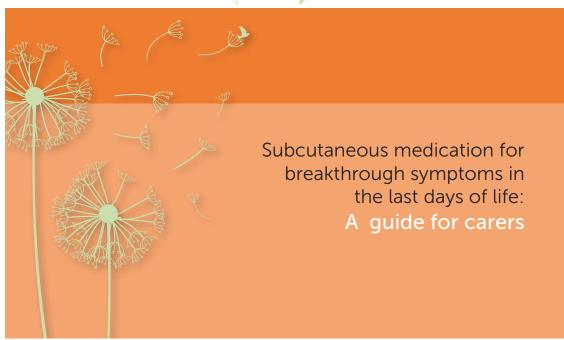
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S'	ymptoms in	home-	-based d	ving r	patients	: the	CARIAD	open r	oilot RCT	-

## Supplementary File 1: Carer materials

'Subcutaneous medication for breakthrough symptoms in the last of	days of life: A
guide for carers'	Page 2 of 108
Carer Diary (Intervention)	Page 31 of 108
Carer Diary (Usual care)	Page 66 of 108
Step-by-step guides	Page 100 of 108
Injection training pack	Page 107 of 108







## **Contents**

		ant information about this booklet uction	
1.	FA	Q – Frequently Asked Questions About Symptom	
		anagement and Subcutaneous Injections	7
Syn	npt	om Management	7
-		What is meant by the term 'symptom management' in the last days of life?	
	b.	Why is it important to keep symptoms well managed?	7
	c.	What is meant by 'as-needed,' 'breakthrough' or 'PRN' medication?	7
	d.	How will I know which medication to give?	8
	e.	How long do I have to wait for the medication to work?	8
	f.	How often can I give as-needed subcutaneous medications for breakthrough symptoms?	
	~	Can I give medication for every symptom that the person I am caring for	9
	g.	experiences?	9
	h.	Can I give unlimited number of doses of medication?	10
	i.	What if I give too much medication?	10
	j.	What are side effects of medication and are they avoidable? What do I do if	10
	l,	they happen?  Can the medications I am giving cause serious harm to the person	10
	к.	· · · · · · · · · · · · · · · · · · ·	11
		I am looking after or make them die more quickly?	11
Sub	cut	aneous Cannula	12
	a.	What is a subcutaneous cannula and why is it used?	12
	b.	What is a subcutaneous injection and why is it used?	12
	c.	Where is a subcutaneous cannula inserted?	13
	d.	How do I care for the cannula?	13
	e.	How will I know if the cannula is not working? What should I do if	
	thi	s happens?	14
Sub	cut	aneous Injections	15
		What is meant by 'continuous medication(s)'?	
		What is meant by 'as-needed' medication(s)'?	
		How do I give as-needed no-needle injections into a subcutaneous cannula?.	

2. Pain Management       18         Overview of pain management
3. Information About Other Common Symptoms21Overview of Common Symptoms21Symptom Management: Commonly Used Subcutaneous Medications23
4. Problems you might encounter
Documentation Forms and Instruction Guides

## Important information about this booklet

The content of this booklet is intended as a guide for a carer to assist in their understanding of as-needed subcutaneous medications commonly given to people being cared for at home in the last days of life.

The information was adapted from the Brisbane South Palliative Care Collaborative Caring Safely at Home booklet entitled 'Subcutaneous Medications and Palliative Care: A guide for caregivers' and is presented by the research team for the purpose of the CARIAD trial. It should only be used for the purpose for which it has been supplied. It is only to be used in conjunction with thorough training from local healthcare teams and does not replace usual care.

While the CARiAD team has exercised due care in ensuring the accuracy of the material contained in the booklet, the booklet is a general guide only to appropriate practice, to be followed subject to the healthcare team's judgement and the carer's preference in each individual case.

If you are unhappy or dissatisfied about any aspect of your participation in the CARiAD trial, please contact the trial team about this in the first instance, so that we can try to resolve any concerns and find a solution. Regardless of this, if you wish to make a complaint about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints procedures will be available to you. If you would like independent support with these procedures please contact:

**For participants in Wales** contact the Community Health Councils Complaints Advocacy Service on 02920 235 558.

**For participants in England** contact NHS England on 0300 311 22 33 and ask for your local Patient Advice and Liaison Service (PALS).

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#### Introduction

Palliative care is care provided for people of all ages who have a life limiting illness, with little or no prospect of cure, when the primary treatment goal is improved quality of life. During the palliative phase, care is focussed on promoting the person's comfort by keeping symptoms under control as much as possible with medication, and trying to fulfil wishes the person may have expressed about their death. For many people, this includes being cared for and dying at home. The likelihood of a person being able to remain at home during this phase is often dependent on the availability of carers beyond the healthcare team — usually a close family member or friend. These carers often take on the responsibility of managing the person's medications, as well as helping with self-care.

As people get weaker in the last weeks or days of life, they usually cannot swallow and are no longer able to take medications by mouth. In the UK, when this happens, it is standard practice for medications to be given under the skin to relieve symptoms. This is sometimes called **subcutaneous medication** (subcutaneous means "under the skin") and can be done using a needle or a **cannula**. A cannula is a small plastic tube which is placed under the skin. Unlike needles, which are used separately each time a medication is needed, a cannula can be kept in for several days. If a person is on regular medications, a syringe driver or pump is often connected to the cannula to give medications continuously throughout the day and night to keep symptoms controlled.

The person may still experience some symptoms even when this is in place – these are called 'breakthrough' symptoms they may require extra as-needed doses of medication to be given. The most common breakthrough symptoms are pain, agitation, nausea and noisy breathing (rattle). When the person experiences breakthrough symptoms, the carer is usually advised to call the healthcare team, often a district nurse. They will visit and give the patient as-needed subcutaneous medication (medicine under the skin using a needle or a cannula that is in place). But, it can take a long time, often much more than an hour, for the healthcare team to arrive and give the as-needed medication. This wait can be distressing for patient and carer and the symptom can worsen during this time. Carers tell us that this makes them feel powerless to help the person they are caring for.

You have been given this booklet as one part of an education package that has been developed to train carers like yourself to be able to give these as-needed medications, using a cannula that is already in place. This means you do not need to use needles to give the medications – they are often called **no-needle injections.** 

Using this education package, you will be trained how to recognise breakthrough symptoms described above. You will learn how to prepare and give no-needle injections. You'll learn to how to see if they work to relieve the symptom, and what to do next if they do not. This booklet forms part of the training that the nurse will give you, and explains common symptoms in the last days of someone's life and how this could be treated with subcutaneous medication.

The person you are caring for will receive all their regular healthcare visits and medication as normal. The only thing that will change is that you will be trained to give as-needed medication for breakthrough symptoms. It is important to know that it is completely legal for carers to give symptom-relieving medications to dying patients as long as they are supported to do so. Even after you have been trained to give injections, you do not have to give it if you do not feel confident to do so. If you are in doubt if an injection is needed, you can, at any time, call the healthcare team looking after the person you are caring for at home.

Managing symptoms in the last days of life can sometimes be challenging. However, understanding the medications that are commonly used will help you identify the correct medication to give to control a particular symptom. To manage symptoms successfully it is essential that you talk with the healthcare team and let them know when symptoms are becoming bothersome or difficult to manage.

If you need any more detail on any aspect of caring for someone dying at home, please talk to the healthcare team supporting you at home.

#### The booklet is divided into four main sections:

- 1. Frequently Asked Questions About Symptom Management and Subcutaneous Injections
- 2. Pain Management
- 3. Information About Other Common Symptoms
- 4. Problems you might encounter

# 1. FAQ – Frequently Asked Questions About Symptom Management and Subcutaneous Injections

#### **Symptom Management**

a. What is meant by the term 'symptom management' in the last days of life? Symptom management in the last days of life refers to care given to treat unwanted experiences, such as pain or nausea, sometimes associated with the dying phase. Symptom management includes many different types of care that can range from simple things such as changes in position, to needing extra medications. This booklet only considers the use of as-needed subcutaneous injections for symptom management of four common symptoms in dying people: pain, agitation, nausea/vomiting and noisy breathing (rattle).

#### b. Why is it important to keep symptoms well managed?

Symptoms can be distressing for people and decrease their quality of life. This is why we try to keep them well managed. People who have expressed a wish to be cared for and die at home may be less likely to have unplanned admissions to hospital or hospice if their symptoms are well managed.

If pain or other symptoms that cause discomfort are allowed to build up, they can become much harder to control than if steps are taken to manage them at the first sign of their appearance – this is what good symptom management is all about.

c. What is meant by 'as-needed,' 'breakthrough' or 'PRN' medication? Symptoms are often controlled with medications given at regular times, or continuously through a syringe pump, throughout the day and night. Sometimes, however, the person may experience some symptoms even when this is in place – these are called 'breakthrough' symptoms and the most common ones are pain, agitation, nausea/ vomiting and noisy breathing (rattle).

Dealing with the breakthrough symptom may require giving an extra dose of medication, often called 'as-needed,' 'breakthrough' or 'PRN' medication. Such medications will be prescribed by the healthcare team.

Symptoms in people in the last days of their life can appear very quickly. We prepare for this by reviewing the person regularly to see what changes in medications or

other treatment may be needed. Sometimes we can predict what may occur (like the common symptoms of pain, agitation, nausea/vomiting and noisy breathing) and have plans in place in case it actually does occur. This is why 'as-needed,' 'breakthrough' or 'PRN' medications are prescribed in advance. This is known as anticipatory prescribing and sometimes called 'just in case' medications. This medication should be given at the first sign of an unwanted symptom, before it has a chance to build up, remembering that medications can take up to 20 minutes to take effect.

#### d. How will I know which medication to give?

If a person cared for at home is on any continuous or as-needed subcutaneous medication, this will be clearly prescribed on a medication chart which is left in the house. Usually, only members of the healthcare team will record on this, for example when a syringe driver or pump is reloaded or they have given any as-needed injections.

