

Document Title:	Dorset Shared Care Protocol for informal carer administration of subcutaneous medications for pain and symptom management in Community Palliative care
Version:	3.6
Date:	April 2020
Review:	April 2021
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## Dorset Shared Care Protocol for informal carer administration of subcutaneous medications for pain and symptom management in Community Palliative Care

### Background and rationale

*With the imminent threat from the Coronavirus global pandemic, it is anticipated that large numbers of patients will be dying at home, with or without COVID-19, with reduced access to health care staff due to a depleted workforce and the requirements for infection prevention and control. In this context, it is more important than ever to empower relatives to care for a dying loved one and ensure they have a peaceful death.*

Palliative care services strive to support patients to live and to die within a setting of their choice, usually at home. Most people prefer to die at home and in recent years, more people than ever have been managing to achieve this goal. This has had a major impact upon the work of the primary health care team involved in caring for palliative care patients in the community. The likelihood of patients remaining at home often depends on availability of able and willing informal carers (1, 2, 3). These carers take on numerous care tasks, often including the responsibility of assisting patients to have their oral as-needed medications.

Uncontrolled pain and symptoms are a common concern among relatives caring for loved ones at the end of life (4) and have the potential to prevent patients being able to die peacefully at home, especially when patients are no longer able to tolerate oral medication. Medication for breakthrough symptoms is usually prescribed in advance (anticipatory prescribing) and kept in the patient's home. Medication administration can be severely delayed by healthcare professionals (HCPs') travel time to the home; delays happen even with dedicated out-of-hours (OOH) 'rapid response' nursing services for home-based dying patients. Extending the role of carers to include administering subcutaneous (SC) injections has proven to be key in achieving a peaceful home death in other countries (5).

Training carers to administer SC medication requires education and resources to allow them to manage confidently this aspect of their caregiver role. This role is promoted by others in palliative care (6,8,9,10,11,12). In addition, it is common practice that carers administer other SC medication such as Clexane/ Insulin. It is also quite common practice in Australia for carers to administer in palliative care (13) and has been for 30 years. Indeed, in Australia the benefits of this practice have been reported as not only immediate symptom relief, but also carers highly valued this role and felt that it gave them a sense of empowerment, pride, achievement and avoided feelings of helplessness (14).

## Objectives

This protocol has been developed to give health care professionals a safe framework to work within when the patient's symptoms may not be controlled by the usual methods (oral/ transdermal medication or 24 hour syringe driver) and to support patient choice. This will facilitate effective symptom control, respecting patient choice, carer involvement and achieving preferred place of care. This will be delivered within a safe and supportive environment.

## Scope and purpose

**This protocol is only for known palliative patients with the agreement of an MDT including the patients GP and Specialist Palliative Care; it is expected to be used infrequently.**

In a small minority of cases an informal carer may be supported to administer a drug by **a needle-less closed SC catheter (e.g. Saf-T-Intima) or via SC needle injection**, to optimise 24 hour effective symptom control in the community.

For the purpose of this protocol informal carer(s) relates to lay carer(s)/ relative(s) of the patient, in the community, who are unpaid for the care they are giving.

If the carer is a registered clinician, they must contact their union palliative care representative i.e. RCN palliative care lead, to ensure that they are working within their professional boundaries and have that support. They should also consult with their line manager.

The need to implement this procedure should be led by the needs of the patient/ carer and should not be imposed on the patient/ carer by health care professionals. It is not anticipated that this procedure will be relevant to all carers.

It must be made clear to the patient (if feasible) and carer(s) that from the outset they are able to discontinue this procedure at any time, should they wish to.

In order to reduce risk, easy dosing (e.g. using full vials/ easy drawing up of part vials) should be considered and this may guide drug choices/ vial sizes where possible.

This protocol is to be read in conjunction with the Wessex Palliative Care Green Book. The Community Palliative Care Drug Administration Chart will be used to record all doses given by the carer or health professional administering medication and to record remaining vials to ensure there are sufficient quantities for future use.

