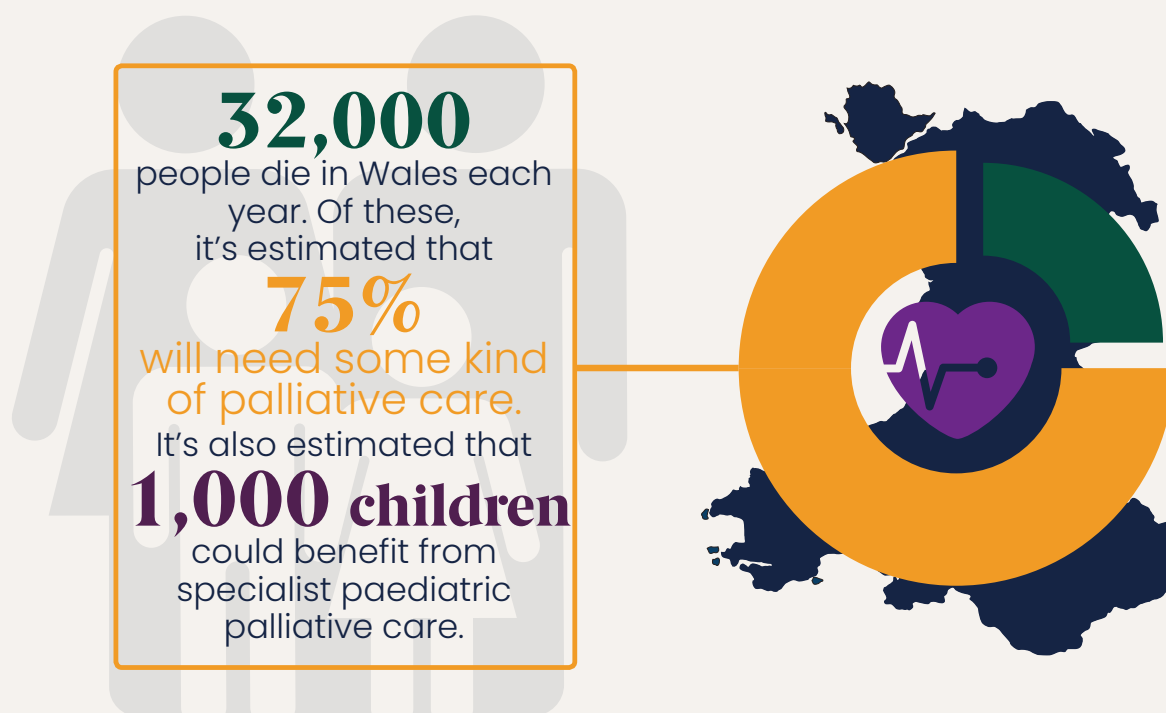


Figure 1. Supporting statistics ^{4, 1, 5}

Paediatric Palliative and End of Life Care

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."*⁶

It's 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"*.⁶ This document endorses this principle and emphasises that the clinical expertise of pharmacists is essential in achieving this.

Figure 2. Steps to better care

In order 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 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 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 emphasises 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.⁷ 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.



DELIVERY PLAN PRIORITY

To ensure all written information is available in formats that are understandable to the relevant patient and family populations.

Medicines can be of significant benefit during palliative and end of life care to control symptoms such as pain 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 palliative 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, but also openness about 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.

When diagnosed with a palliative condition, the amount of information to process can be overwhelming for patients and their families. Providing patient friendly written information on medicines and treatment regimens is important. This way, patients and their families can refer to and digest information whenever they feel comfortable and ready. This may lead to more 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 Governments 'active offer', patients should be offered services through the medium of Welsh rather than having the burden of asking for the service.⁸

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.



DELIVERY PLAN PRIORITY

To deliver well-coordinated palliative and end of life care on a 24/7 basis in line with published guidance, including 7-day multi-professional specialist palliative care services that respond rapidly to urgent referrals, and 24/7 specialist advice available to health and social care professionals.

As the most accessible health care professional, pharmacists and the pharmacy team are ideally placed to highlight sources of support for patients and families. They can also appropriately refer 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 that patients and their families can access for support. Information about out of hours support such as these should also be available through community pharmacies.

Furthermore, centres like Velindre Cancer Centre are harnessing advances in technology to help ensure that patients can access information 24/7. They are using Artificial Intelligence (AI) technology to power a chatbot that can engage patients in their health care and treatment by scouring the web for information and responding to psychological cues such as tone of voice. It's hoped that using this technology will alleviate treatment anxiety and enable patients to feel in control of their health care, by becoming better informed, more engaged and able to make better choices.⁹ Similar use of technology could be considered for palliative care.