For the CARiAD study, the healthcare team will still prescribe on this medication chart and leave it in the house. Then, the nurse training you will give you further information that will help you understand more detail about the medication(s). This will help you to be able to give the best medication at the right time for a particular symptom. The nurse will write these detailed instructions in the Carer Diary so that you can check this every time you think an injection is needed. This will remind you exactly what medications to give, how much to give and how often you can give them.

The nurse will show you how to complete the details of any medication you have given in your Carer Diary. A member of the visiting healthcare team will check the Carer Diary with you at every visit and carry over parts of the information to complete the medication chart: they will write the medication details and time given, and note that you have given it.

All carers who have been trained to give as-needed subcutaneous medications to the person they are caring for will need to complete the Carer Diary. Even if you decide you do not want to give the injection yourself, there is space to record what happens each time the person you are caring for experiences breakthrough symptoms. Some carers may feel that they want to complete both the Carer Diary page and enter the additional information into the formal medication chart (usually completed by the healthcare team). Your nurse will discuss this with you and agree the best plan for you. Even if you decide you do not want to give the as-needed medication yourself you should still complete the Carer Diary and indicate that you called the healthcare team to do this.

#### e. How long do I have to wait for the medication to work?

You should check the patient after 30 minutes to see whether the symptom is getting better after giving an injection (and record this in the Carer Diary), but it may take up

to one hour to be sure if it has helped or not. If, in that hour, the symptom for which you have given the injection is getting worse, not getting any better at all, or if you are worried for any reason, call your healthcare team straight away. It is likely that a doctor or nurse will want to come and visit the person you are caring for to see why the medication is not working.

## f. How often can I give as-needed subcutaneous medications for breakthrough symptoms?

Most of the medications that you will be shown how to use for breakthrough symptoms should not be given more than once every four hours.

The as-needed medication for pain can sometimes be used slightly differently. If the first no-needle injection does not reduce the person's pain enough within the first hour after it has been given, you may be allowed to give the next dose early instead of having to wait for four hours to pass. This might mean that you are given permission to give an extra dose of as-needed medication for pain one hour after the previous dose if this has not worked. If you need to give this extra dose, you should inform your healthcare team straight away. The doctor or nurse may wish to come to visit the person you are caring for.

Being allowed to give an extra dose after one hour may not be the best course of action for everyone so the decision will be made by your healthcare team who will discuss this with you.

## g. Can I give medication for every symptom that the person I am caring for experiences?

No, you will not be able to give no-needle injections for every possible symptom that someone might experience in the last days of life. There are several reasons for this. Firstly, as we are testing the practice of training carers to give as-needed medications by no-needle injection it makes sense to do this in a careful and focussed way. Therefore, the CARiAD study is focussing on four common symptoms that may happen in the last days of life. These are pain, agitation, nausea/vomiting and noisy breathing (rattle). Because they are very common symptoms we already know a lot about how these symptoms might look in patients and which drugs are the best to use.

We know that some less common symptoms may also need medication via subcutaneous injection, for example breathlessness or seizures. If the person you are caring for experiences these symptoms, you will be asked to call the healthcare team to give an injection. As part of the CARiAD study, you should not give injections for any other reason than pain, agitation, nausea/vomiting and noisy breathing (rattle).

The second reason that you will not be able to give injections for all symptoms is that not all unwanted experiences or symptoms in the last days of life are best dealt with giving an injection. An example of this is itching where the use of skin creams would be used instead of a no-needle injection.

It is also important to remember that you can only give medications for breakthrough symptoms whilst the person you are caring for is receiving care in their own home (or usual place of residence). If the person is admitted to an inpatient unit, including a hospital or hospice, the medical team will be responsible for their medications and you should not give any medications yourself.

#### h. Can I give unlimited number of doses of medication?

No, you cannot give more than three (3) doses of medication for the same symptom in any 24 hour period. The reason for this is that, if someone needs frequent as-needed medication, the symptom might not be controlled well enough and a doctor or nurse should see the patient. They can then assess the person and the regular medication they are receiving to see if this needs to be changed to help control the symptoms. After you have given three doses of medication for the same symptom in less than 24 hours, you will need to let your healthcare team know straight away so that they can come to review the person you are caring for. You should not wait until the next dose is needed.

#### i. What if I give too much medication?

If you think you have made an error with the amount of drug you have given or you have given too many doses, you should contact your healthcare team straight away and make them aware of this. If you think you have given the correct doses but the person you are caring for is having unusual symptoms or you are concerned about their response to a no-needle injection, you should contact the healthcare team.

## j. What are side effects of medication and are they avoidable? What do I do if they happen?

Medications are given to help control symptoms and keep the person you are caring for as comfortable as possible, but they may also cause unwanted effects (also known as adverse or side effects). Your healthcare team will always consider the symptoms a person is experiencing and weigh up the benefit of a medication compared to the risk of side effects. The goal is to get the right dose of a medication to treat the symptoms, whilst keeping the side effects as low as possible. This is why it is important to closely follow the instructions given by the healthcare team on how much medication to give, as it may be different for different people. If side effects do happen, you should let the healthcare team know as soon as possible. Side effects vary for different medications, but can include experiences such as drowsiness, muddled thinking or constipation.

It is important to know what the possible side effects of the medications used by a person might be. If you understand them, you can manage the side effects if they happen. You will find more detail on side effects of commonly used medication later on in this booklet. If the person you are caring for is prescribed a medication for you to give by no-needle injection that is not listed in this booklet, the nurse who are training you will add details about any of its potential side effects to your Carer Diary.

## k. Can the medications I am giving cause serious harm to the person I am looking after or make them die more quickly?

We do not expect any problems with the drugs that will be used in this trial because they are the same as those used in standard practice and are generally well-tolerated. The drugs used are very commonly given to seriously ill patients to control symptoms and a nurse will give you very detailed training on how to give the no-needle injections.

There may come a time when you are giving the injections when the person you are caring for is very ill and will soon die. This might mean that the time when they die is near to when you have last given them medication. It is very important for you to know that these two things are not related and the medication has not ended their life. The nurse training you to give injections will discuss any worries or concerns you may have about this.

#### **Subcutaneous Cannula**

#### a. What is a subcutaneous cannula and why is it used?

People who are seriously ill and nearing the end of their life may find it difficult to take medications by mouth – either because they are experiencing nausea or vomiting or because they are becoming too weak to swallow. In the UK, when this happens, it is usual practice for a cannula to be put in – this is a small plastic tube placed under the skin designed to carry medication into a person's body. The cannula is sometimes called a 'Saf-T-Intima' by nurses.

One end, inserted by a registered nurse, sits just under the person's skin. The other end divides into two parts and is shaped like a Y. One part of the Y-arm can be connected to a syringe driver or pump; the other can be used for subcutaneous injections (See figure 1).

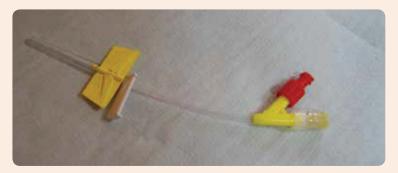


Fig. 1 Saf-T-Intima cannula

The nurse will usually insert a second cannula in a different part of the body. This allows for back up in case the original cannula stops working. This can be especially useful if the original cannula stops working at night when nurses are not readily available.

The healthcare team will check the cannula most days and change it on a regular basis.

#### b. What is a subcutaneous injection and why is it used?

Subcutaneous means 'just under the skin'. So, a subcutaneous injection means giving an injection just under the skin. There is a good blood supply under the skin and this carries the drug into the rest of the body. Subcutaneous injections are normally less painful than an injection into the muscle and are easier to give than an intravenous (in the vein) or intramuscular (in the muscle) injection. When a cannula is in place, subcutaneous medication can be given without the use of needles.

The subcutaneous method is a safe and effective way of giving medications, especially when a person is experiencing swallowing problems or has nausea and/or vomiting.

#### c. Where is a subcutaneous cannula inserted?

The cannula can be inserted into the person's abdomen (tummy) or chest, upper thigh or upper arm. If the person is confused or muddle and is likely to remove the cannula, it can be placed in the upper back.

The nurse will secure the cannula to the person's body (see figure 2) using clear film, so that you can see the insertion site. This allows you and the healthcare team to check the site regularly.



Fig. 2 Saf-T-Intima cannula inserted in the top of the arm

#### d. How do I care for the cannula?

Caring for a cannula is quite easy. You will need to check the insertion site every time you give a no-needle injection using the cannula. If you notice that the cannula site is red, swollen, leaking or smelly, contact your healthcare team as it is likely the cannula will be need to be changed (see figure 3).



Fig 3. Redness at the cannula site

e. How will I know if the cannula is not working? What should I do if this happens? It is normal for a small lump to appear at the insertion site immediately after the injection has been given. This is the medication sitting in the tissue just under the skin. The small lump will disappear as the medication is absorbed into the bloodstream. If it does not, contact your healthcare team.

If it is hard to inject medications or if the medications leak out onto the skin when you inject, then contact your healthcare team as this means the cannula is no longer working. Leave the cannula in place for them to remove. In the meantime, if there is a second cannula, this can be used until the other cannula is changed.

#### **Subcutaneous Injections**

Commonly used palliative care medications can either be given as a continuous infusion over 24 hours or as-needed using subcutaneous injections.

#### a. What is meant by 'continuous medication(s)'?

Continuous medication(s) refers to the giving of medications that enter the bloodstream slowly and continuously throughout the day. Continuous medication(s) are usually given via a syringe driver or pump, which is a portable, battery-operated machine (See figure 4).



Fig. 4 Syringe pump mechanism for continuous medications (no syringe attached)

The syringe driver or pump may be attached to a subcutaneous cannula. Once the cannula has been inserted the person should not experience any discomfort from it.

A nurse will reload the syringe driver or pump regularly and may sometimes change the combination of drugs or the dose of medications in the syringe, after discussion with the prescriber. This may need to occur if the person is experiencing ongoing and increasingly unpleasant symptoms, has required an increase in the number of breakthrough medications daily or has been generally unsettled. It sometimes takes a few days to get the right dose(s) and combination of medication(s).