## Responsibilities

It is the responsibility of **the** healthcare professionals who care for community patients to be familiar with this protocol and abide by organisational policies related to medication and professional guidance co-produced by the Royal Pharmaceutical Society (RPS) and Royal College of Nursing (RCN) to ensure the safe administration of medicines by healthcare professionals (2019).

Registered Nurses are responsible for recognising any limitations in their knowledge and competence and declining any duties they do not feel able to perform in a skilled and safe manner (NMC: The Code – Professional standards of practice and behaviour for Nurses, Midwives and Nursing Associates 2018).

The Multidisciplinary Team (MDT), which must include a GP, as the continuing prescriber and a Specialist Palliative Care (SPC) member will identify the carer(s) responsible for administering the SC injection and the persons responsible for training, monitoring and supporting them through the implementation of the procedure.

In exceptional circumstances (e.g.COVID-19) where a patient is not already **under the care of the local SPC team**, the decision to implement this protocol may be initiated by a medical practitioner/ NMP/ primary prescriber in discussion with the MDT. A discussion with SPC will take place to support this decision as soon as possible to ensure SPC are aware of the patient should the carer or HCP make contact for further support and/ or advice.

The hospice team involved in the decision and supporting the delivering of the training will provide specific contact details to the carer for out of hour's professional advice when using this protocol. Out of hours advice will be available **from the local hospice team** 24hrs a day, 7 days a week, for professionals and carers when using this policy.

It will be the responsibility of a senior Registered Nurse to ensure that the carer who will administer the injection receives appropriate training and is competent to administer SC injections, taught using a step-by-step training procedure (**Appx D & E**). The training must also cover an overview of safe and secure handling of medicines, including how to safely dispose of unwanted/ used medicines and associated apparatus (e.g. needles and syringes) and how to safely store medications in the domiciliary setting. **(16)**

The Dorset Wide Palliative Care Drug Administration Chart must be available in the patient's home for shared care to start. It is the responsibility of the prescriber to ensure that the administration doses are correctly transcribed onto the Palliative Care Drug Administration Chart and that there are spaces on the chart to record both nurses and carer/ relative signatures when giving SC injections.

It is the responsibility of the prescriber to ensure that there are appropriate prescribed medications to manage the symptoms agreed for use in the patient's home.

It is the responsibility of the lead community nurse to ensure that there are sufficient prescribed medications available in the patient's home.

**It is the responsibility of the lead community nurse to ensure that the 'just in case medications' that may be used by the carer are stored separately from the rest of the patients medications. Medication agreed for carer administration will be kept in a box (provided by the patient or carer) labelled 'Carer Administration Medication' and if more than one medicine is available for the carer to administer it must be clearly labelled.**

It is the responsibility of the healthcare team to ensure there are sufficient needles, syringes and sharps containers in the patient's home.

A Registered Nurse will be responsible for ensuring this procedure is administered safely with reviews and monitoring at least weekly (or daily where medication is being administered more than daily).