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.



DELIVERY PLAN PRIORITY

To review the capacity of existing bereavement services and settings in which they are delivered to ensure that needs of all bereaved families and carers are being met

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.¹⁰ 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 DEWIS Cymru.¹¹ 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.

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 the pharmacy for disposal, this should be supported sensitively and made as easy as possible for the individual, with wider support and discussions taking place in the private consultation area, for example.



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, and have up to date advice about medication and how it may affect their condition. In order to fully contribute expertise to the multidisciplinary team and for 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.



DELIVERY PLAN PRIORITY

People receive fast, effective person centred care to maintain quality of life for as long as possible. Patients and their families have their needs identified and met, so they feel well supported and informed.

The Just in Case (JIC) service which is available in many community pharmacies in Wales, provides improved access to key medicines for rapid control of breakthrough symptoms in palliative care. In those local health boards (LHBs) 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.¹²

The JIC service uses a sealed orange bag. Once opened, any unused medicines can be added to other stock 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. An All Wales Medication Record Chart (AWMRC) can be partially completed by the GP 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 of Wales, 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.¹³

Regardless of the services set in place by the 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

Pharmacists and pharmacy technicians must work with prescribers and take responsibility for obtaining the necessary medicines for a patient in a timely manner. Pharmacists in the community should also make sure they communicate any services they provide that will aid medicines provision for palliative and end of life patients to local general practices. Examples of such services include just in case bags and community pharmacies that are commissioned by the local health board to hold an extended list of essential end of life medicines.

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.



DELIVERY PLAN PRIORITY

To develop an all-Wales advance care planning record, to enable advance care plans (adult and paediatric) to be shared across all care settings within Wales.

The recent 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”.¹⁴ While we are pleased to see an increase in the number of patients who are captured on the GP held palliative care register,¹⁵ 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.¹⁶ 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 this policy, 63 per cent of RPS Wales 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 at a palliative stage.

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 their loved ones when they next see the patient.

When an advance 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.

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.



DELIVERY PLAN PRIORITY

Ensure NHS Wales clinical record systems are accessible and link with other relevant IT systems e.g. GPs and ambulance systems. Ensure rapid and secure IT communications links are in place to support clinical care. Develop and maintain good IT links to NHS and non-NHS providers to promote integrated care delivery.

Coordination and communication across the multidisciplinary team is critical to delivering high quality and responsive palliative and end of life care.

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 palliative care patients, 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, with patient consent, 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 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 often high risk medicines. Access to the patient record can, for example, help to clarify a prescriber's intentions with the prescribing of high doses or off licence 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 Wales over recent years with the rollout of the Choose Pharmacy IT platform. 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. 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 that will be of particular benefit to palliative patients, 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 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.



DELIVERY PLAN PRIORITY

Regular multidisciplinary team meetings take place to discuss patients in acute, primary and community settings, and that these involve a member of the specialist palliative care team.

The stated wish of many palliative and end of life care 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 little 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 support 24/7 from home. 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.¹⁷ This approach aligns to the Welsh Government's prudent health principles.

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

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 less 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 Wales, 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 Medicines 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.



GIG
CYMRU
NHS
WALES

Ymddiriedolaeth GIG
Gwasanaethau Ambiwylans Cymru
Welsh Ambulance Services
NHS Trust

Good practice for the paramedic to follow in instances of no drug chart being present dictates the paramedic should make contact with the patient's 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.



Workforce

It's apparent from the numerous interviews and focus groups conducted to inform 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 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 should be embedded in all multidisciplinary palliative care teams to input expertise on prescribing, deprescribing and use of medicines. Pharmacists and the pharmacy team have particularly important roles following a patient's diagnosis of a palliative illness to ensure that the medicines regimen is optimised, as well as to help coordinate the care and medicines supply for patients as they move from one care setting to another.



DELIVERY PLAN PRIORITY

Maintain delivery of evidence based specialist palliative care services through well organised multidisciplinary teams, with clear funding streams for specialist palliative care services in line with national guidelines.

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.

RPS is supportive of the Welsh Government's suggested approach in the palliative and end of life delivery plan; that *"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. These services need to be part of an integrated end of life care service."*¹

In order to sustain and maximise the essential pharmacy contribution available to patients and health care colleagues on the safe and effective use of medicines, the development of pharmacy palliative 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.

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

A national structured approach to the development of pharmacy palliative care teams is required. This will support workforce continuity and succession planning so that patients can access expert knowledge from pharmacists wherever and whenever they need it.