#### b. What is meant by 'as-needed' medication(s)'?

'As-needed medication(s)' refers to medication given occasionally through the day. Intermittent medication(s) can be given by subcutaneous injection either for one-off symptom management or for more regular breakthrough symptom management. So breakthrough medication is a type of intermittent medication, and, as mentioned earlier is used to control a symptom that has re-occurred in spite of regular medication.

c. How do I give as-needed no-needle injections into a subcutaneous cannula? There are a number of options for how to give the no-needle injections. Which

technique you need to use will depend on the as-needed medication that you are giving and the type of container the medication is stored in.

Your nurse will give you personalised training so that you know how to give the asneeded no-needle injections that have been prescribed for the person you are caring for. There are step-by-step guides which give detailed information for each of these different techniques and you should refer to these each time you give a no-needle injection.

The nurse will show you how to prepare the no-needle injection by drawing up the medication. The carer diary will tell you how much liquid (the volume) you will need to draw up into the syringe for the correct dose. This may be different for different medications so check the personalised information in your carer diary carefully.

There are two options available when giving an injection into a subcutaneous cannula; your nurse will explain which one you will use.

#### Option 1

Firstly, remove the blunt drawing up needle from the syringe. Then give the injection by connecting the syringe to the port on the Y-arm using a twisting or screwing motion until the syringe is securely attached, as shown in figure 5. Then slowly push the plunger to give the medication. Once the medication has been given you can remove the syringe by unscrewing the syringe in the opposite direction.



Fig. 5 Injecting using the no-needle technique

#### Option 2

The other side of the Y-arm, which has a white rim or similar (your nurse will advise you), is topped with a special membrane with a slit in it so you can choose to inject the medication straight into this opening without removing the cap using a short blunt needle (see figure 6). Then slowly push the plunger to give the medication.



Fig. 6 Injecting using the blunt needle technique

For further instructions contact your healthcare team or refer to the step-by-step guides in your training pack.

### 2. Pain Management

#### **Overview of pain management**

Pain is often the most feared symptom in the last days of life. Pain management can be simple or complex, according to its cause. Do not ignore pain, as that may only make it harder to manage. Some types of pain are more difficult to manage than others. That is why it is important to talk with the healthcare team, letting them know whether the medication has worked well or not.

When managing pain it helps to have a record about the type of pain that the person experiences (for example what words the person uses to describe it), and when it occurs, and then discuss this with the healthcare team when they next visit. The healthcare team will check the Carer Diary you will be keeping as part of the study that records the medications you have given since their last visit. This will help them to decide if medications need to be changed.

There are many different types of medications that can be used to manage pain, but we will only concentrate on the medication that are commonly given as subcutaneous noneedle injections for people in the last days of life. Choosing the right drug to control pain can sometimes be difficult. Your healthcare team will consider all options and choose the medication that is best suited to the person's individual pain.

There are many types of medications, so there is usually something that will keep the person you are caring for comfortable. Strong pain medications such as **opioids** are often used to manage pain.

Table 1 outlines some of the commonly used opioids given subcutaneously, that help with pain control.

The healthcare team will make every effort to keep the person as comfortable as possible, though it may take some adjustment to get the medication right.

All strong pain medications have side effects that can usually be managed. Nausea/vomiting, drowsiness or poor concentration and itchy skin typically only lasts for a short while after the person first starts to use strong pain medications. Constipation can be managed by taking laxatives regularly as long as the person you are caring for is still able to take medication by mouth.

Dry mouth is common too and can be a side effect of several other medications. If the person is still able to swallow safely, offer sips of water. Otherwise, try to increase their comfort by moistening the mouth (using a damp sponge) or applying lip salve.

Less common side effects, which, if experienced should be reported immediately to the person's healthcare team include:

- Decreased breathing rate;
- Jerking of limbs;
- Confusion.

#### Common myths and misconceptions about strong pain medications

Addiction can occur when a person takes strong pain medications like morphine for recreational purposes. There is a misconception that when people have pain and need to use opioids that they too, can become addicted. This concern can lead to underusage of strong pain medications and can lead to loss of pain control. Concern about physical or psychological dependence is never a reason to delay giving an opioid if it is required.

It is true that a person's tolerance to a particular drug may increase and more medication may be needed as the illness progresses. This is quite normal but if you are concerned you should speak to the healthcare team of the person you are caring for. The healthcare team may alter the dose from time to time to ensure that the person remains as comfortable as possible.

#### **Commonly Used Opioids for Subcutaneous Injection**

Table 1 – Subcutaneous Pain Medication

Name of drug	What is it used for?	How long does it take to work after subcutaneous injection?	Common side effects
Morphine Sulphate (Morphine)	• Pain	20 minutes to take effect and peaks around 30-60 minutes.	<ul> <li>constipation</li> <li>nausea and vomiting*</li> <li>dry mouth</li> <li>itchy skin*</li> <li>confusion*</li> <li>drowsiness*</li> <li>*usually temporary</li> </ul>
Oxycodone Hydrochloride (Oxycodone)	• Pain	20 minutes to take effect and peaks around 30-60 minutes	See above
Diamorphine	• Pain	20 minutes to take effect and peaks around 30-60 minutes	See above

Check instructions left for you by the healthcare team. They will explain to you how often the medication can be given.

You may be given permission to give an extra dose of as-needed medication for pain one hour after the previous dose if this has not worked. If you give this extra dose, you should inform your healthcare team straight away. The doctor or nurse may wish to come to visit the person you are caring for.

Being allowed to give an extra dose after one hour may not be the best course of action for everyone so the decision will be made by your healthcare team who will discuss this with you.

## 3. Information About Other Common Symptoms

#### **Overview of Common Symptoms**

The information provided in this section is a guide to other symptoms which you may be trained to give as-needed medication for. It aims to provide information about what to expect, simple suggestions that can ease the symptoms and outlines subcutaneous medications that can assist with management. For information about other symptoms consult your healthcare team.

#### Agitation

Agitation or restlessness is common, particularly in the last days or hours of life. The person may seem anxious or unsettled, have fidgety movements, make distressed sounds, or have twitching. The person may pick at the bedclothes, or they may moan or call out, or make a noise each time they breathe. This can be distressing for carers to see.

Check to see if the person is experiencing any pain, or anything obvious that may be causing the problem.

You may be able to help reduce the restlessness by simply sitting with the person and reassuring them that they are safe and loved. The healthcare team will be able to help work out whether pain is causing restlessness, and if so, how to treat it. Refer to Table 2 for commonly used subcutaneous medications that your healthcare team may have prescribed.

Anxiety can also make someone look restless. The causes of anxiety may be physical, emotional or a combination of both. If a person becomes anxious it can increase other symptoms such as pain, nausea/vomiting or breathlessness. It is important to recognise if the person you are caring for becomes anxious, so that you can relieve this with the medication that has been prescribed by the healthcare team. Table 2 outlines some of the common subcutaneous medications used for anxiety.

#### Nausea and vomiting

There are many reasons why someone can feel nauseous (sickly) or vomits, including side effects of strong pain medications. Nausea may be experienced with or without vomiting. It may help if the person rests for about one hour after taking strong pain medications.

Nausea and/or vomiting can be treated with medications, given either in a syringe driver or pump or given as breakthrough medication via the cannula or a combination of both. There are several medications that assist with nausea and vomiting – Refer to Table 2 for commonly used subcutaneous medications that your healthcare team may have prescribed.

#### Noisy breathing (rattle)

Towards the end of life a person's breathing may become noisy. This is likely to be because of some fluid collecting at the back of their throat as they are too weak to swallow, which can cause a rattling sound. Noisy breathing does not seem to cause distress to the dying person, but may be upsetting to hear. It may be helpful to change the person's position so that they are lying more onto their side with their head slightly raised. There are medications which may help to reduce noisy breathing. Refer to Table 2 for commonly used subcutaneous medications that your healthcare team may have prescribed.

#### Other symptoms

#### **Breathlessness:**

Some people may experience difficulty with breathing. This may be related to their disease, to anxiety or a combination of both. If this is a new symptom please report it to the healthcare team. Often, shortness of breath can contribute to anxiety.

Some strategies that can help a person with breathing difficulties include:

- Using an electric fan or fanning the person to keep them cool
- Opening a window to allow air to flow through the room;
- Use of relaxation and breathing techniques.

If breathlessness is causing the person discomfort, let your healthcare team know.

#### Itch

Itchiness is common towards the end of life and can be caused by many things such as dry skin, allergy, side effects of medications or the disease itself. If left untreated it may cause the person to become restless or anxious. Applying skin creams that are water-based, especially after a bath will help.

## **Symptom Management: Commonly Used Subcutaneous Medications**

Table 2 – Commonly Used Subcutaneous Medications

Name of drug	What is it used for?	How long does it take to work after subcutaneous injection?	Common side effects
Glycopyrronium	<ul> <li>noisy breathing (rattle / respiratory secretions)</li> </ul>	15-20 minutes; peaks within 45 minutes.	can irritate the skin;     give slowly; your     nurse will guide you     nausea     blurred vision     dry mouth
Hyoscine Hydrobromide	<ul> <li>noisy breathing (rattle / respiratory secretions)</li> </ul>	30 minutes to take full effect and lasts about 4 hours	<ul><li>drowsiness</li><li>dry mouth</li><li>blurred vision</li><li>rash</li><li>agitation</li></ul>
Levomepromazine (Nozinan)	<ul><li>nausea and vomiting</li><li>agitation/ restlessness</li></ul>	60 minutes to take full effect	• drowsiness • rash • dry mouth
Midazolam	• agitation/ restlessness • anxiety	10-15 minutes, short acting.	can irritate the skin;     give slowly; your     nurse will guide you     drowsiness     forgetfulness
Cyclizine	nausea and vomiting	60 minutes to take full effect.	drowsiness     nausea     dry mouth     blurred vision

Check instructions left for you by the healthcare team. They will explain to you how often the medication can be given.

