



Version & Reference Number:

**CARiAD for Covid-19**

**Version 1.0**

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**CARer-Administration  
of as-needed subcutaneous medication  
for common breakthrough symptoms  
in home-based dying people in Wales  
(The CARiAD Package)**

'cariad', from the Welsh 'to love'

**In the context of the national (Welsh) COVID-19 response**

**POLICY AND PROCEDURE**

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*N.B. Staff should be discouraged from printing this document. This is to avoid the risk of out of date printed versions of the document. The Intranet should be referred to for the current version of the document.*

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### **Important notes:**

This document details the policy and procedures for extension of the lay carer role to include administration of as-needed subcutaneous medication in the management of common symptoms in the last days of life of people who expressed a wish to be at home when they die, under normal and usual circumstances.

For the purposes of this document, the term 'lay carers' refers to family members or friends or other lay carers looking after their loved one at home, and who are not paid to do this work. It includes healthcare professionals acting in the lay carer role for a loved one.

**Specific considerations in relation to the national COVID-19 response are indicated in red font throughout the text.** It is understood that more patients may need to be palliated at home due to extreme demand on health services during the infectious disease pandemic.

## List of abbreviations

DN	District Nurse
EqIA	Equality impact assessment
GP	General Practitioner
HCP	Healthcare professional
HTA	Health Technology Assessment
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
OOH	Out-of-hours
PPE	Personal protective equipment
RA	Risk Assessment (document)
SC	Subcutaneous
SPC	Specialist palliative care
UK	United Kingdom

## 1. Introduction/Overview

The specific practice that this document refers to is that of:

- Lay (unpaid) carer (friends of family, or healthcare professional [HCP] acting as lay carer for loved one) role-extension, i.e. being trained to competency, to administer
- Needle-less as-needed subcutaneous (SC) medication via needle-less closed SC catheter, e.g. Saf-T-Intima (as a separate line), for
- The five common symptoms in the last days of life (pain, nausea/vomiting, restlessness/agitation, noisy breathing/rattle, breathlessness) in those in their
- Last days of life who expressed a wish to be in their own home when they die.

This CARIAD package was explored successfully as part of the National Institute for Health Research (NIHR) Health Technology Assessment (HTA)-funded CARIAD study (HTA project 15/10/37), (1,2) with one exception: the practice described in this current policy document adds breathlessness to the list of common symptoms. The reason for adding breathlessness is, firstly, that it is described in the NICE 2015 guidelines on care of the dying adult as one of the five common symptoms in the last days of life. (2) **Secondly, it is important in the context of the response to COVID-19 infection as the expected mode of death will result from hypoxia, acute respiratory distress syndrome and system failure from overwhelming sepsis. Therefore the palliative management of breathing difficulties will be key in those dying of the infection.**

The practice described above is legal in the UK (see Appendix, Legal Framework) and is already practiced in some areas in the UK. (4) It is, however, a new practice for most areas in Wales.

This document assumes HCPs are following current national guidance on anticipatory prescribing for the last days of life, (3,5,6,7) and will arrange for patients to have the necessary equipment (to administer SC injections) at home. It is noted that this practice is complementary to the use of the Care Decisions for the Last Days of Life guidance. (8)

### *Why is this important?*

Under usual circumstances,

- dying people can wait significant times for HCPs to attend their homes to administer as-needed SC medication, even if anticipatory SC medication is already in their home as per national guidance. Hence, this practice aims to improve time to symptom control for those in the last days of life cared for in their own homes.
- Also, in countries where it is usual practice for lay carers to have this role, they overwhelmingly reflect positively on the practice (empowerment, ability to support a wish to die at home). This is also borne out by the findings of the embedded qualitative element of the CARiAD feasibility pilot trial. (2)

In relation to COVID-19, additional reasons for the importance of this practice may apply:

- The burden of non-communicable disease palliative care may increase if the health care system cannot offer any active treatment e.g. life-sustaining oncological treatment due to service constraints.
- COVID-19 affected patients palliated at home will still require face to face clinical assessment. Community clinical staff will require specific training and equipment to deal with these patients. Special infection control measures will be required to deliver, maintain, use and dispose of materials used in the context COVID-19.
- Healthcare provider workforce may be reduced due to self-isolation or illness, or overwhelmed by increasing numbers of patients dying at home.

Therefore, 'extended scope' considerations are necessary:

- People in the last days of life being cared for in their own homes, who did not necessarily wish to be cared for in their last days at home, including those dying of COVID-19 - as inpatient facilities – acute hospitals and hospices do not have available beds.



- Regular SC medication for those in the last days of life in event of shortage of syringe pumps, or HCP workforce depletion to the extent that syringe pumps can't be refilled daily.
- SC medication given as a needle injection in event of shortage of needle-less closed SC catheter e.g. Saf-T-Intima, or when an HCP can't insert the SC catheter.
- As needed (or regular) SC medication for those not in last days of life (e.g. malignant bowel obstruction, those on chemotherapy requiring SC anti-emetics, cancer pain management where people can't take oral medication).
- For other symptoms in the last days of life e.g. seizures, massive haemorrhage.
- Lay carers who would not otherwise have wished to take on this task, but now feel obligated as HCPs can't attend consistently (either because HCP workforce is depleted or as there is someone with active COVID-19 in the home and there is shortage of personal protective equipment [PPE] for HCPs to use).
- Training paid carers in the practice – but note that legal framework for HCSW/social care workers is not necessarily clarified.

In this document, we have added notes where applicable on all the above 'extended scope' considerations, except for the inclusion of paid carers.