## Procedures and safeguards for informal carers giving s/c injections

- The following will be undertaken to ensure safeguards are in place to support and protect the patients' best interests and support the identified carer.
- Participation of carer(s) in administration of SC injections must be entirely voluntary. The healthcare professional assessing suitability must ensure that the carer has not been subjected to undue pressure from the patient, another family member or a healthcare professional to take on this role.
- Where possible, discuss with the patient the possibility of their carer(s) administering SC injections.
- Carers, particularly if Registered Nurses or doctors should not feel obliged to **take on the carer role of** administering injectable analgesia **under this protocol and must be aware they can** withdraw from the agreement with the healthcare team at any time.
- Carer's fears must be explored, including the possibility of the patient dying shortly after an injection. Carers will be trained and advised to only administer medications at the legally prescribed doses. Any concerns raised by healthcare staff that this is not happening should lead to a review of the agreement.
- The carer should be advised to contact the specialist palliative care team/community nursing team for advice if unsure about administering a medication.
- Should a drug error occur, the carer's competency comes into question or the carer's intentions are in any doubt, then the procedure must be stopped immediately leading to a review of the agreement.
- **Any concerns about a drug error should initially be discussed as a priority with the specialist palliative care team.**
- The Prescriber and MDT will need to decide the appropriateness and number of injections available for the carer to give. It may be that not all subcutaneous drugs are prescribed for the carer to give.
- The carer will be advised to only administer a maximum of 2 prescribed SC injections in any 24 hour period without consulting the patient's own GP/ Non-medical prescriber. If symptoms persist, they must consult with the patient's own GP/ specialist palliative care doctor or nurse or community nurse. This could be 2 doses of the same or different drugs.
- In addition, once an injection(s) has been given, the carer must ensure that the patient has a review by their community nurse team within the next 24hrs.
- All carers will be provided with a sharps bin and taught the correct technique for sharps disposal. Carers will be informed of the steps to take in case of needle stick injury according to local protocol. All carers will also be informed about how to safely dispose of unwanted/ used medicines and how medicines should best be stored in the patient's home.



- All adverse incidents and significant untoward events are to be reported by normal reporting arrangements and communicated to all involved in the patient's care.

### **Carers must:**

- Be trained and assessed as competent and understands the boundaries of their own competence. This must be documented and retained within the home and patients clinical records.
- Be provided with written information for each drug including the name, dose, indication, likely undesirable effects (**including how to manage them**), the time before a repeat dose is permitted and maximum number of injections over 24 hours (Appx B)
- Have a risk assessment form (Appx C) and a training checklist completed by the assessing nurse or doctor/consultant (Appx D) **for each carer**. A copy of this together with the consent form will be attached to the patients' clinical record as well as a copy to be left in the patients' home.
- Be provided with an information leaflet (Appx E).
- Agree with the healthcare team and the patient, (where feasible) to work within a joint approach for the delivery of SC injectable medication as prescribed.
- Keep a record of all injections given including date, time, drug strength, formulation and dose and name of person giving the injection using the Community Palliative Care Drug Administration Chart.
- Be provided with contact telephone numbers for both in and out of hours support.

### **Criteria for Suitability**

- Patients with unpredictable symptoms where 'as needed' injections maybe required.
- Patients who have been referred to the community nurse team.
- **Patients who may require a stat dose of a medication in the event of an anticipated emergency, for example, seizure.**
- Patients who would like the appropriate carer to undertake the procedure.

The decision for a carer(s) to administer 'as needed' SC injections in a community setting must be agreed prior to discussions with patient and/ or family/ carer(s), by a minimum of 2 multidisciplinary team members, which includes either the patient's own GP or palliative care doctor in liaison with a member of the nursing team who will be supporting the carer.

- The willingness and capability of the carer to undertake the procedure must be ascertained.
- The carer(s) must be over the age of 18 years.

**The carer will only be allowed to administer a maximum of 2 prescribed SC injections in any 24 hour period without consulting the patient's own Hospice professional or GP.**

A consent for the shared care of injectable medications to be agreed (Appendix A) and signed by the patient (where possible), the named carer and the Registered Nurse. The agreement must be reviewed if the patients end of life care plan changes or if the carer indicates they do not wish to continue.

**This shared care excludes:**

- Situations where there is concern that the carer will not be able to cope physically/ psychologically with undertaking the procedure.
- This procedure **MUST NOT** be undertaken by any family members/ carer with a known history of substance misuse or where there is someone known to misuse substances who has access to the house.
- Situations where the family member/ carer lacks the mental capacity to undertake this role in accordance with the Mental Capacity Act 2005.
- Situations where there is a safeguarding concern about the family member/carers.