## 4. Problems you might encounter

#### a. What happens if I run out of medications?

This is a problem that can cause worry. However, with some planning you can minimise the likelihood of it occurring. A few suggestions to ensure that you always have enough medication(s) include:

#### Make contact with your local pharmacist.

- Discuss your needs, and the medications you might require from time to time.
- Try to get prescriptions to the pharmacist at least one day before you need them.

#### Check if the pharmacist has an after-hours service.

• If not, ask whether they can give you another contact in case you need supplies out of daytime opening hours.

#### Check your stock of medication before 9am each day

- Make sure you have enough to see you through, especially if a weekend or public holiday is approaching
- Some pharmacies have a home delivery service. Ask your pharmacist.

#### b. What if the ampoule would not open?

Sometimes glass ampoules can be a bit tricky to open.

- Your nurse will provide you with an ampoule opener and show you how it is used.
- Some ampoules have a 'dot' located on the neck of the ampoule. If there is a dot
  on the ampoule this shows where the weak point in the neck is and where the
  ampoule should break. Ensure the dot is facing away from you.
- Hold the ampoule in one hand, place the ampoule opener on to the top of the ampoule using the other hand. With your thumb, push the neck of the ampoule away from you to snap the top off.

#### c. What if the injection is painful when I give it?

Subcutaneous injections can sometimes cause mild discomfort when being given.

- Some medications do sting more than others. Giving the injection slowly can help to minimise the stinging.
- Cold injections can cause pain and irritation. To overcome this, gently rub the
  unopened ampoule between your palms for a couple of seconds. This will warm up
  the solution enough to lessen the stinging.

#### d. What do I do if the injection site is leaking?

Contact your healthcare team if you think that the site is leaking. Do not use the cannula to give injections until a doctor or nurse have visited.

## e. What if I am not available to give a medication when a breakthrough symptom occurs?

Only carers who have been trained directly by the healthcare professionals to give subcutaneous medications should administer these. You should not try to train anyone else to give these medications in your absence. If you are not available or if you don't feel able to give a medication the healthcare professionals should be contacted so they can attend to give the medication.

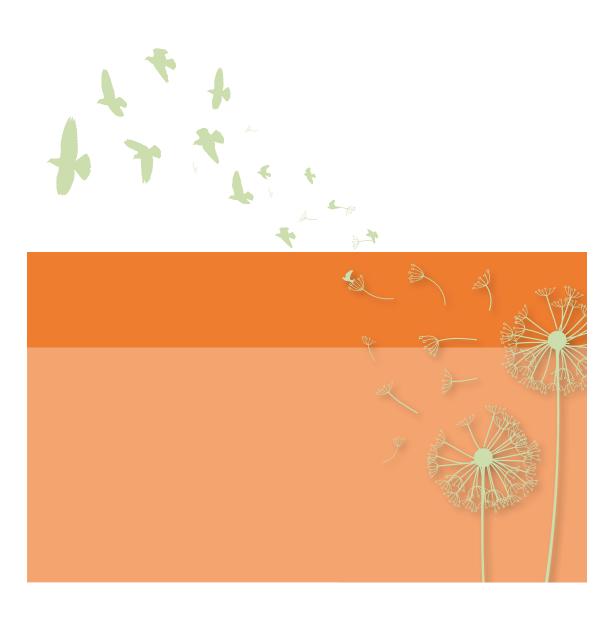
#### **Documentation Forms and Instruction Guides**

In addition to this book, your training pack will include:

- A Carer Diary
- Step-by-step guides

Remember, if you are worried about any aspect of care, please let your healthcare team know. Carer support services are also available, please ask your doctor or nurse about this.

Notes



CARer-ADministration of as-needed subcutaneous medication for breakthrough
symptoms in home-based dying patients: the CARiAD open pilot RCT
Carer Diary (Intervention)











To assist you in your caring role, this diary has been developed specifically to assist you with recording the as-needed subcutaneous medications that are given to the person you are caring for each day. You should complete a page in this diary each time the person you are caring for experiences a breakthrough symptom that requires asneeded subcutaneous medication, even if you do not administer the medication yourself.

This diary has been developed as one part of the education and training package provided to you as part of the CARiAD trial. The diary was adapted from the Brisbane South Palliative Care Collaborative Caring Safely at Home booklet entitled 'Caregiver Daily Medication Diary' and is presented by the research team for the purpose of the CARiAD trial. It should only be used for the purpose for which it has been supplied. It is only to be used in conjunction with thorough training from local healthcare teams and does not replace usual care.

There are instructions on how to use the diary on the following pages and your healthcare team will go through these with you. If you have any further questions please speak to your healthcare team or contact the CARIAD trial research team.

## **Contact Details**

District Nurse Service	
Team	
Named DN	-
(if applicable)	
Contact details	
Working hours	
In hours GP service	
GP Surgery	
Usual GP	
(if applicable)	
Contact details	
Working hours	$\bigcup$
Out of Hours GP Service	
Contact details	
Working hours	
Local Pharmacy	
Name	
Telephone	
Fax/Email	

	Specialist Palliative Care Service
Team	
Named DN (if applicable)	
Contact details	
Working hours	
	Other important contacts
Person or service	
Named Contact (if applicable)	
Contact details	
Working hours	
Person or service	
Contact details	
Working hours	

## **Medical Appointments**

Date	Time	Place	Healthcare professional

# **Caregiver diary instructions**

For **each** medication you give, please complete the following:

Date and time that symptom developed	Write the date (day/month/year) and time that you or the person you are caring for feels that a symptom
(30/11/16)	is developing that is not being controlled by any
8.35 pm	regular medication or previous doses of as-needed medication.
Noted by:	The dicution.
☑ Patient	Tick the box to indicate who noted the symptom
☐ Carer	developing.
Breakthrough symptom	Tick the box which best explains the reason you are giving the medication. Sometimes you may need to
Pain	give different medications, for example one for pain
☑ Nausea/vomiting	and one for nausea. If so, record each on a separate
Agitation	page.
☐ Noisy breathing	
Symptom score before	If possible, ask the person how they would rate their
(0-10)	symptom on a scale of 0-10. 0 is no symptom and 10 indicates the worst that symptom can possibly be.
7	If the person is not able to tell you, you can record
Assessed by:	how bad you think the symptom is in your experience
Patient	of caring for the person. Record the number for the
Carer	symptom. This will help you to see later on if the
	symptom has improved.
	Tick the box to show who rated how bad the symptom was, you or the patient.

#### Write the name of the medication each time you Medication given Name: Tick the box to show if you gave the medication or if a Cyclizine healthcare professional (HCP) was called and gave it. Given by: Patient HCP Write the dose of the medication each time you Dose give it. Remember to put the number and the units 50 mg (the letters after the number). You should check this is correct using the chart at the front of your diary before giving the medication. Write the time that the as-needed medication was Time medication was given. given at 8.55 pm After 30 minutes have passed since the medication Symptom score was given, check to see if the symptom has improved. 30 minutes after Again, if possible, ask the person how they would rate medication (0-10) their symptom on a scale of 0-10. 0 is no symptom 3/10 and 10 indicates the worst that symptom can possibly be. If the person is not able to tell you, you can record Assessed by: how bad you think the symptom is in your experience Patient of caring for the person. Record the number for the Carer symptom. HCP Tick the box to show who rated how bad the symptom was. This may be you, the patient or a healthcare professional if one was called. Remember: Everyone is different and for some

for further advice.

people, the as-needed medications can take between

15-30 minutes to work. Allow this time for the medication to work before checking and recording the symptom score for this section of the diary. If you are concerned you can contact your doctor or nurse

#### When the patient's symptoms have improved to When were symptoms an acceptable level, tick the box to indicate if this resolved to an happened within 30 minutes of the medication being acceptable level? given, or if it took longer. If it took longer than 30 Within 30 mins minutes, write down the time it took for the symptom to improve to an acceptable level. of medication If longer please Tick the box to show who made the assessment of specify time: when the symptom was resolved. This may be you, the patient or a healthcare professional if one was Assessed by: called Patient Carer ☐ HCP If you gave the medication, rate how confident you How confident were were in preparing and giving the injection on a scale you in giving the of 1-7 injection (1 = not at all confident, 3/7 7 = extremely confident). Tick the box to indicate if you called a healthcare Was healthcare professional (such as a nurse or out of hours services) professional support to visit you at home as a result of the breakthrough sought? symptom. If so, there is a section at the bottom of the Yes page they should complete. V No At the bottom of the table there is a space for you to add any extra comments that might be helpful to you. This can be anything that you might want to remind yourself of later or anything you might want to remember to discuss with the person's healthcare team.

As well as completing the diary each time a breakthrough symptom occurs, there is a questionnaire (QOLLTI-F) to be completed every 48 hrs about your experiences as a carer, see page 25 onwards.

It is important that no pages are removed from your diary. If you make a mistake, cross it out and use a fresh page. If you are running out of space in your diary you should let your healthcare team know.