## 2. Policy Statement

In Wales, we are committed to people having a healthy, realistic approach to dying, and to be able to plan appropriately for the event. (3)

The extension of the lay carer role to include administration of as-needed SC medication in the management of common breakthrough symptoms in the last days of life of people who expressed a wish to be at home when they die, has several potential benefits: it can improve time to symptom control for the dying, and empower lay carers to support a wish to die at

home or in the event of a person dying at home due to hospital shortages. It has been shown to be safe, when practiced in the context of a carefully constructed programme. (2)

As such, the practice will support good care of the dying in Wales.

### 3. Aims/Purpose

The document intends to provide a framework for the provision of carer-administration of as-needed SC medication for common breakthrough symptoms in home-based dying people.

The authors were asked to speedily construct a procedure for the practice in Wales given the COVID-19 pandemic. Specific considerations in relation to the national COVID-19 response are indicated in red font throughout the text. It is understood that these considerations may become applicable at different stages of the national COVID-19 response, based on clinical need, equipment availability (e.g. syringe pumps) and HCP workforce capacity. It is also understood that different areas in Wales may instigate alternative arrangements for certain aspects in relation to the CARIAD package at different time points in the pandemic.

### 4. Objectives

The document will achieve its aim by:

- Setting the scene for the practice, and describing the evidence-base
- Providing a framework for the practice, and the supporting documentation/materials, under normal and usual UK circumstances
- Highlighting specific considerations in relation to the national COVID-19 response

## 5. Scope

This document relates to all HCPs in Wales who are supporting people in the last days of their life in the community setting.

The work associated with the CARIAD package is heavily weighted towards the SPC team, and this is based on learning from the NIHR HTA-funded CARIAD study. (2) Primary care teams are essential for people in the community but have many competing tasks. SPC teams' singular focus on providing good palliative care will enable them to help coordinate and support care for those choosing to be at home when they die. SPC clinicians are also well-placed as they are proficient in prognostication (including understanding the inherent uncertainties) and raising advance care planning discussions.

This document relates to all lay carers who are supporting home-based dying people in Wales with use of as-needed SC medication for common breakthrough symptoms.

## 6. Roles and Responsibilities

### *Roles*

For the purposes of the CARIAD package, these roles are important:

- Local lead e.g. nurse specialist, SPC team
- Local coordinator e.g. District Nurse (DN), Advanced Nurse Practitioner (ANP), Clinical Nurse Specialist (CNS)
- SPC clinicians
- SPC manager
- Lay carer

### *Responsibilities*

#### *Local lead*

- The local lead should be a senior clinician, most likely within the local SPC team.
- They take the overall responsibility for the implementation and running of the practice in their area, and are accountable to their line manager.
- They should consider 24/7 access to SPC advice in their area, and whether this can be accessed directly by patients and carers, or whether it is advice to HCPs (i.e. patients and carers will call primary care HCPs in the first instance, who can in turn access SPC advice.)
- **They will lead discussions and decision-making on which aspects of the CARIAD package need alternative arrangements at certain time points in the COVID-19 pandemic, and be responsible for recording these decisions.**
- They may wish to delegate some of the tasks related to coordination to another team member.

#### *Local coordinator*

- If this role is delegated from the local lead, the local coordinator is accountable to the local lead.

- The local coordinator should:
  - Keep an up-to-date log of patient/carer(s) who are suitable for the practice, who have been offered the practice and who chose to participate, including contact details of carer(s).
  - Keep an up-to-date log of lay carers who have been given Carer Diaries, and who are administering injections.
  - Collect and file all completed risk assessment (RA) forms, Competency Checklists, Carer Diaries (even if a carer did not administer SC medication) as well as completed Case Review sheets and Structured Debrief Questionnaires.
- The local coordinator is also responsible for (and could choose to delegate):
  - Preparing the injection training packs according to standard contents list. **As part of the all-Wales COVID-19 response these packs will be prepared centrally and posted to SPC teams.**
  - Preparing documentation folder for patients and carer(s) with the supporting documents (Carer Diary, carer information booklet, step-by-step guides, competency checklists) in a plastic wallet. **As part of the all-Wales COVID-19 response these documentation packs will be prepared centrally and posted to SPC teams. An insert will be included on special considerations during the time of the pandemic, which can be amended as needed.**
  - Setting up a mechanism to deliver the materials (to include the injection training pack and documentation folder) to patients' homes. **For the COVID-19 response and depending on considerations about the specific patient and their context, delivery would not necessarily equate to a face-to-face contact. The pack could foreseeably be left at the front door.**
  - Informing primary care teams and out-of-hours (OOH) services of patients and their lay carers who have accepted the practice.
  - Training lay carers in medicines management, SC administration technique, and use of the Carer Diary and ongoing support. **For COVID-19 considerations in relation to carer training, please see relevant section.**
  - Completion of Case Review sheet

- Post-bereavement follow-up phone call using structured debrief questions and review of documents (RA form, Competency Checklist, Carer Diary).  
**Please see relevant section.**

#### *SPC clinicians*

- SPC clinicians should
  - Ensure they are familiar with the details of the procedure for the practice.
  - Support the local coordinator and lead by relaying up-to-date information to them about patients and their lay carers who have accepted the practice (i.e. when lay carers start to administer SC medication, any safety concerns)

#### *SPC manager*

- SPC managers should
  - Ensure there are resources available to print supporting documents and prepare the injection training packs. The latter should include ampoule openers. **See above regarding central printing and preparation.**
  - Work with the local lead and local coordinator to ensure clear routes to access 24/7 SPC advice is articulated.