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**APPENDIX A**

**Record of consent**

**Carer administration of subcutaneous injectable medicine**

**CARER CONSENT**

I have been fully informed about my role in administering subcutaneous medicines and I am happy to participate in this role as a carer to:

Patient name ..... Date of birth .....  
 NHS number .....

I have been taught the procedure and shown the associated documentation and I have been observed in administering a dose of medication (or of sterile water).  
 I feel confident to proceed with this delegated task in knowledge that I have contact numbers for support and can relinquish the role at any time.

I will inform the community nursing team/ GP/ hospice team if I have given 2 injections and I am not expecting a visit from a health care professional within the next 24 hours.

Carer signature.....

Print name .....Date.....

**PATIENT CONSENT (witnessed by assessing senior nurse or doctor)**

I have been fully informed about my carer's role in administering subcutaneous medicines and I am happy for them to participate in this role as my carer	Patient signature, name and date .....
<b>Or</b> the patient is unable to sign but has indicated their consent (e.g. verbally)	Health professional signature, name, date .....
<b>Or</b> the patient lacks capacity to participate in this decision but carer administration is in their best interests. (A copy of the Best Interest Meeting notes are to be included within the records, to include date, time and those present)	Health professional signature x2, name, date ..... ..... ..... .....

**HEALTH PROFESSIONAL**

I have assessed the carer as competent to participate in this procedure after:

- discussing the risks and benefits, as identified in the procedure
- working through the procedure checklist in the patient/carers information leaflet with the carer
- checking that the prescriber agrees to the use of the carer administration process
- observing the carer giving a test dose of medication (or sterile water).

Date	Time	Signature	Name	Role

### INFORMATION ABOUT MEDICATION FOR CARERS

NAME OF DRUG	INDICATION FOR USE	POSSIBLE SIDE EFFECTS
Morphine Sulphate	PAIN, BREATHLESSNESS, SEVERE COUGH	Nausea, vomiting, constipation, dry mouth
Oxycodone Hydrochloride	PAIN, BREATHLESSNESS, SEVERE COUGH	Nausea, vomiting, constipation, diarrhoea, dry mouth
Metoclopramide	NAUSEA, VOMITING	Headache, confusion, twitching arms, legs, face
Levomepromazine	NAUSEA, VOMITING, RESTLESSNESS, DISTRESS	Drowsiness, dry mouth
Cyclizine	NAUSEA, VOMITING	Drowsiness, dry mouth, blurred vision, insomnia
Haloperidol	NAUSEA, VOMITING, RESTLESSNESS, DISTRESS	Constipation, diarrhoea, drowsiness, dizziness, dry mouth
Midazolam	ANXIETY, BREATHLESSNESS, RESTLESSNESS	Blurred vision, drowsiness, dizziness, headache
Hyoscine Butylbromide	NOISY BREATHING	Dry mouth, constipation, blurred vision, dry skin

**APPENDIX C**

**RISK ASSESSMENT TEMPLATE**

Patient's Name:

NHS Number:

DOB:

Assessor's Name ..... Role .....

Injectable medication given by informal carer.....

Date completed: .....

Hazard	Who might be harmed	Likelihood/5	Consequences/5	Risk Score	Control Measures	Further action
Wrong drug given	Patient (and carer emotionally)				Assessment of carer competence undertaken before giving medication by the carer. Assessment repeated until carer feels confident. Written information (Drug Administration Chart) in home with drug name and doses. Telephone advice available for 24 hour support.	
Wrong dose given	Patient (and carer emotionally)				Assessment of carer competence undertaken before giving medication by carer. Assessment repeated until carer feels confident. Written information (Drug Administration Chart) in home with drug name and doses. Telephone advice available for 24 hour support.	

<p>Carer distress - Carer may feel burdened by needing to give injections, may feel distressed if has to give injections close to end of life</p>	<p>Carer</p>				<p>Discuss this openly with carer and patient. Provide ongoing support at appropriate level for carer. Telephone advice available for 24 hour support.</p>	

Signed..... Name..... Date.....