Potential side Effects (If different from those listed in carer booklet)						
Special Instructions (e.g. additional top up doses)						
Maximum number of doses in 24 hours						
Volume needed for required dose						
Dose						
As-needed medication						
Breakthrough symptoms	Pain	Nausea or	vomiting	Anxiety or	restiessness	Noisy breathing

Was healthcare professional support sought?	□ Yes					
How confident were you in giving the injection (1-7)						
When were symptoms resolved to an acceptable level?		Assessed by:    Patient     Carer     HCP		Outcome:		
Symptom score 30 minutes after medication (0-10)	/ 10	Assessed by:    Patient     Carer     HCP				
Time medication was given at	am/pm			Assessment made:		
Dose				Assess		
Medication given	Name	Given by: Carer  HCP		Time attended		
Symptom score before (0-10)		Assessed by:    Patient     Carer     HCP		ıme,		
Breakthrough symptom	☐ Pain ☐ Nausea //vomiting ☐ Agitation ☐ Noisy breathing			HCP details (Name, profession, signature		
Date and time that symptom developed	-/_/ ===================================	Noted by:   Patient	Comments	To be completed by HCP if applicable:		
CARiAD Carer Diary interven	tion v2 July 2017	E	ntr	y: 1	Pag	ge: 10

/ 10	by: Assessed by: t		Outcome:	
			:come:	
			:come:	
/ 10	by:		Out	
1	Assessed by:    Patient     Carer     HCP			
am/pm			Assessment made:	
			Assess	
Name	Given by:		Time attended	
	Assessed by:  Patient  Carer  HCP		me,	
☐ Pain ☐ Nausea ☐ /vomiting ☐ Agitation ☐ Noisy breathing			HCP details (Na profession, signature	
	Noted by:    Patient     Carer	Comments	To be completed by HCP if applicable:	
	8u u 8u	Pain Nausea /vomiting Agitation Noisy breathing y: Assessed by: ient Carer HCP	Pain Nausea /vomiting Agitation Dreathing breathing  Assessed by: ient Er Assessed by: ints Assessed by: ints	Deain  Nausea  /vomiting  Agitation  Noisy by: trient arer  HCP details (Name, signature signature  Deaing  Assessed by: Carer  HCP details (Name, signature  In the signature  Deaing  Assessed by: Carer  Assessed by: Carer  Assessed by: Carer  Assessed by: Carer  Assessed by: Signature

Was healthcare professional support sought?	Ves No					
How confident were you in giving the injection (1-7)						
When were symptoms resolved to an acceptable level?	<ul><li>── Within 30</li><li>── mins of</li><li>── medication</li><li>── If longer</li><li>── please</li><li>specify time:</li></ul>	Assessed by:    Patient     Carer     HCP		Outcome:		
Symptom score 30 minutes after medication (0-10)	/ 10	Assessed by:  Patient  Carer  HCP				
Time medication was given at	;am/pm			Assessment made:		
Dose				Assess		
Medication given	Name	Given by: □Carer □HCP		Time attended		
Symptom score before (0-10)		Assessed by:  Patient  Carer  HCP		ıme,		
Breakthrough symptom	☐ Pain ☐ Nausea //vomiting ☐ Agitation ☐ Noisy breathing			HCP details (Name, profession, signature		
Date and time that symptom developed	-\ : am/pm	Noted by:    Patient     Carer	Comments	To be completed by HCP if applicable:		
CARiAD Carer Diary interver	tion v2 July 2017	E	ntr	y: 3	Pag	ge: 12

No No				
☐ Within 30 mins of medication ☐ If longer please specify time:	Assessed by:    Patient   Carer   HCP		Outcome:	
/ 10	Assessed by:    Patient     Carer     HCP			
am/pm			ment made:	
			Assess	
Name	Given by:   Carer   HCP		Time attended	
	Assessed by:  Patient  Carer  HCP		ıme,	
Pain Nausea /vomiting Agitation Noisy breathing			HCP details (Na profession, signature	
/_/ ==:	Noted by:    Patient     Carer	Comments	To be completed by HCP if applicable:	
	Pain Name :		Pain	Pain   Pain   Name

Was healthcare professional support sought?	No No				
How confident were you in giving the injection (1-7)					
When were symptoms resolved to an acceptable level?	☐ Within 30 mins of medication ☐ If longer please specify time:	Assessed by:    Patient     Carer     HCP		Outcome:	
Symptom score 30 minutes after medication (0-10)	/ 10	Assessed by:    Patient     Carer			
Time medication was given at	am/pm			Assessment made:	
Dose				Assess	
Medication given	Name	Given by:   Carer   HCP		Time attended	
Symptom score before (0-10)		Assessed by:    Patient     Carer     HCP		me,	
Breakthrough symptom	☐ Pain ☐ Nausea // Vomiting ☐ Agitation ☐ Noisy breathing			HCP details (Name, profession, signature	
Date and time that symptom developed	_/_/_ am/pm	Noted by:   Patient   Carer	Comments	To be completed by HCP if applicable:	

∨es □ No				
☐ Within 30 mins of medication ☐ If longer please specify time:	Assessed by:    Patient   Carer   HCP		Outcome:	
/ 10	Assessed by:    Patient     Carer     HCP			
am/pm			ment made:	
			Assess	
Name	Given by:   Carer   HCP		Time attended	
	Assessed by:    Patient     Carer     HCP		ıme,	
Pain Nausea /vomiting Agitation Noisy breathing			HCP details (Na profession, signature	
/_/ =================================	Noted by:    Patient     Carer	Comments	To be completed by HCP if applicable:	
	Pain Name :		Pain	Pain   Pain   Name

Was healthcare professional support sought?	□ Yes					
How confident were you in giving the injection (1-7)						
When were symptoms resolved to an acceptable level?	☐ Within 30 mins of medication ☐ If longer please specify time:	Assessed by:    Patient     Carer     HCP		Outcome:		
Symptom score 30 minutes after medication (0-10)	/ 10	Assessed by: Patient Carer				
Time medication was given at	am/pm			Assessment made:		
Dose				Assess		
Medication given	Name	Given by: Carer  HCP		Time attended		
Symptom score before (0-10)		Assessed by:  Patient  Carer  HCP		(Name,		
Breakthrough symptom	☐ Pain ☐ Nausea // Nausea // Nausea // Paitation ☐ Agitation ☐ Noisy breathing			HCP details (Na profession, signature		
Date and time that symptom developed	_/_/_ :: am/pm	Noted by:    Patient   Carer	Comments	To be completed by HCP if applicable:		
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Was healthcare professional support sought?	∨es □ No				
How confident were you in giving the injection (1-7)					
When were symptoms resolved to an acceptable level?	Within 30 mins of medication If longer please specify time:	Assessed by:    Patient     Carer     HCP		Outcome:	
Symptom score 30 minutes after medication (0-10)	/ 10	Assessed by:    Patient     Carer     HCP			
Time medication was given at	am/pm			Assessment made:	
Dose				Assessi	
Medication	Name	Given by:   Carer   HCP		Time attended	
Symptom score before (0-10)		Assessed by:    Patient     Carer     HCP		(Name,	
Breakthrough symptom	Pain Nausea /vomiting Agitation Noisy breathing			HCP details (Na profession, signature	
Date and time that symptom developed	-/-/- ::	Noted by:    Patient     Carer	Comments	To be completed by HCP if applicable:	
ge: 17	Entry: 8	CARIAD	Care	Diary interventi	on v2 July 20

are ional t						
Was healthcare professional support sought?	□ Yes					
How confident were you in giving the injection (1-7)						
When were symptoms resolved to an acceptable level?	☐ Within 30 mins of medication ☐ If longer please specify time:	Assessed by:    Patient     Carer     HCP		Outcome:		
Symptom score 30 minutes after medication (0-10)	/ 10	Assessed by:    Patient     Carer				
Time medication was given at	am/pm			Assessment made:		
Dose				Assess		
Medication given	Name	Given by: □Carer □HCP		Time attended		
Symptom score before (0-10)		Assessed by:  Patient  Carer  HCP		(Name,		
Breakthrough symptom	☐ Pain ☐ Nausea // Vomiting ☐ Agitation ☐ Noisy breathing			HCP details (Na profession, signature		
Date and time that symptom developed		Noted by: Patient  Carer	Comments	To be completed by HCP if applicable:		
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	-				
Was healthcare professional support sought?					
How confident were you in giving the injection (1-7)					
When were symptoms resolved to an acceptable level?	☐ Within 30 mins of medication ☐ If longer please specify time:	Assessed by:    Patient     Carer     HCP		Outcome:	
Symptom score 30 minutes after medication (0-10)	/ 10	Assessed by:    Patient     Carer     HCP			
Time medication was given at	md/me			Assessment made:	
Dose				Assess	
Medication	Name	Given by:   Carer   HCP		Time attended	
Symptom score before (0-10)		Assessed by:    Patient     Carer     HCP		ıme,	
Breakthrough symptom	☐ Pain ☐ Nausea //omiting ☐ Agitation ☐ Noisy breathing			HCP details (Name, profession, signature	
Date and time that symptom developed	/_/ =================================	Noted by:    Patient     Carer	Comments	To be completed by HCP if applicable:	
re: 19	Entry: 10	CARIAD	Care	r Diary interventi	on v2 July 20

nal nal						
Was healthcare professional support sought?	No □					
How confident were you in giving the injection (1-7)						
When were symptoms resolved to an acceptable level?	☐ Within 30 mins of medication ☐ If longer please specify time:	Assessed by:    Patient     Carer     HCP		Outcome:		
Symptom score 30 minutes after medication (0-10)	/ 10	Assessed by:    Patient     Carer     HCP				
Time medication was given at				Assessment made:		
Dose				Assess		
Medication given	Name	Given by: Carer  HCP		Time attended		
Symptom score before (0-10)		Assessed by:    Patient     Carer     HCP		me,		
Breakthrough symptom	☐ Pain ☐ Nausea //vomiting ☐ Agitation ☐ Noisy breathing			HCP details (Name, profession, signature		
Date and time that symptom developed	/_/ =================================	Noted by:    Patient     Carer	Comments	To be completed by HCP if applicable:		
ARiAD Carer Diary interver	ntion v2 July 2017	Er	ntry	: 11)	Pag	ge: 2

Was healthcare professional support sought?	Ves No				
How confident were you in giving the injection (1-7)					
When were symptoms resolved to an acceptable level?	Within 30     mins of     medication     □ If longer     please     specify time:	Assessed by:    Patient     Carer     HCP		Outcome:	
Symptom score 30 minutes after medication (0-10)	/ 10	Assessed by:    Patient     Carer     HCP			
Time medication was given at	md/me			Assessment made:	
Dose				Assess	
Medication given	Name	Given by:   Carer   HCP		Time attended	
Symptom score before (0-10)		Assessed by:    Patient     Carer     HCP		Name,	
Breakthrough symptom	☐ Pain ☐ Nausea // Vorniting ☐ Agitation ☐ Noisy breathing			HCP details (Na profession, signature	
Date and time that symptom developed	_/_/_ ::	Noted by:   Patient     Carer	Comments	To be completed by HCP if applicable:	
re: 21	Entry: 12	CARIAD	Care	Diary interventi	on v2 July 20