#### *Carer*

- Lay carers trained to competency should
  - Assess common symptoms
  - Give as-needed medication if they feel able to do so. **If there is a shortage of syringe pumps, or the workforce is depleted to the extent that syringe pumps can't be refilled daily, lay carers may need to administer regular SC medication as well. If this is the case, HCP teams should consider if regular doses of medication are to be recorded in the Carer Diaries (including full information on before and after symptom scoring) or not. If not, consider if the all-Wales Medication Administration Record can be used by lay carers to record regular medication.**

- Document symptoms and medication administration using the medication administration diary entries. The importance of record-keeping should be emphasised to lay carers, in order to review effects of medication. **See above regarding regular medication.**
- Seek assistance as indicated/required. **Health service responses is likely to be different (than during usual times) during the pandemic. There may be additional time constraints or different formats may be utilised (e.g. via telephone or using digital platforms or via telephone).**
- **Monitor themselves for symptoms of COVID-19 and follow latest guidance.**

## 7. Procedure

This procedure (including the supporting materials) is informed in significant ways by the NIHR HTA-funded CARIAD study (HTA 15/10/37) design and results. (2)

### *Context*

Community settings in Wales, where patients are likely to be at home when they die in accordance with their wishes, and without the provision of round-the-clock paid care.

### *Patient and carer suitability*

All patients under the care of the SPC team who are deemed to be in the last weeks of life should be considered. SPC teams may have local arrangements with primary care teams who could flag potential patients to the SPC team.

Patients who may be appropriate for this practice should satisfy the following criteria:

- are adult people (aged  $\geq 18$  years);
- who have a life-limiting diagnosis;
- who are aware of their life-limiting diagnosis;
- who are aware that their prognosis is limited (i.e. they are coming towards the end of life);
- who have had the opportunity and willingness to consider wishes regarding future care (including, specifically, a wish to be at home when they die);
- who, having expressed the wish to be at home when they die, hold this view strongly and in a sustained way;
- who have a carer(s) willing and able to support the wish to die at home (including taking on the additional tasks this requires in the context of no 24/7 paid care);



**Notes:**

- Patient suitability is not reliant on cognitive status.
- Prognostication is reliant on the professional judgement of, and agreement within, the attending HCP team (i.e. clinical estimate of survival).
- There is an assumption that the carer(s) will spend a significant amount of time with the patient.

**COVID-19 notes regarding extending the scope of the practice:**

- To include people who are being cared for at home who did not necessarily wish to be at home when they died, including those dying of COVID-19, as inpatient facilities (acute hospitals and hospices) do not have available beds.
- To include as-needed (or regular) SC medication for those not in last days of life (e.g. those with malignant bowel obstruction, or those on chemotherapy requiring SC anti-emetics, or cancer pain management where people can't take oral medication).
- To include other symptoms in the last days of life e.g. seizures, massive haemorrhage.
- To include lay carers who would not otherwise have wished to take on this task, but now feel obligated as HCPs can't attend consistently (either because HCP workforce is depleted or as there is someone with active COVID-19 in the home and there is shortage of personal protective equipment [PPE] for HCPs to use).

*Risk Assessment*

When a patient and their lay carer(s) have been deemed suitable, a risk assessment should be performed. This should be completed by the HCP team who decides whether this type of support is appropriate. This is likely to be the SPC team, who may delegate this to, e.g., the DN. Best practice is that this risk assessment is done before the patient or their lay carer(s) are informed of the practice by any HCP. If the patient or their lay carer(s) ask about the practice, HCPs should be clear that the suitability criteria and risk assessment processes will need to be satisfied first. Where there is more than one carer, each will need a RA form completing. The RA forms should be held in the local coordinator's office.

The risk assessment will identify where carer-administration of as-needed SC medication is not appropriate (as reflected in the RA form). This is based on the RA tool used as part of the CARIAD study, which was adapted from an existing self-medication risk assessment instrument. (2,10) A patient and their lay carers will not be suitable if any ONE of the following criteria are present:

- A patient has only paid/formal care, or a known allergy/adverse reaction to any one of the usually prescribed anticipatory medication with no suitable alternative, or a known history of substance abuse, or an objection to the concept of lay carer-administration of SC medication, or is unwilling for available healthcare support systems to be accessed (e.g. OOH services).
- A carer who has cognitive problems (i.e. who are confused, disorientated or forgetful or unable to understand the importance of medications and information relating to them), or significant visual problems, or insufficient literacy skills to understand and complete the relevant documentation, or insufficient dexterity to prepare and give SC injections, or a known history of substance abuse or an objection to the concept of lay carer-administration of SC medication, or is unable and unwilling to engage with and access available healthcare support systems (e.g. OOH services).
- The context/environment where there are known relational issues between carer and patient which contraindicates carer-administration of medication (e.g. where either the patient or carer can assume this practice intentionally hastens death), or where there are known issues of substance misuse in immediate circle of family and/or friends, or where there is no suitable place for medications to be stored.

The RA form should be completed:

- Prior to approaching patients and lay carers
- At intervals (at the discretion of the HCP team) for patients and lay carers involved in the practice. If the criteria do not continue to be met, the practice should be withdrawn. If the practice is withdrawn, this should be clearly documented and kept in the local coordinator's office.

