

## Access to end of life medication in Wales 2023-24

**Briefing Paper** 

#### June 2025

#### 1. Introduction

Timely access to end of life medication is an essential part of palliative and end of life care.

Good symptom control at the end of life through access to medication can help to avoid unnecessary patient and carer distress and reduce unplanned and emergency use of services. While each patient has individual needs, "many acute events during the palliative period can be predicted and management measures put in place."

However, research has shown that while in theory medicines can be prescribed, collected and administered in most areas, in practice medication is often only partially available, difficult to access or involves long waiting times.<sup>3</sup>

Issues can relate to availability and access. Community pharmacies won't always stock end of life medicine, as they are not regularly dispensed.<sup>4</sup> Problems have also been identified in accessing medication, particularly at weekends and overnight.<sup>5</sup> In fact, accessing medicines can require "considerable coordination work for patients, families, carers and/or

<sup>&</sup>lt;sup>1</sup> Marie Curie (2022) Better End of Life 2022 Policy commentary on Mind the Gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers

<sup>&</sup>lt;sup>2</sup> BMA "Anticipatory prescribing for end of life" <a href="https://www.bma.org.uk/advice-and-support/gp-practices/prescribing/anticipatory-prescribing-for-end-of-life-care">https://www.bma.org.uk/advice-and-support/gp-practices/prescribing/anticipatory-prescribing-for-end-of-life-care</a> [Accessed 23/04/2025]

<sup>&</sup>lt;sup>3</sup> Marie Curie (2022) Better End of Life 2022 Policy commentary on Mind the Gaps

<sup>&</sup>lt;sup>4</sup> Marie Curie (2024) Better End of Life 2024 Time to Care in Wales Implications for Wales of 'Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales' Policy Briefing
<sup>5</sup> Ibid.

healthcare professionals. Often due to parts of the access process functioning poorly."

The result of poor access to medication can be poor symptom control. A post bereavement survey conducted in 2022 found that 36% of people who died in Wales were severely or overwhelmingly affected by pain in their final week, and 40% were severely or overwhelmingly affected by breathlessness.<sup>7</sup>

Delays in access to medication have been associated with8:

- GP services.
- Lack of medicines in community pharmacies.
- Palliative care nurse specialists' lack of access to electronic prescribing.
- Health care professionals' limited access to shared electronic prescribing patient records.

Community pharmacists can play a critical role in supporting access to medication at the end of life, but too often they are not sufficiently involved in the multi-disciplinary team or provided with information about their patients. A 2018 survey of pharmacists in Wales found that 63% were never made aware if a patient they care for is on a palliative care register, and 81% had never seen an advanced care plan for their patients.9

To better understand the availability and accessibility of end of life medication in Wales, analysis has been undertaken of existing data and Freedom of Information (FOI) responses from all seven health boards. This paper sets out the findings from this exercise and provides a starting point for further research to determine whether people living with a terminal illness in Wales have consistent and timely access to medication.

# 2. Anticipatory prescribing and just in case packs

Access to medication at the end of life can be improved through the use of anticipatory prescribing, also known as just in case packs. This means the

<sup>&</sup>lt;sup>6</sup> Latter, S. et. al (2022) "Patient and carer access to medicines at end of life: the ActMed mixed methods study" Health Services and Delivery Research, Vol. 10, Issue: 20

<sup>&</sup>lt;sup>7</sup> Marie Curie (2024) Better end of life 2024 Time to Care in Wales Implications for Wales of 'Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales

<sup>&</sup>lt;sup>8</sup> Latter, S. at al (2022) "Patient and carer access to medicines at end of life: the ActMed mixed methods study"

<sup>&</sup>lt;sup>9</sup> Royal Pharmaceutical Society Wales (2018) Palliative and End of Life Care: Pharmacy's contribution to improved patient care

provision of medication in advance to people at the end of life, which someone can be given quickly if they have sudden, distressing symptoms such as pain or agitation.<sup>10</sup>

Anticipatory prescribing ensures that "there is a supply of drugs in the patient's home, they have the equipment needed to administer them and drugs are available to an attending clinician when appropriate."

While not a panacea, anticipatory prescribing can help to alleviate challenges such as those outlined above, but only when needs are recognised early.<sup>12</sup>

## 3. Methodology

Analysis was undertaken of data available via StatsWales to determine the number of community pharmacies offering the nationally agreed, locally commissioned just in case scheme in 2023-24. The following data sets were used:

- Community pharmacies by local health board and year
- Services provided at community pharmacies by local health board

In May 2025, FOI requests were sent to all seven health boards in Wales. These asked a number of questions depending on whether data demonstrated that the nationally agreed, locally commissioned just in case scheme was in operation.