June   Pain   Name   Image	Date and time that symptom developed	Breakthrough symptom	Symptom score before (0-10)	Medication given	Dose	Time medication was given at	Symptom score 30 minutes after medication (0-10)	When were symptoms resolved to an acceptable level?	How confident were you in giving the injection (1-7)	Was healthcare professional support sought?
hy: Intent Inten	/-/ am/pm	Pain Nausea /vomiting Agitation Noisy breathing		Name		am/pm	/ 10	Within 30 mins of medication     ☐ If longer please specify time:		□ Yes □ No
HCP details (Name, Time Assessment made: sted by profession, signature signature	Noted by:    Patient     Carer		Assessed by:  Patient  Carer  HCP	Given by:			Assessed by:    Patient     Carer     HCP	Assessed by:    Patient     Carer     HCP		
HCP details (Name, Time Assessment made: sted by profession, attended signature signature	Comments									
	To be completed by HCP if applicable:	sl , ر	эте,	Time attended	Assessn	nent made:		Outcome:		

Was healthcare professional support sought?	\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \				
How confident were you in giving the injection (1-7)					
When were symptoms resolved to an acceptable level?		Assessed by:    Patient     Carer     HCP		Outcome:	
Symptom score 30 minutes after medication (0-10)	/ 10	Assessed by:    Patient     Carer     HCP			
Time medication was given at				Assessment made:	
Dose				Assessi	
Medication given	Name	Given by: □Carer □HCP		Time attended	
Symptom score before (0-10)		Assessed by:  Patient  Carer  HCP		(Name,	
Breakthrough symptom	☐ Pain ☐ Nausea //vomiting ☐ Agitation ☐ Noisy breathing			HCP details (Na profession, signature	
Date and time that symptom developed	_/_/ ==================================	Noted by:    Patient     Carer	Comments	To be completed by HCP if applicable:	
ge: 23	Entry: 14	CARIAD	Care	Diary interventi	on v2 July 20

Jain   Pain   Name   Image	□ <del>+</del> ĕ	Date and time that symptom developed	Breakthrough symptom	Symptom score before (0-10)	Medication	Dose	Time medication was given at	Symptom score 30 minutes after medication (0-10)	When were symptoms resolved to an acceptable level?	How confident were you in giving the injection (1-7)	Was healthcare professional support sought?
by:  stient arer  Carer  HCP details (Name, signature signature signature  Assessed by:  Given by:  Carer  HCP details (Name, signature	a l		Pain Nausea /vomiting Agitation Noisy breathing		Name		am/pm	/ 10	☐ Within 30 mins of medication ☐ If longer please specify time:		No No
HCP details (Name, Time Assessment made: sted by profession, attended signature signature	Ž	oted by:   Patient   Carer		Assessed by:  Patient  Carer  HCP	Given by:  Carer  HCP			Assessed by:    Patient     Carer     HCP	Assessed by:    Patient     Carer     HCP		
HCP details (Name, Time Assessment made: sted by profession, attended signature signature	ŏ	omments									
	カンドを	be ompleted by CP if oplicable:	_	ıme,	Time attended	Assessr	nent made:		Outcome:		

### **QOLLTI-F: Quality of Life During Serious Illness – Family Carers**

Please read these instructions before answering the questionnaire.

There are no right or wrong answers. Honest answers will be most helpful.

This questionnaire includes a series of statements that we would like you to respond to by choosing a number from 0 to 10.

These numbers extend from one extreme answer (for example, 'not at all') to its opposite (for example, 'completely'). Please choose or circle the number between 0 and 10 that best represents how you feel.

Note that sometimes the best situation is at the 0 end of the scale, and sometimes the best situation is at the 10 end of the scale.

We are interested in learning about your OVERALL quality of life, so please consider any issues that affect you, even if they are not related to your caregiving role.

A blank in a sentence refers to the person you are caring for, but please do not write any name to keep this confidential.

(Date://)												
1. Over the past two day hospital, other) was the						ndei	red	if th	ne p	lac	e	was staying (home,
Never	0	1	2	3	4	5	6	7	8	9	10	Always
2. Over the past two day	s (4	8 h	ours	s) I I	nad	the	pri	vac	y I v	war	ited.	
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
3. Over the past two day	s (4	8 h	ours	s) th	ie c	ond	itio	n o	f		_ was	s distressing to me.
Not often	0	1	2	3	4	5	6	7	8	9	10	Always
4. Over the past two day	s (4	8 h	ours	s) th	ie a	mo	unt	of o	on	trol	I hav	e over my life was:
Not a problem	0	1	2	3	4	5	6	7	8	9	10	A huge problem
5. Over the past two day	s (4	8 h	ours	s) I l	nad	tim	e to	ta	ke d	care	of m	yself.
Never	0	1	2	3	4	5	6	7	8	9	10	Always
Page: 25 Que	stic	nn	air	e: 1		$\supset$			CARi	iAD (	Carer Di	ary intervention v2 July 2017

6. Over the past two day	s (4	8 h	ours	s) I v	was	abl	e to	thi	ink	clea	arly.	
Not often	0	1	2	3	4	5	6	7	8	9	10	Always
7. Over the past two day	s (4	8 ho	ours	s) pl	hysi	call	y I f	elt:				
Extremely poor	0	1	2	3	4	5	6	7	8	9	10	Extremely good
8. Over the past two day	s (4	8 ho	ours	s) eı	mot	ion	ally	I fe	lt:			
Extremely poor	0	1	2	3	4	5	6	7	8	9	10	Extremely good
9. Over the past two day made me feel good:	s (4	8 ho	ours	s) bo	eing	ab	le to	o pr	ovi	de (	care o	or company for
Rarely or never	0	1	2	3	4	5	6	7	8	9	10	Always
10. Over the past two da spirituality:	ys (	48 h	nou	rs) I	wa	s cc	mf	orte	ed b	y m	ny out	tlook on life, faith or
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
11. Presently I feel that n	ny li	fe h	nas	me	anir	ng:_			:			
Very little meaning	0	1	2	3	4	5	6	7	8	9	10	Very much meaning
For questions 12 and 13, if past two (2) days, please a												need health care in the
12. Over the past two da	ys (	48 ł	iou	rs) I	agı	reed	l wi	th t	he	way	/ deci	sions were made for
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
13. Over the past two da	ys (	48 ł	nou	rs) t	the	qua	lity	of	hea	lth	care v	we received was:
Unsatisfactory	0	1	2	3	4	5	6	7	8	9	10	Extremely good
CARiAD Carer Diary interven	ntion	v2 J	uly 2	017				(	Que	esti	onna	Page: 26

14. Over the past two	days (4	48 l	nou	rs) I	fel	t m	y in	tera	acti	on v	with	was:
	0	1	2	3	4	5	6	7	8	9	10	
Very comfortable												Stressful
15. Over the past two people most importan				•	ove	rall	, I f	elt ı	my	inte	raction	ns with the other
	0	1	2	3	4	5	6	7	8	9	10	
Very comfortable												Stressful
16. Over the past two											n has b	een stressful:
Not at all												Completely

**Questionnaire: 1** 

### **QOLLTI-F: Quality of Life During Serious Illness – Family Carers**

Please read these instructions before answering the questionnaire.

There are no right or wrong answers. Honest answers will be most helpful.

This questionnaire includes a series of statements that we would like you to respond to by choosing a number from 0 to 10.

These numbers extend from one extreme answer (for example, 'not at all') to its opposite (for example, 'completely'). Please choose or circle the number between 0 and 10 that best represents how you feel.

Note that sometimes the best situation is at the 0 end of the scale, and sometimes the best situation is at the 10 end of the scale.

We are interested in learning about your OVERALL quality of life, so please consider any issues that affect you, even if they are not related to your caregiving role.

A blank in a sentence refers to the person you are caring for, but please do not write any name to keep this confidential.

maine to keep this confide	iiiliai	•										
(Date://)												
1. Over the past two day hospital, other) was the						ndei	red	if th	ne p	lac	e	was staying (home,
Never	0	1	2	3	4	5	6	7	8	9	10	Always
2. Over the past two day	ys (4	8 ho	ours	s) I I	nad	the	pri	vac	уIv	war	ited.	
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
3. Over the past two day	ys (4	8 h	ours	s) th	ie c	ond	litio	n o	f		_ wa	s distressing to me.
Not often	0	1	2	3	4	5	6	7	8	9	10	Always
4. Over the past two day	ys (4	8 h	ours	s) th	ne a	mo	unt	of (	con	trol	I hav	e over my life was:
Not a problem	0	1	2	3	4	5	6	7	8	9	10	A huge problem
5. Over the past two day	ys (4	8 h	ours	s) I I	nad	tim	ne to	o ta	ke d	are	of m	yself.
Never	0	1	2	3	4	5	6	7	8	9	10	Always
									Que	esti	ionna	aire: 2
CARiAD Carer Diary interve	ntion	v2 J	uly 2	017			-		•			Page: 28