**Note:** All patients who are deemed to be in the last weeks of life should be considered for suitability and each patient and carer(s) should have the benefit of a RA being completed objectively. HCPs will be reminded to carefully consider all the RA criteria and not to come to a summary (or intuitive) judgement on the suitability of a patient and their carer(s)—as this risks excluding people who would have been able to benefit from the practice. (2)

### *Approach*

- If all the RA criteria are met, the patient and their carer(s) should be approached with more information (verbal and written) about the practice and asked to consider if they wish to take up the offer. Clinical judgement should be used to determine if this approach is more appropriate with patient and carer(s) together or separately to avoid coercion from either party.
  - If the person acting as a lay carer is a HCP holding current registration, they should be aware that, though this is a legal practice, it is not widespread in the UK at present and that some colleagues or managers may feel hesitant about them taking on such a role. They need to know that there is a risk (likely low) that they will be reported to their registering body, but that this will not lead to disciplinary action as long as they have been trained to competency and acted within the parameters of the policy. They would be encouraged to show the paperwork to their manager to facilitate discussion.

**Note:** A full consideration of the available lay carers may be necessary to identify an appropriate carer (or two) and, where possible, this decision should be patient-led.

**Note:** Data shows that there is often an assumption that, if there is a lay carer with a HCP background in the patient's immediate circle, that person would be best-placed to be trained to give SC medications. (2) Though this may be true for some families, it is not

true for all, and such an assumption risks excluding other, more appropriate, lay carers (without HCP background).

### *Setting up at home*

Led by the local coordinator, there should be

- Anticipatory medications available in the home, with appropriate medication authorisation/prescription sheet.
- Needle-less closed SC catheter (e.g. Saf-T-Intima) in place to use for as-needed medication. It is best practice that the SC catheter used for as-needed injections is separate to the one used for regular medication (i.e. via a syringe pump). Therefore, patients with a syringe pump in situ will have two SC catheters in place.
- HCP support available, which is clearly articulated to the patient and carer(s). This should include contact details and what they could expect in terms of regular review/visits. In each area there should also be consideration of 24/7 access to SPC advice, and whether this advice can be sought directly by patients or lay carers or via primary care HCPs.
- Circumstances may be foreseen where there is a shortage of needle-less closed SC catheter (e.g. Saf-T-Intima), or when an HCP can't insert the SC catheter. Then, the local coordinator and HCP team will need to consider if SC medication can be given as a needle injection (as opposed to a needle-less injection as described in the CARIAD package) or whether the carer can be trained to insert the SC catheter. Please note that the CARIAD package does not include training materials for needle-injections, nor for training lay carers to insert SC catheters.
- Gastrointestinal symptoms (nausea, diarrhea and vomiting) have been reported in some cases of COVID-19, and lay carers should be alerted to this, along with advice on disposal of human waste products that may increase the transmission of the virus.

## *Carer training*

- A maximum of two lay carers can be trained to administer SC medications. Where more than two lay carers are available and where possible, the patient should be asked to identify which carer(s) they would like to be trained to administer medications. Additional lay carers can be present for the training to enable them to contribute to shared decision-making.
- Carer training will be supported by a manualised training package based on the NIHR HTA-funded CARIAD study. (2) Training will be one-to-one (one-to-two), face-to-face, delivered by an HCP (usually a DN or SPC nurse) and supported by written materials. The training will cover: common symptoms that may occur in the last days of life and how to assess if a medication is needed for a particular symptom; how to prepare (draw up) medication and dispose of sharps (glass ampoules and drawing up needles) – using the injection training pack; how to administer SC medication by needle-less technique (utilising a ‘butterfly’ SC catheter placed by HCP) – using *either* blunt needle *or* no needle technique; how to assess the effect of the medication; how often medication should be given and support available in their area.
- **Digital alternatives to face-to-face training should be explored, including videoconferencing (e.g. via Zoom, Skype or Whatsapp). Adequate training can’t be given via telephone/audio link, as the trainer would not be able to observe for competency.**
- The HCP training the carer(s) should decide whether to train the carer to give SC injections *either* using a blunt needle *or* using a no-needle technique. A carer does not need to be trained in both techniques. Step-by-steps guides are available for both techniques; the HCP training the carer should ensure that only the appropriate step-by-step guide is provided in the carer’s pack.
- The HCP training the carer can choose whether to advise the carer to flush with water for injection or normal saline, in line with local practice; the step-by-step guides mention normal saline, but if the HCP chooses water for injection, they should ensure this is indicated on the step-by-step guide.
- Training should be tailored to the individual lay carer. As competence and confidence in practical tasks develop over time for most people, HCPs should be

ready to deliver the training over the course of a few visits until the carer attained competency. Before a carer is allowed to administer SC medication without HCP supervision, a Competency Checklist needs to be completed, and all items listed satisfied. Please clearly indicate on the Competency Checklist in which technique the carer has been trained (*either blunt needle or no-needle*).

- As part of the NIHR HTA-funded CARIAD trial it was shown that some lay carers could successfully be trained in one visit, even in the context of a patient's prognosis being 'short days'. (2) As far as possible and even given the extraordinary circumstances, the focus should remain on attaining competency (however long or short time that takes) and not on compressing competency acquisition in as short a time as possible. This is because the sign-off of competency is an important part of the safeguards of the CARIAD package.
- When carer competency in the task is attained, HCPs will offer ongoing support in the decision making and building confidence. Support may include:
  - to call out an HCP when the patient has a symptom, to administer the SC medication so that the carer can observe.
  - to call out an HCP when that patient has a symptom, so that the carer can administer the SC medication whilst an HCP is present and can observe.
  - These arrangements may need to be different during the COVID-19 response. HCPs should clearly explain to lay carers the support available in their local area that is specific to the practice, and whether this is via primary care services in the first instance or whether they have direct access to a SPC advice line. Digital alternatives will need to be explored.
- The carer, even if trained to give SC medication, is not under any obligation to actually administer it if they feel they shouldn't do so at the time. Given likely health service constraints, lay carers may well feel an obligation to take on a task such as this, which they wouldn't have wanted to do given usual circumstances. HCPs should be sensitive to this, and alert the local coordinator if they feel this is the case, as it may impact on the way the carer reflect on the practice at their post-bereavement structured debrief.