Health boards where the just in case scheme was in operation, were asked to:

- Provide a figure for how many just in case packs were supplied to patients in 2023-24.
- Provide a figure for how many community pharmacies were commissioned to hold an extended supply of end of life medications in 2023-24.

https://www.mariecurie.org.uk/information/symptoms/just-in-case-medication#:~:text=A%20doctor%20or%20specialist%20nurse%20will%20prescribe%20the%20medicines%20before,specialist%20nurse%20or%20district%20nurse. [Accessed 28/24/2025]

<sup>10</sup> Marie Curie "Just in case medications"

<sup>11</sup> BMA "Anticipatory prescribing for end of life"

<sup>&</sup>lt;sup>12</sup> Marie Curie (2022) Policy commentary on Mind the Gaps

Confirm whether the CARiAD<sup>13</sup> package was provided to carers.

Health boards where the just in case scheme did not appear to be in operation were asked the above, and the following additional questions:

- Whether an alternative to the nationally agreed, locally commissioned just in case service was in operation?
- How many community pharmacies were commissioned to deliver this alternative service in 2023-24?

All seven health boards responded in full to the questions posed to them.

## 4. Welsh policy context

In Wales, there are a number of policies relevant to the provision of medication to people at the end of life:

- The Quality statement for palliative and end of life care states
  that people should have "24/7 single point of access to coordinated care, medication, and advice about end of life care,
  wherever they are located in Wales to reduce distress and the
  likelihood of unwarranted admission to secondary care."<sup>14</sup>
- The National Just in Case Pack Service is noted by Community Pharmacy Wales as being commissioned in five out of seven health boards.<sup>15</sup> This service provides those with a valid prescription access to a Just in Case pack from any participating pharmacy.<sup>16</sup> The Just in Case Pack will include medication to treat four symptoms – pain, nausea/ vomiting, respiratory and anxiety.<sup>17</sup> Betsi Cadwalader University Health Boards and Cardiff and the Vale University Health Board "both have developed other alternatives for anticipatory prescribing

<sup>&</sup>lt;sup>13</sup> The CARiAD package supports willing and able carers to administer needle-less as needed subcutaneous medication for common breakthrough symptoms in the last days of life. <a href="https://executive.nhs.wales/functions/networks-and-planning/peolc/professionals/the-cariad-">https://executive.nhs.wales/functions/networks-and-planning/peolc/professionals/the-cariad-</a>

package/#:~:text=The%20CARiAD%20package%20supports%20willing,at%20home%20when %20they%20die. [Accessed 05/06/2025]

<sup>&</sup>lt;sup>14</sup> Welsh Government "Quality statement for palliative and end of life care in Wales" <a href="https://www.gov.wales/quality-statement-palliative-and-end-life-care-wales-html">https://www.gov.wales/quality-statement-palliative-and-end-life-care-wales-html</a> [Accessed 28/04/2025]

<sup>&</sup>lt;sup>15</sup> Community Pharmacy Wales "National Just in Case Pack Service" https://cpwales.org.uk/clinical-services-2/additional-clinical-services/national-just-in-case-pack-service-d10/ [Accessed 28/04/2025]

<sup>17</sup> Ibid.

- of palliative care medicines."18 Limited information could be found online about these services.<sup>19</sup>
- Additionally, the Community Pharmacy Contractual Framework, has been reformed in recent years to better integrate community pharmacy within primary care clusters.<sup>20</sup> The Welsh Government stated that "...people in Wales should be able to expect services available in one pharmacy to be readily available in them all."21

# 5. Findings: Just in Case Pack Service

## 5.1. Is a just in case pack service available?

The nationally agreed, locally commissioned just in case pack service was available in four health board areas in 2023-24 - Powys Teaching Health Board, Hywel Dda University Health Board, Swansea Bay University Health Board and Cwm Taf Morgannwg University Health Board.

Table One sets out the number of community pharmacies commissioned to deliver this service in these four health board areas.

# Table One: Availability of the nationally agreed, locally commissioned just in case pack service

Health Board	Number of pharmacies registered to deliver just in case service	Percentage of pharmacies registered to deliver just in case service
Cwm Taf Morgannwg UHB	90	83%
Hywel Dda UHB	85	89%
Powys THB	13	57%
Swansea Bay UHB	54	59%

In Betsi Cadwalader University Health Board, the local End-of-Life Medicines hub service was in operation in 2023-24. 11 community pharmacies were commissioned to deliver this service, equal to 8% of community pharmacies

<sup>&</sup>lt;sup>19</sup> A 2020 service specification for End of life care medicines hubs in Betsi Cadwalader was available via Community Pharmacy Wales. https://cpwales.org.uk/wpcontent/uploads/2023/11/BCU-LAC-EoLC-Medicines-Hub-Enhanced-Service-v1-Agreed-with-CPW-24-Jun-2020-1.pdf [Accessed 28/04/2025].