DELIVERY PLAN PRIORITY

Have in place named pharmacists in each health board to support improvement of medicine management for seriously ill and dying patients.

Review existing specialist palliative care workforce capacity skills and have in place short and long term workforce plans to address future need, recognising diversity and co-existing need.

The RPS has developed a roadmap which outlines career pathways for pharmacists.¹⁸ 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 below suggested structure.



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

The RPS Faculty is a key element of the roadmap which provides a framework for pharmacist's professional development through advanced practice. The tools available as a part of the faculty journey will help pharmacists to identify areas of good practice and areas for development, helping to focus learning needs

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'.¹⁹ Consultant pharmacist roles have now existed within the NHS for over 10 years. The **Department of Health Guidance for the Development of Consultant Pharmacists Posts** ²⁰ 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 consultant pharmacists are currently decided at a local level.²¹

The consultant pharmacist would provide leadership at an all Wales 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 in Wales. The post holder would lead a network of specialist pharmacists in palliative and end of life care across Wales. They would also be ideally positioned to feed into the National End of Life Delivery Board or any similar structures that are developed in the future.

Specialist Pharmacist

Health Boards should employ or have access to specialist palliative care pharmacists. Depending on the geographical landscape of the LHB and population there is a likelihood that there could be a need for a number of specialists per LHB. Specialist pharmacists should be available to input their knowledge into the multidisciplinary palliative care teams within their LHB. 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 across Wales would help 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 services 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 LHB as well as to help ensure further continuity of care for patients.

RPS advocate the benefit of all pharmacists in the above structure being independent prescribers and using this skill working within the multidisciplinary team. Making sure care is coordinated for the patient is vital, so decisions should not be made in isolation of the medical consultant. 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.²²

Pharmacy technicians will also have a crucial patient facing role and can counsel 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 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

An All Wales lead paediatric palliative care pharmacist role should be developed to provide strategic leadership and improvements in the use of medicines for children with life-limiting conditions across Wales. This role should be complemented by a support network of paediatric pharmacists with a special interest in palliative and end of life care.



DELIVERY PLAN PRIORITY

Consider putting in place a lead paediatric pharmacist at the Children's Hospital of Wales with palliative care training to support improvement of medicine management for children with life-limiting conditions in hospital, community and children's hospice settings.

Paediatric Specialist Pharmacist

There is currently no paediatric specialist palliative care pharmacist employed in Wales. 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.

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.



DELIVERY PLAN PRIORITY

Professionals caring for people with palliative and end of life care needs are equipped in all health care settings to support patients and their families to make informed choices over their care and supported to cope with uncertainty.

The establishment of Health Education and Improvement Wales (HEIW) as a single body to support the development of our health workforce in Wales offers new opportunities for multidisciplinary workforce planning as well as education and training. It was recommended in a recent 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'*.¹⁴ 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.

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. In support of this, opportunities for students to undertake placements within a hospice or care home environment would be beneficial.

Pre-registration

Pre-registration training is an important step in the journey to become a pharmacist. Pre-registration training is a training placement under the supervision of an assigned tutor. Trainees will spend at least 52 weeks in an approved training site, where they will be developing their practice to meet a range of performance standards that are specified by the regulatory body for pharmacists, The General Pharmaceutical Council (GPhC).²³

During pre-registration training and subsequent early career 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.

Continual Professional Development

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 through HEIW (WCPPE) in both consultation skills and palliative care for generalist use.

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 electronic package 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. The Palliative Care Formulary is also available through the NHS Wales electronic library.

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.²⁴ There are numerous courses available throughout the UK, accredited by the GPhC. Pharmacists can undertake this training as a part time course alongside their work and will take around 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.

Giving pharmacists an opportunity to undertake a module in palliative and end of life care as a part of the MSc in Clinical Pharmacy or other forms of foundation training would be beneficial. This would enable foundation practitioners to explore and learn about the expert management of medicines in palliative and end of life care practitioners in the field.

To support pharmacists in becoming palliative care specialists and 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.²⁵

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. Consultants could work with HEIW and Universities to develop and deliver educational sessions on palliative and end of life pharmaceutical care, as well as maintaining professional recognition through the RPS faculty.

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 in Wales.

The Royal Pharmaceutical Society in Wales 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 – this will include case studies demonstrating best practice.

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.²⁶

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)²⁷

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.²⁸

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.'*²⁹

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 technicians are taking on prescribing data analysis roles but would not undertake clinical reviews.

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

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The Royal Pharmaceutical Society is the 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 health 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 health care.

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