- If the carer needs the support of an HCP, either because they would feel more confident having an HCP present when they administer medication or they wish the HCP to assess and give medication, they should obtain it via the usual routes in their area. **See above considerations.**
- A maximum of three medication administrations for each indication per 24 hour period is permitted unless the prescribing clinician advised a maximum of *fewer* than three. If the carer has reached the limit of the number of administrations which should be given in 24 hours or has concerns, they should contact an HCP as review is indicated. The Prescriber Information sheet as part of the CARiAD package specifically states that an HCP must not change the prescription (e.g. increase the dose or frequency of administration) by discussion with the carer over the telephone – prescriptions can only be changed after direct (face-2-face) assessment. This is important as the Carer Diary needs updating so that the carer is very clear, at all times, what they can administer. **Stating a maximum of three as-needed medication administrations for each indication per 24 hour period is an important part of the safeguards of the CARiAD package, as is the need for review when this limit is reached. Though best practice would indicate face-to-face review when the limit is reached, to re-assess and amend medication if appropriate, this may well need to be different during the pandemic. Digital alternatives will need to be explored, whilst ensuring the safeguards (of reassessment and updating the Carer Diary) are honoured.**
- Usual routes for support include DN team, GP, GP/DN out-of-hours, Hospice at Home team or a SPC advice line. The use of such support will be captured in Carer Diaries. **See above considerations regarding clarity of support available.**
- If a patient who was offered the practice is admitted to an inpatient unit (including hospital, hospice or nursing home), lay carers should be made aware that they should not administer SC medications to the patient during the admission.

**Notes:**

- Reconstitution has not been covered in the supporting materials of the CARIAD package as diamorphine is not a first line medication. Should the use of diamorphine be required, variance to carer training will be needed and this is not contraindicated.
- Drawing up of as-needed medication in advance of the symptom occurring (and storing these in the fridge) is not covered by the CARIAD package as there is no clear legal framework for this, and lay carers should be made aware during training that this should not happen.

*Supporting documentation (for lay carers and HCPs)*

The supporting documentation and materials are based on those used for the CARIAD study. (2) The work-up of the CARIAD study materials benefited from robust public involvement (in terms of content, wording and design) and from review by the Research Ethics Committee.

Supporting documents/materials for lay carers as part of the CARIAD package: (see standalone documents)

- Information sheet for patients and carers (A4)
- 'Subcutaneous medication for breakthrough symptoms in the last days of life: A guide for carers' (A5 size) **An insert will be included on the special considerations during the time of the pandemic. This can be amended by the local coordinator as needed, so as to be specific about considerations at that time.**
- Carer Diary (A5 size), with a medication information table (which includes dose volume information and a reminder of the maximum number of administrations in 24 hours per indication) and 20 medication administration diary entries. If more booklets are needed, the local coordinator can be contacted. **For the COVID-19 response, extra Carer Diaries will be printed and posted to the local coordinator/SPC teams.**
- Step-by-step guides with images illustrating required actions
  - A step by step guide to opening and drawing up medications from an ampoule.



- 10 step plan for preparing and giving as-needed subcutaneous injections using a blunt needle technique.
- 10 step plan for preparing and giving as-needed subcutaneous injections using a no-needle technique.
- Injection training pack **which will be prepared centrally and posted to SPC teams**

Supporting documents for HCPs:

- Risk Assessment (RA) form
- Information for prescribers
- Carer Competency Checklist
- Injection training pack content list
- Flowchart for HCPs
- Case review sheet
- Structured debrief questionnaire

In addition, information sheet(s) or alerts for other HCP teams involved in the patient's care will be explored, including for primary care teams, Marie Curie services and Hospice at Home services.

### *Medication regimens*

Guidelines for anticipatory prescribing for last days of life care are in place across Wales, including via the all-Wales Care Decisions for the Last Days of Life guidance. (3,5,7,8) They cover common symptoms in the dying phase: pain; nausea and/or vomiting; anxiety/agitation/restlessness; noisy 'rattly' breathing; and breathlessness. Prescribers are advised to follow usual prescribing practice for dosing of anticipatory medication.

For the purposes of the CARIAD package, prescribers are provided with specific additional advice, including instructions not to prescribe dose ranges/steps, and that

dose changes can only be made after a face-to-face assessment (and not remotely, i.e. over the telephone).

### **COVID-19 considerations**

Studies of the disease course so far have identified shortness of breath at onset in a third of cases, hypoxaemia in around 50% of cases and acute respiratory distress syndrome in up to 30% of cases. Clinically this will present with confusion and difficulty breathing, exacerbated by a dry cough (46-82%). In the absence of oxygen, the palliative and supportive treatment of breathlessness, distress and agitation can be achieved with opioid and sedative medication. However, these drugs should be avoided or used with caution in patients who have further options for treatment escalation, or in whom escalation decisions have not been clarified.