<sup>&</sup>lt;sup>20</sup> Welsh Government (2021) A new prescription: the future of community pharmacy in Wales 21 Ibid.

in the health board area. This local service was replaced by the nationally agreed, locally commissioned service in April 2024.

Just in case packs were <u>not</u> available in either Cardiff and the Vale University Health Board or Aneurin Bevan University Health Board.

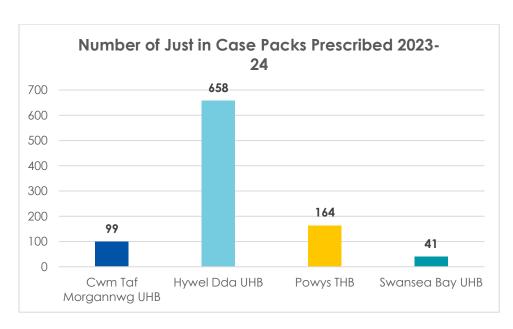
### 5.2. How many just in case packs were prescribed?

The number of just in case packs provided varies significantly across the four health board areas where the nationally agreed, locally commissioned service was available. This will be shaped in part by the number of people at end of life in different parts in Wales, as well as wider factors.

It should also be noted that this data demonstrates how many just in case packs were prescribed, not how many people used the service. Some patients may have been prescribed multiple just in case packs, while others none at all.

Table Two: Number of just in case packs prescribed in 2023-24

Health Board	Number of just in case packs prescribed
Cwm Taf Morgannwg UHB	99
Hywel Dda UHB	658
Powys THB	164
Swansea Bay UHB	41



No just in case packs were prescribed in Betsi Cadwalader UHB via the alternative scheme that was in operation in 2023-24.

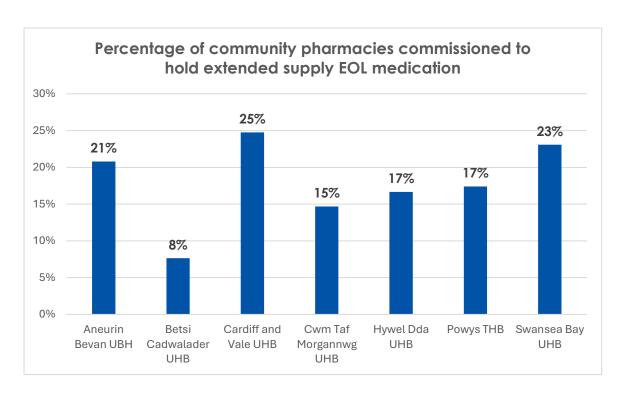
# 6. Findings: Commissioning of Extended Supply and Urgent Medication Service

Another means of ensuring access to end of life medications is to commission community pharmacies to hold an extended supply of common medications needed by people living with a terminal illness. This is sometimes combined with an out-of-hours service to further ensure timely access.

Community pharmacies in all seven health board areas were commissioned to hold an extended supply. Some health boards referred to this as the Urgent Medication Service.

Table Three: Number and percentage of community pharmacies commissioned to hold an extended supply of end of life medication

Health Board	Number of pharmacies registered to hold extended supply	Percentage of pharmacies registered to hold extended supply
Aneurin Bevan UHB	26	21%
Betsi Cadwalader UHB	11	8%
Cardiff and the Vale UHB	25	25%
Cwm Taf Morgannwg UHB	16	15%
Hywel Dda UHB	16	17%
Powys THB	4	17%
Swansea Bay UHB	21	23%



## 7. Findings: CARIAD Package

The CARiAD package supports willing and able carers to administer needleless as needed subcutaneous medication for common breakthrough symptoms in the last days of life.

Just <u>two</u> health boards confirmed that the CARIAD package was available in their area – **Betsi Cadwalader UHB** and **Powys THB**. In Powys, the package was available everywhere expect for Ystradgynlais. The service is not available in the other five health board areas.

#### 8. Conclusion

This analysis shows that there is inconsistency across Wales when it comes to the availability and accessibility of end of life medications. While a data analysis of this type can only provide a partial picture, it does suggest that the experiences of terminally ill people across Wales are likely to differ significantly in relation to access to medication.

This inconsistency will make it more difficult to achieve the goals of the quality statement on palliative and end of life care, and to measure progress.

Further research is required to understand how this inconsistency in provision is impacting people living with a terminal illness, and whether those living in areas without a just in case pack service, or with only a small number of community pharmacies commissioned to hold extended supplies of medication, are being negatively affected.

Additionally, future analysis should consider the geographic spread of pharmacies commissioned within a health board to hold an extended supply and/or provide out-of-hours services to determine whether access is equitable across the whole area.