	0	1	2	2		5	6	7	8	9	10	
Not often		_			_						10	Always
7. Over the past two da	ys (48	3 ho	ours	) pł	hysi	call	y I f	elt:				
Extremely poor	0	1	2	3	4	5	6	7	8	9	10	Extremely good
3. Over the past two da	ys (48	3 ho	ours	) er	mot	ion	ally	I fe	lt:			
Extremely poor	0	1	2	3	4	5	6	7	8	9	10	Extremely good
9. Over the past two da made me feel good:	ys (48	3 ho	ours	s) be	eing	g ab	le to	o pr	ovi	de (	care o	r company for
	0	1	2	3	4	5	6	7	8	9	10	
Rarely or never												Always
Rarely or never  10. Over the past two d spirituality:	ays (4							orte			ny out	
10. Over the past two d	ays (4							orte				Always look on life, faith or Completely
10. Over the past two d spirituality:	ays (4	1	2	3	4	5	6	orte				look on life, faith or
10. Over the past two d spirituality: Not at all	ays (4	1 fe h	2 nas	3 mea	4 anir	5 ng:_	6	7	8	9		look on life, faith or
10. Over the past two d spirituality: Not at all 11. Presently I feel that	ays (4 0 my li 0	1 fe h	2 nas   2	3 mea 3	4 anir 4	5 ng:_ 5	6 6	7 7 ant	8 : : 8	9 9	10 10	Completely Very much meaning
10. Over the past two despirituality:  Not at all  11. Presently I feel that  Very little meaning  or questions 12 and 13, i	ays (4 0 my li 0	1  fe h  dia  er f	2 2 2 1 notion t	3 3 t mea	4  anir 4  ake	5 5 imp	6 6	7 7 ant	8 : 8 dec	9 9	10 10 ons or	Completely  Very much meaning  need health care in the
10. Over the past two despirituality:  Not at all  11. Presently I feel that  Very little meaning  or questions 12 and 13, in a great two (2) days, please	o my li o f you answ	1 fe h  dia er f	2 2 I no for t	3 3 tt mothe l	4  anir 4  ake	5 5 impfew	6 6 oort:	7 7 ant	8 deceyyou	9 9 way	10 10 ons or	Completely  Very much meaning  need health care in the
10. Over the past two despirituality:  Not at all  11. Presently I feel that  Very little meaning  or questions 12 and 13, in ast two (2) days, please 12. Over the past two despired in the past tw	ays (4 0 my li 0 f you answ ays (4	1 fe h 1 dia er f 1 1	2 2 2 I no for t	3 3 tt mohe l	4  anir 4  ake last agi	5 5 impfew reecc	6 6 coort tim	7 7 ant nes	8 :: 8 dec	9 9 way	10  10  ons or decisor 10	Completely  Very much meaning  need health care in the  sions were made for  Completely

	0	1	2	2	1	_	6	7	Q	۵	10			
Very comfortable		_			_			_	0		10			Stressful
5. Over the past two depose most important					ove	rall	, I fe	eltı	my	inte	ractior	ns with	the o	other
Very comfortable	0	1	2	3	4	5	6	7	8	9	10			Stressful
6. Over the past two d	lays (4	48 h	ioui	rs) r	my f	fina	ncia	al si	tua	tion	has b	een st	ressfu	l:
Not at all	0	1	2	3	4	5	6	7	8	9	10		C	ompletely

CARiAD Carer Diary intervention v2 July 2017

**Questionnaire: 2** 

Page: 30

### **QOLLTI-F: Quality of Life During Serious Illness – Family Carers**

Please read these instructions before answering the questionnaire.

There are no right or wrong answers. Honest answers will be most helpful.

This questionnaire includes a series of statements that we would like you to respond to by choosing a number from 0 to 10.

These numbers extend from one extreme answer (for example, 'not at all') to its opposite (for example, 'completely'). Please choose or circle the number between 0 and 10 that best represents how you feel.

Note that sometimes the best situation is at the 0 end of the scale, and sometimes the best situation is at the 10 end of the scale.

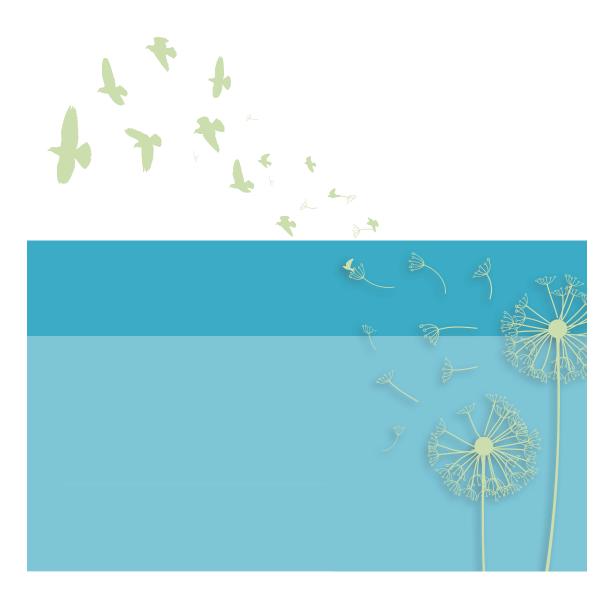
We are interested in learning about your OVERALL quality of life, so please consider any issues that affect you, even if they are not related to your caregiving role.

A blank in a sentence refers to the person you are caring for, but please do not write any name to keep this confidential.

(Date://)												
1. Over the past two days hospital, other) was the r						nder	ed	if th	ne p	lac	e	was staying (home,
Never	0	1	2	3	4	5	6	7	8	9	10	Always
2. Over the past two days	s (48	3 ho	ours	s) I I	nad	the	pri	vac	y I v	war	ited.	
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
3. Over the past two days	s (48	3 ho	ours	) th	ne c	ond	itio	n o	f		_ was	s distressing to me.
Not often	0	1	2	3	4	5	6	7	8	9	10	Always
4. Over the past two days	s (48	3 ho	ours	) th	ne a	mo	unt	of o	con	trol	I have	e over my life was:
Not a problem	0	1	2	3	4	5	6	7	8	9	10	A huge problem
5. Over the past two days	s (48	3 ho	ours	s) I I	nad	tim	e to	ta	ke d	are	of m	yself.
Never	0	1	2	3	4	5	6	7	8	9	10	Always
Page: 31 Ques	stio	nn	air	e: 3	3	$\supset$			CARi	AD (	Carer Di	ary intervention v2 July 2017

6. Over the past two days (48 hours) I was able to think clearly.												
Not often	0	1	2	3	4	5	6	7	8	9	10	Always
7. Over the past two day	s (4	8 ho	ours	s) pl	hysi	call	y I f	elt:				
Extremely poor	0	1	2	3	4	5	6	7	8	9	10	Extremely good
8. Over the past two day	s (4	8 ho	ours	s) eı	mot	ion	ally	I fe	lt:			
Extremely poor	0	1	2	3	4	5	6	7	8	9	10	Extremely good
9. Over the past two days (48 hours) being able to provide care or company for made me feel good:												
Rarely or never	0	1	2	3	4	5	6	7	8	9	10	Always
10. Over the past two days (48 hours) I was comforted by my outlook on life, faith or spirituality:												
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
11. Presently I feel that my life has meaning::												
Very little meaning	0	1	2	3	4	5	6	7	8	9	10	Very much meaning
For questions 12 and 13, if you did not make important decisions or need health care in the past two (2) days, please answer for the last few times you did.												
12. Over the past two days (48 hours) I agreed with the way decisions were made for:												
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
13. Over the past two days (48 hours) the quality of health care we received was:												
Unsatisfactory	0	1	2	3	4	5	6	7	8	9	10	Extremely good
CARiAD Carer Diary interven	ntion	v2 J	uly 2	017				(	Que	esti	onna	Page: 32

14. Over the past two	days (4	48 l	nou	rs) I	fel	t m	y in	tera	acti	on v	with	was:
	0	1	2	3	4	5	6	7	8	9	10	
Very comfortable												Stressful
15. Over the past two days (48 hours), overall, I felt my interactions with the other people most important to me were:												
	0	1	2	3	4	5	6	7	8	9	10	
Very comfortable												Stressful
16. Over the past two days (48 hours) my financial situation has been stressful:  0 1 2 3 4 5 6 7 8 9 10												
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
INUL at all												Completely



CARer-ADministration of as-needed subcutaneous medication for breakthrough symptoms in home-based dying patients: the CARiAD open pilot RCT
symptoms in nome-based dying patients. the CAMAD open phot NC1
Carer Diary (Usual care)











To assist you in your caring role, this diary has been developed specifically to assist you with recording the as-needed subcutaneous medications that are given to the person you are caring for each day. You should complete a page in this diary each time the person you are caring for experiences a breakthrough symptom that requires asneeded subcutaneous medication.

This diary has been developed as part of the CARiAD trial. The diary was adapted from the Brisbane South Palliative Care Collaborative Caring Safely at Home trial and is presented by the research team for the purpose of the CARiAD trial. It should only be used for the purpose for which it has been supplied.

There are instructions on how to use the diary on the following pages and your healthcare team will go through these with you. If you have any further questions please speak to your healthcare team or contact the CARIAD trial research team.

## **Contact Details**

	District Nurse Service
Team	
Named DN (if applicable)	
Contact details	
Working hours	
	In hours GP service
GP Surgery	
Usual GP (if applicable)	
Contact details	
Working hours	
	Out of Hours GP Service
Contact details	
Working hours	
	Local Pharmacy
Name	
Telephone	
Fax/Email	

	Specialist Palliative Care Service
Team	
Named DN (if applicable)	
Contact details	
Working hours	
	Other important contacts
Person or service	
Named Contact (if applicable)	
Contact details	
Working hours	
Person or service	
Contact details	
Working hours	

# **Medical Appointments**

Date	Time	Place	Healthcare professional

## **Caregiver diary instructions**

Each time the person you are caring for experiences a breakthrough symptom that requires as-needed medication, complete a page in the diary.

Date and time that symptom developed	Write the date (day/month/year) and time that a	
(30/11/16) 8.35 pm	symptom develops that is not being controlled by any regular medication.	
Noted by:  Patient Carer HCP	Tick the box to indicate who noted the symptom developing. This may be you, the patient or a healthcare professional (HCP).	
Breakthrough symptom  ☐ Pain ☐ Nausea/vomiting ☐ Agitation ☐ Noisy breathing	Tick the box which best explains the reason the medication is being given. Sometimes different medications may need to be given at the same time, for example one for pain and one for nausea. If so, record each on a separate page.	
Date and time healthcare professional (HCP) was contacted:	Write the date (day/month/year) and time that a healthcare professional (e.g. district nurse, GP, out hours service) was contacted about the symptom thas developed. If a HCP was already present when	
(30/11/16) 8.35 pm	the symptom developed, you can note this here.	
Symptom score when HCP was called (0-10)	If possible, ask the person how they would rate their symptom on a scale of 0-10. 0 is no symptom and 10 indicates the worst that symptom can possibly be.	
Assessed by: Patient Carer HCP	If the person is not able to tell you, you can record how bad you think the symptom is in your experience of caring for the person. Record the number for the symptom. This will help you to see later on if the symptom has improved.  Tick the box to show who rated how bad the symptom was, you or the patient.	