### ***Regular follow-up***

Each time there is a review by an HCP (whether this is a primary care HCP or SPC HCP), tasks include:

- Review of carer diaries, including
  - accuracy of medication information table (compared to the usual prescription chart e.g. all-Wales Medication Administration Record)
  - medication administration diary entries
    - the appropriateness of administration (is administration accompanied by evidence of need?);
    - proportionality (has the correct dose been administered?);
    - side effects both anticipated and not anticipated;
    - carer confidence scores (does the carer need more training or support?)

- Review of how carer(s) are coping (in general and specific to this practice) and whether there were any events e.g. injury, accidental or purposeful self-administration
- Review of medicines management at home, including
  - drug accountability (do stocks tally?) – use local mechanisms in place e.g. stock balance sheets used by some DN teams
- Review of patient events, e.g. unscheduled hospital or hospice admissions

The review should be recorded in the patient's clinical record and any concerns escalated appropriately.

### *Record-keeping*

Record-keeping is an important part of the safeguards in the CARiAD package. Therefore these arrangements should be kept as far as possible.

There are three specific elements in addition to records kept in the patient's clinical record – the medication administration diary entries (including updating the usual prescription chart), the structured debrief and case review sheet.

### *Carer Diaries*

Lay carers will be asked to use the medication administration entries in the Carer Diary to record medication administration.

The Carer Diary has a medication information table which lay carers will be asked to refer to each time they give an injection.

Data points in each medication administration diary entry include: initial time breakthrough symptom triggered perceived need for an additional SC dose; whether noted by patient lay carer or HCP; medication and dose, and time given; reason for

medication (pain, nausea/vomiting, anxiety/agitation/restlessness, noisy breathing, breathlessness); symptom score before and 30 min after medication administration; and when symptom control/reduction of symptom to acceptable level was achieved. Also, confidence in administering SC medication. Lay carers will be asked to initial and sign each medication administration diary entry. There is also space to indicate whether HCP support was sought, and the outcome of any HCP interaction e.g. visit.

The importance of accurate record-keeping should be emphasised to lay carers. It is understood that carer(s) will potentially be administering these medications at all hours of the day, and that there may be times that they cannot manage to complete every single part of each medication administration diary entry.

The usual prescription chart (e.g. all-Wales Medication Administration Record) will need to be updated at regular intervals. This could either be done by the lay carer(s) or by HCPs. 'Carer-admin' could be entered in the signature box.

#### *Case review sheet*

This should be completed for each patient who had a carer(s) trained to administer SC medication. The local coordinator is responsible for this to be completed and filed.

Data items include: Patient demographics (name and date of birth); number of carers trained; RA forms received?; Competency Checklist received?; Patient's diagnosis, preferred place of care, preferred place of death, actual place of death and date of death; and whether the patient had any unscheduled hospital or hospice admissions. Space is provided to record any concerns around medication administration or any general concerns or difficulties.

#### *Structured Debrief Questionnaire*

As part of the CARiAD package all trained lay carers should be offered the opportunity to take part in a structured debrief. This should be delivered via telephone by a local coordinator nominated person.

Ideally the structured debrief will be carried out with each trained lay carer approximately 4-6 weeks post bereavement. In instances where more than one lay carer was trained but only one is available, the available lay carer should still be debriefed. The 4-6 week interval is given to allow lay carers a grieving period but also ensure that the experience is still easily recalled. Findings from the NIHR HTA-funded CARiAD study indicated that if a longer interval is given there may be issues with recall or loss of contact due to lay carer relocation. (2) However, lay carer wellbeing is paramount so HCPs should use their clinical judgement to ascertain the best timing of this debrief.

Findings from the qualitative component of the CARiAD study have identified key areas of importance to be covered within the structured debrief. (2) These are as follows:

- Training and materials
- Use of medications and equipment
- Recognition and management of symptoms
- Potential carer burden
- Contact and support from HCPs
- A home death and wish fulfilment
- Concerns regarding last injections/ hastening death
- Carer confidence

The structured debrief is designed to cover these key areas and it is advised that all questions be asked of each trained lay carer, and in the order specified below:

1. Do you think you received adequate training to know how and when to give the medications?
2. Did you feel you were able to manage the symptoms effectively by giving the medications?
3. Do you think you received adequate care and support from your healthcare professional team?
4. Overall, how would you describe your experience of the CARiAD package?
5. Are there any ways you think the CARiAD package could be improved?

A structured debrief record-keeping sheet forms part of the CARiAD package.

## *Governance*

This will be the responsibility of the SPC team, via the local coordinator and local lead.

The local lead is accountable to their line manager.

All key documents should be safely stored:

- The original RA forms and Competency Checklists should be filed in the patient's clinical records with a copy held in the local coordinator's office. HCPs will record lay carers' competence at intervals and as required after the initial training. The RA form will also be updated at intervals and as required.
- Ongoing review will be recorded in the patient's clinical records, and on Case Review sheets, by SPC teams collating the information either from their own interactions with the patient or carers as well as requesting information from DNs. Case Review sheets will also be held in the local coordinator's office.
- After the patient's death, the completed/used Carer Diaries (even if the carer(s) did not administer medication) should be sent to the local coordinator's office where it will be reviewed and filed. The Structured debrief record will also be held here.

The local lead and local coordinator should review all the CARiAD documentation at regular intervals and collate information on patient selection and outcomes. This is important as it will help to increase understanding of how this practice works in the Welsh setting, and for whom, and in what way. This, in turn, will inform future decisions on what role this practice should have in the management of symptoms for those wishing to be at home when they die.