Agreed by ..... Role ..... Date .....

Date for Review .....

## APPENDIX D

# Checklist for Palliative Care Nurse to Train Informal Carer to Administer as Needed Subcutaneous Medication at Patient's Home.

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**Patient Name**

**Address**

**DOB**

**NHS number**

Date of checklist completion:

Name and role of nurse providing training:

Name of informal carer receiving training and support:

This assessment form should be completed by the carer and assessor together for each episode of supervised practice.

	Y/N	Initial Carer	Assessor
Check that medication, dose and vial size, frequency and maximum dose in 24hrs has been agreed at MDT			
Ensure all 'just in case' medication is prescribed specifically as agreed			
Explain medication <ul style="list-style-type: none"> <li>• Use</li> <li>• Side effects</li> <li>• Dose/ route/ frequency</li> </ul>			
Provide contact details and support.			
Ensure carer understands the patient can refuse medication, and in this event must be supported in this decision.			
Ensure carer is aware to contact specialist palliative care for support if required before proceeding to give an injection.			
Ensure the carer is clear about the circumstances in which they must refer back to specialist palliative care			
Provide an equipment pack and ensure there is labelled plastic boxes for carer medication with separate boxes for community nurse 'just in case' medication			

For the use of the training nurse, tick each box as relevant

Carer understands all prescribed medicines			
Carer understands all equipment supplied			
Carer can demonstrate checking records			
Carer can demonstrate checking prescription			
Carer can demonstrate checking ampoules and 'water for injection' (if required) for correct medication and expiry dates			
Carer understands how to check the subcutaneous site for pain, discomfort, swelling, hard lumps, redness, leakage of fluid and bleeding			
Carer understands the need to phone the advice line before administration if concerned			
Carer understands 'the last injection' explanation			
Carer can demonstrate effective hand washing and drying			
Carer understands a no touch technique			
Carer can demonstrate systematic following of guidelines for preparation for administration			
Carer can demonstrate systematic following of guidelines for drawing up solution medication			
Carer can demonstrate systematic following of guidelines for drawing up flush			
Carer can understand the need to fully expose a cannula			
Carer can understand the use of a needle free access device			
Carer can understand the need to clean a needle free access device			
Carer can understand the need to wait for 30 seconds for alcohol to dry			
Carer can demonstrate systematic following of guidelines for administering medication			
Carer can demonstrate systematic following of guidelines for administering a flush			

Carer can understand the need to flush the cannula after administration			
Carer can demonstrate systematic following of all guidelines for disposing of equipment			
Carer can understand the need to dispose of any unused drug			
Carer can understand the equipment that must be disposed in a yellow sharps bin and what equipment can be disposed of in a household bin			
Carer can demonstrate systematically following guidelines for after administration			
Carer can understand the need to record the exact time medication given			
Carer can understand the need to maintain a stock balance			
Carer can understand the need to phone the advice line if needed			

All stages above need to be met to meet competence.

Person assessing competence

..... (Name of carer) is competent to undertake a subcutaneous injection via an injection or injection line.

Signature ..... Role .....

Date ..... Date Reassessment Due .....

**\*\*Please keep a copy of this assessment in the patient's notes\*\***

As patients become more unwell they often lose the ability to swallow oral medication or liquids. General pain relief and symptom control can often be managed via a small pump called a syringe driver. This is managed by the community nurses and gives the patient a regular amount of medication.

However, at times patients may experience increased pain or troublesome symptoms that require extra medication often by a small injection. This can occur at any time of the day or night. Sometimes family members or informal carers may wish to be taught how to give these injections to ensure comfort and the control of pain and other symptoms. This is similar to when you gave oral pain relief/ other oral medication but just the route of giving has changed as the patient is no longer able to swallow.

In addition there may be other occasions when injections are prescribed such as if patients are suffering with nausea/ vomiting, not tolerating oral medications or requiring injections without being on a syringe driver.

The doctors and nurses will support you in this task and teach you how it is done. You do not have to do these injections unless you want to and feel comfortable.

**If at any time you feel you can no longer do these injections or feel concerned, please speak to the nurse or doctor: community nurses can take over this role.**

### **What you will be taught/ need to know**

1. The nurses will insert a plastic needle (cannula) just under the skin so that when you give the injection you only inject into the device/ line, not into the patient. In certain circumstances carers may be taught to administer direct into the skin but this will be the exception rather than the rule.
2. You will be taught what each medication/ injection is for, how much to give, when to give it and any likely side effects.
3. You will be taught how to draw up the required amount of drug into a syringe and how to give the injection.
4. After giving the drug you will be taught how to flush the device with 0.5ml of water to ensure the entire drug is given to the patient.
5. You will be shown how to record each injection given.

6. You will be advised to only give up to a maximum of 2 injections in any 24 hour period before contacting a doctor/ nurse for further help in any one day.
7. At each visit by a healthcare professional, the patient's regular medication will be reviewed so that hopefully further injections may not be needed.

### **Steps involved in administering injection:**

1. Wash and dry your hands thoroughly.
2. Check the drug administration sheet for the time the last dose was given and the total number of doses given in the last 24 hours; making sure it is ok to give an injection.
3. Check the site of the injection device for inflammation, redness, hardness or soreness. If any concerns with this or any problems in administering injections please contact community nurse team.
4. Assemble equipment:
  - Needle and Syringe
  - Drug to be given and sterile water for injection (if required)
5. Drawing up medication:
  - Check the label for correct medication and check expiry date
  - Attach the needle to the syringe
  - Break open the vial of the drug to be given by snapping the top off
  - Draw up the drug into the 1<sup>st</sup> syringe and draw up water for injection to flush into the 2<sup>nd</sup> syringe (if required)
  - If you have an air bubble in the syringe, with needle pointing up, push the plunger in slightly to remove the bubble – do not worry about small bubbles
6. Administer the drug via the injection site device/ line, or directly into the skin, as previously taught.
7. Flush injection site device/line with 0.5ml of water
8. Dispose of the vial, syringe and needle in the sharps bin provided.
9. Write on the drug administration sheet the time, date, drug, dose, route and sign to record you have given it.
10. Wash your hands thoroughly.
11. If you have given 2 injections in a 24 hour period, contact your doctor/nurse before giving a further injection. If you are not expecting a visit from your community nursing team in the next 24 hours, then you must ring the District Nurses and inform them you have given injection(s) so they can plan a visit within 24 hours to review further.

### **Needle stick injuries:**

If you accidentally stab your finger with a needle, encourage it to bleed a little with gentle pressure, then wash it under the cold tap and apply a plaster. Then phone 111 for further advice.

It is extremely difficult to accidentally inject yourself with medication – but if this were to happen, phone 999 and ask for the ambulance service.

### **Important points to remember**

1. If in any doubt, need advice, support or help then please contact either:

Local Hospice contact number.....  
District Nurses (08.30-22.30hrs) .....  
Night Nursing Team (10pm-8am) .....  
Your GP surgery .....  
Out of Hours – 111  
They will be happy to help / advise.

2. Patients experience symptoms or pain at any time during their illness and even at the end of their life. It may be that a prescribed injection you give to ease their discomfort comes close to the end of their life. This is quite normal and does not mean that the injection was in any way a cause of the end of the patient's life/ death. It is purely to help reduce pain or ease other symptoms and maintain comfort and a good dignified death.

3. If you are unsure whether to give an injection please phone your local hospice for advice and support.

4. Please do not hesitate to ask a healthcare professional any question that will enable you to care for the patient and allow them to remain comfortable.

5. If you have given an injection and are not expecting a visit by a healthcare professional in the next 24 hours then please ring (.....) and inform your community nursing team that an injection has been given.



## **Giving subcutaneous medication at home**

### **A guide for carers in Dorset**