The local lead should report to their line manager, who will, in turn report to the National Clinical Lead for Palliative Care.

The central CARiAD team (lead by the main authors and based in North Wales) will be responsible for version control of all documents pertaining to the CARiAD package, and will make amendments as needed.

It is important that these arrangements are followed during the pandemic, to ensure the practice works as best it can. It is envisaged that the more regular reviews of patient selection and outcomes are needed during the pandemic, perhaps even monthly.

## 8. Equality including Welsh Language

For the purposes of the COVID-19 response, only English materials will initially be available. Welsh translation will follow as soon as practicable.

The CARIAD study materials had in-depth peer and research ethics review, and robust public contribution. (2) For this policy, an equality impact assessment (EqIA) was carried out by the main authors and the NIHR-funded CARIAD study trial manager. Protected characteristics that may be impacted are age and disabilities, but these relate to ensuring patient safety. Details of how these impacts can be mitigated have been detailed in the policy and EqIA. There are no concerns relating to discrimination under equality legislation.

## 9. Resources

### *Financial*

- Printing of patient/carer-facing materials, presented in plastic folder with popper (from quote provided by Business Print & Design, Wrexham, on 20/3/2020)
  - Per 500 = £5,749.73
- Injection training pack (including container with lid and ampoule opener) (current ballpark costs £12 per pack, which includes £7 per pack for equipment. Indicative costs for plastic container and packing to follow)
  - Per 500 =£6,000
- Courier costs (25 packs per box @ approximately £7)



- Per 500 = £150
- Welsh translation (costings to follow in due course, likely via Welsh Government)

So, at present:

Per 500 = £11,899.73 (£23.80 per patient)

### *Time*

- SPC clinicians' workload and hence time is impacted (as per the tasks listed before). Local arrangements should be put into place to acknowledge this in job plans.

### *Training*

- SPC clinicians' time to familiarise themselves with the procedure and supporting materials
- Lay carers' time to be trained, to assess symptoms, administer medication, re-assess symptoms and record outcomes

## 10. CARiAD for COVID-19 and emergency action plan

During the COVID-19 pandemic, we anticipate a significant impact on professional resources. Whilst this policy is seen as a way to improve the situation, it may not always be easy to implement standard practice (which is indicated in black text in this document). What follows are suggestions for different situations or statuses, and it considers governance, risks that could be considered, and actions to mitigate further risk. It summarises points already raised earlier in the document.

### *Contingency planning*

#### *Normal practice*

I.e. no shortage of staff e.g. SPN, DN or GP workforce, and no shortage of medication or equipment e.g. syringe pumps, and carer availability: this policy should work smoothly as long as governance arrangements are in place.

#### *Shortage of staff*

Consider alternative ways of training carers if possible (using digital video platforms) and clinical review (including telephone review). Be clear about threshold for offering face-to-face visits, based on risk assessment of the situation and aligned with current advice. Liaison between HCPs about clinical cases will likely be via telephone.

#### *Shortage of equipment*

If there is a shortage of syringe pumps, regular SC medication might need to be administered by lay carers every 4 to 6 hours. Local leads will need to consider the best way to support this, including whether to ask lay carers to use the Carer Diary medication administration entries or perhaps the usual prescription chart (i.e. all-Wales Medication Administration Record).

It is less likely that there will be a shortage of needle-less closed subcutaneous catheters (e.g. Saf-T-Intima). If stocks get low, the local lead will need to consider if reverting to needle-injections by lay carers is appropriate. Careful monitoring will be needed as this is a significant departure from the CARiAD package.

### *Drug shortages*

Access to medication is important, given the likelihood that consumption may rise and therefore stocks should do in line. Ensuring adequate stocks of medication is being explored in a parallel work stream.

### *Carer shortage*

A carer may become ill while delivering this practice. Local teams need to consider the best course of action if this happens; this may include training another lay carer. (As this is a practice supporting those in the last days of their life, it is not envisaged that the patient will be well enough to give medication themselves.)

It is imperative that lay carers have a clear route to ask for help from HCPs, as described earlier in this document.

### *Worst case scenarios*

This may include:

- Families who have a loved one dying at home and are unsupported, and therefore feel abandoned. Carers may feel an obligation to engage in the practice.
- HCPs not following the steps ensuring safety e.g. introducing this practice without performing a risk assessment, poor training including not discussing 'last injection' concerns, poor quality follow-up, 'battlefield triage' – this practice may lose its credibility during normal times.

## 11. Training

The local lead is responsible for training of SPC clinicians in their team. They should keep a log of those members of staff who have been trained.

Primary care colleagues are likely to take on some tasks related to the CARiAD practice, especially regarding regular follow-up of patients at home. The local lead needs to ensure that mechanisms are in place that appropriate training is disseminated and training logs kept.

## 12. Implementation

Implementation will be devolved to individual Health Boards. They will need to devise an action plan, and articulate the time scales as well as level of training required.

## 13. Review

This policy and procedure will be reviewed every three months for the first year, **and more frequently during the COVID-19 response if needed (based on feedback from SPC teams/local coordinators).**

## 14. Acknowledgements

This document and the associated supporting materials were significantly informed, and retains the acronym of, the NIHR HTA-funded CARiAD study (HTA project 15/10/37). (2) The final report of the project is in press. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

On special request and due to the time-sensitivity of informing the Welsh Government COVID-19 response, the NIHR Journals Library kindly expedited the process toward publication of the final report.

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## 16. Appendices

## *Legal framework*

Clarity on legal issues is a significant aspect of this research to ensure lay carers and clinicians alike have legal protection. Our Australian partners have given us full access to their reference resources. (11,12,13,14,15) Their medication handling guidelines document covers a broad range of topics on the handling of medication in community-based palliative care services. It covers medication management, drug storage (security of medications, responsibility for medication storage, disposal of medication), prescribing, and medication administration (who can administer, record of administration) in the context of lay carer-administration.

The premise:

A lay carer can legally administer medication individually prescribed for a third party, including controlled drugs such as morphine, as long as the carer has been appropriately trained and assessed as competent, specifically in medication management. This is true even if the medication is given to a patient lacking capacity, and/or if the medication is administered via injection. At present, injections are prepared immediately before administration (and not in advance, requiring relabelling). Carers should be trained to assess symptoms and should have access to dedicated support.

In support of these statements, the relevant sections from UK legislation and guidance are detailed below:

### **A lay carer can administer medication individually prescribed for a third party, including controlled drugs such as morphine,**

- Section 7(3) of the Misuse of Drugs Regulations 2001 states: *“Any person other than a doctor or dentist may administer to a patient, in accordance with the directions of a doctor or dentist, any drug specified in Schedule 2, 3 or 4.”* (12)
- This was confirmed by the UK Medical Defence Union. (13)
- NHS NPC guidance (2009) states: *“A carer/relative can, with consent, administer a controlled drug (CD) that has been individually prescribed for a third party. As CDs are included within the legal category of prescription-only medicines (POMs), home*

*carers who are competent to administer medicines should also be competent to administer CDs". (14)*

- Morphine is listed in Schedule 2, and Midazolam in Schedule 3. (15)

**As long as the carer has been appropriately trained and assessed as competent,**

- Nursing & Midwifery Council (NMC) guidance, Standard 17 (valid until 28 January 2019): Delegation stated: *"A registrant is responsible for the delegation of any aspects of the administration of medicinal products and they are accountable to ensure that the patient, carer or care assistant is competent to carry out the task. This will require education, training and assessment of the patient, carer or care assistant and further support if necessary. The competence of the person to whom the task has been delegated should be assessed and reviewed periodically. Records of the training received and outcome of any assessment should be clearly made and be available."*<sup>95</sup> From 28 January 2018, NMC Delegation and accountability guidance states: *"These requirements apply, regardless of who the activity is being delegated to. This may be another registered professional, a non-registered colleague, or a patient or carer. These expectations are that people on the NMC register: only delegate tasks and duties that are within the other person's scope of competence, making sure that they fully understand the instructions; make sure that everyone they delegate tasks to are adequately supervised and supported so they can provide safe and compassionate care; confirm that the outcome of any task delegated to someone else meets the required standard."* (16)
- Department of Health, Social Services and Public Safety (Northern Ireland) guidance states: *"home carers who are appropriately trained and assessed as competent are authorised to administer orally prescribed controlled drugs". (17)*
- The Durham and Tess Valley Regional Medication Policy Group states: *"The cornerstone of the policy is a risk assessment to identify appropriate support for service users and the provision of appropriate training for those staff that will assist service users with medication. A carer administering a medicine will not be held responsible for any adverse effects, providing a medicine has been given in accordance with a prescriber's instructions and local policies have been followed.*

*Employing organisations should include medication tasks in any indemnity insurance they arrange.” (18)*

**Specifically in medication management.**

- The Durham and Tess Valley Regional Medication Policy Group continues: *“Carers will operate within a safe system which will be based on a risk assessment and this will need to be underpinned by a structured programme of education and learning in the safe handling, administration and management of medication.” (18)*
- Procedures are already in place in the UK to handle/store medications (including for anticipatory care purposes) in the patient’s home. (5)

**This is true even if the medication is given to a patient lacking capacity,**

- Medication can be given to a patient who lacks capacity if it is in his or her best interests. The Mental Capacity Act (MCA) 2005 Section 1(5) states: *“An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.” (19)*
- The MCA 2005 permits the relevant actions to be performed by those with appropriate skills or expertise (as long as the carer has been appropriately trained and assessed as competent). The Code of Practice explains: *“To receive protection from liability under section 5, all actions must be related to the care or treatment of the person who lacks capacity to consent. Before taking action, carers must first reasonably believe that:*
  - *the person lacks the capacity to make that particular decision at the time it needs to be made, and*
  - *the action is in the person’s best interests.” (20)*

**And/or if the medication is administered via injection.**

- The Durham and Tess Valley Regional Medication Policy Group states that for specialist tasks (including injections) a suitable health professional needs to give additional training and confirm that the carer is competent to provide such care. (18)

**At present, injections are prepared immediately before administration**

- NMC Guidance, standard 14 states: *“Registrants must not prepare substances for injection in advance of their immediate use or administer medication drawn into a syringe or container by another practitioner when not in their presence.”* The guidance continues: *“Where a registrant has delegated to a named individual for a named patient’s medication, this may be drawn up in advance to enable the healthcare assistant (HCA) or family to administer the medication. The registrant is accountable for the delegation, and a full risk assessment should be documented in the patient’s records ensuring the registrant is aware of the risks before agreeing to delegate.”*
- Note: There is evidence that the practice of drawing up and leaving these medications in syringes, for this type of practice, is safe in terms of sterility, potency and stability. (21) The team tested a full range of medications for 28 days.

**Carers should be trained to assess symptoms, use the least invasive methods of administration and should have access to dedicated support.**