#### Time HCP arrived

am/pm

Note the time that the healthcare professional arrived. This may take some time and may vary at different times of the day. The healthcare professional will always try to reach you as soon as possible after they have been contacted. If they were already present when the symptom developed please note this here.

#### Medication given

Name:

Cyclizine

Write the name of the medication given by the healthcare professional.

Tick the box to show if you gave the medication or if a healthcare professional (HCP) was called and gave it.

#### Dose

50 mg

Write the dose of the medication given by the healthcare professional. Remember to put the number and the units (the letters after the number). You may want to ask the healthcare professional to help you with this.

#### Time medication was given at

8.55 pm

Write the time that the as-needed medication was given.

After 30 minutes have passed since the medication

their symptom on a scale of 0-10. 0 is no symptom

was given, check to see if the symptom has improved.

Again, if possible, ask the person how they would rate

and 10 indicates the worst that symptom can possibly be. If the person is not able to tell you, you can record

how bad you think the symptom is in your experience

of caring for the person. Record the number for the

#### Symptom score 30 minutes after medication (0-10)

3/10

Assessed by:

- Patient
- Carer
- HCP

symptom. Tick the box to show who rated how bad the symptom was. This may be you, the patient or a healthcare professional if one was called.

Remember: Everyone is different and for some people, the as-needed medications can take between 15-30 minutes to work. Allow this time for the medication to work before checking and recording the symptom score for this section of the diary.

# When were symptoms resolved to an acceptable level?

Within 30 mins of medication

If longer please specify time:

Assessed by:

Patient

Carer

☐ HCP

When the patient's symptoms have improved to an acceptable level, tick the box to indicate if this happened within 30 minutes of the medication being given, or if it took longer. If it took longer than 30 minutes, write down the time it took for the symptom to improve to an acceptable level.

Tick the box to show who made the assessment of when the symptom was resolved. This may be you, the patient or a healthcare professional.

At the bottom of the table there is a space for you to add any extra comments that might be helpful to you. This can be anything that you might want to remind yourself of later or anything you might want to remember to discuss with the person's healthcare team. There is also a separate table for the healthcare professional who attends to give the medication to sign the page and make their own comments.

As well as completing the diary each time a breakthrough symptom occurs, there is a questionnaire (QOLLTI-F) to be completed every 48 hrs about your experiences as a carer, see page 24 onwards.

It is important that no pages are removed from your diary. If you make a mistake, cross it out and use a fresh page. If you are running out of space in your diary you should let your healthcare team know.

/_/		contacted	called (0-10)	3
	Pain  Nausea or vomiting Agitation  Noisy breathing	_/_/_ _:am/pm	/ 10	
Noted by:    Patient   Carer   Carer   HCP   Carer   C			Assessed by:    Patient     Carer	
Medication given Dose		Time medication was given at	Symptom score 30 minutes after medication (0-10)	When were symptoms resolved to an acceptable level?
Name:		am/pm	/10	<ul><li> Within 30 mins of medication</li><li> If longer please specify time</li></ul>
			Assessed by:    Patient     Carer	Assessed by:    Patient     Carer     HCP
Comments				
HCP details (Name, profession, signature)	ure)	Comments		

Date and time that symptom developed
--------------------------------------

Date and time that symptom developed	Breakthrough symptom	Date and time healthcare professional (HCP) was contacted	Symptom score when HCP was called (0-10)	Time HCP arrived:
_/_/_ _:am/pm	☐ Pain ☐ Nausea or vomiting ☐ Agitation ☐ Noisy breathing	_/_/_ :am/pm	/ 10	
Noted by:    Patient   Carer   HCP			Assessed by:    Patient   Carer   HCP	
Medication given	Dose	Time medication was given at	Symptom score 30 minutes after medication (0-10)	When were symptoms resolved to an acceptable level?
Name:		am/pm	/ 10	<ul><li>✓ Within 30 mins of medication</li><li>✓ If longer please specify time</li></ul>
			Assessed by:    Patient     Carer     HCP	Assessed by:    Patient     Carer     HCP
Comments				
HCP details (Name, profession, signature)	signature)	Comments		

developed am/pm  .:am/pm  Noted by:  Carer Carer HCP Medication given

symptom Breakthrough Date and time healthcare Symptom score Time HCP symptom symptom professional (HCP) was arrived: contacted called (0-10)	☐ Pain	Assessed by:    Patient     Carer     HCP	Dose Time medication was Symptom score When were 30 minutes after symptoms medication (0-10) resolved to an acceptable level?	—————————————————————————————————————	Assessed by:  Assessed by:  Patient  Carer  HCP		e, profession, signature) Comments	
Date and time that symptom developed	_/_/_ am/pm	Noted by:    Patient   Carer   HCP	Medication given	Name:		Comments	HCP details (Name, profession, signature)	

Date and time that symptom developed	Breakthrough symptom	Date and time healthcare professional (HCP) was contacted	Symptom score when HCP was called (0-10)	Time HCP arrived:
_/_/_ .:am/pm	☐ Pain ☐ Nausea or vomiting ☐ Agitation ☐ Noisy breathing	_/_/_ :am/pm	/ 10	
Noted by:    Patient   Carer			Assessed by:    Patient   Carer   HCP	
Medication given	Dose	Time medication was given at	Symptom score 30 minutes after medication (0-10)	When were symptoms resolved to an acceptable level?
Name:		am/pm	/10	<ul><li>✓ Within 30 mins of medication</li><li>☐ If longer please specify time</li></ul>
			Assessed by:    Patient     Carer	Assessed by:    Patient     Carer     HCP
Comments				
HCP details (Name, profession, signature)	signature)	Comments		

Date and time that sympleveloped am/pm am/pm  Dated by: Carer Carer HCP Medication given  Name:  Comments  HCP details (Name, prof
--

□ Noisy breathing Dose	Pain Noisy breathing Se Time medication was	when HCP was called (0-10)  / 10  Assessed by:    Patient   Carer   HCP	arrived:am/pmwhen were
Dose	lime medication was given at	Symptom score 30 minutes after medication (0-10)	When were symptoms resolved to an acceptable level?
	am/pm	/ 10	<ul><li>  Within 30 mins of medication</li><li>  If longer please specify time</li></ul>
		Assessed by:    Patient     Carer     HCP	Assessed by:    Patient   Carer   HCP
HCP details (Name, profession, signature)	Comments		

Date and time that symptom developed	titing  Time medication was given at comments  Comments	Symptom score when HCP was called (0-10)  Assessed by: Carer Carer HCP Symptom score 30 minutes after medication (0-10)  Assessed by: Carer HCP HCP Medication (0-10) HCP HCP HCP HCP	Time HCP arrived: am/pm  .:am/pm  when were symptoms resolved to an acceptable level?    Within 30 mins of medication   If longer please specify time Assessed by:   Patient   Carer   HCP
--------------------------------------	---	---	--

HCP details (Name, profession, signature)  Comments	

Date and time healthcare Symptom score Time HCP professional (HCP) was arrived: called (0-10)	/_/am/pm _:am/pm	Assessed by:    Patient     Carer     HCP	Time medication was Symptom score When were 30 minutes after symptoms medication (0-10) resolved to an acceptable level?	am/pm	Assessed by:    Patient   Patient     Carer   Carer     HCP   HCP		Comments	
Breakthrough Dispension Properties of Co.	☐ Pain☐ Nausea or vomiting☐ ☐ Agitation☐ ☐ Noisy breathing ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐		Dose					
Date and time that symptom B developed	_/_/_ :am/pm	Noted by:    Patient   Carer   HCP	Medication given	Name:		Comments	HCP details (Name, profession, signature)	

#### **QOLLTI-F: Quality of Life During Serious Illness – Family Carers**

Please read these instructions before answering the questionnaire.

There are no right or wrong answers. Honest answers will be most helpful.

This questionnaire includes a series of statements that we would like you to respond to by choosing a number from 0 to 10.

These numbers extend from one extreme answer (for example, 'not at all') to its opposite (for example, 'completely'). Please choose or circle the number between 0 and 10 that best represents how you feel.

Note that sometimes the best situation is at the 0 end of the scale, and sometimes the best situation is at the 10 end of the scale.

We are interested in learning about your OVERALL quality of life, so please consider any issues that affect you, even if they are not related to your caregiving role.

A blank in a sentence refers to the person you are caring for, but please do not write any name to keep this confidential.

(Date://)												
1. Over the past two days hospital, other) was the						dei	ed	if th	ne p	lac	e	was staying (home,
Never	0	1	2	3	4	5	6	7	8	9	10	Always
2. Over the past two days	s (4	8 h	ours	) I I	nad	the	pri	vac	уIч	war	ited.	
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
3. Over the past two days	s (4	8 h	ours	) th	ne c	ond	itio	n o	f		was	s distressing to me.
Not often	0	1	2	3	4	5	6	7	8	9	10	Always
4. Over the past two days	s (4	8 h	ours	) th	ne a	mo	unt	of o	on	trol	I have	e over my life was:
Not a problem	0	1	2	3	4	5	6	7	8	9	10	A huge problem
5. Over the past two days	s (4	8 h	ours	s) I I	nad	tim	e to	ta	ke d	are	of my	yself.
Never	0	1	2	3	4	5	6	7	8	9	10	Always
								O	IPC	tio	nnair	e: 1
CARiAD Carer Diary Control v	/2 Ju	ly 20	17				_	Qι	463		man	Page: 24

	n	1	2	2	1	5	6	7	8	9	10	
Not often		_	_	_	_	_	_	_	_	_		Always
7. Over the past two day	ys (48	3 ho	ours	) pł	hysi	call	y I f	elt:				
Extremely poor	0	1	2	3	4	5	6	7	8	9	10	Extremely good
3. Over the past two da	ys (48	3 ho	ours	) er	mot	ion	ally	I fe	lt:			
Extremely poor	0	1	2	3	4	5	6	7	8	9	10	Extremely good
9. Over the past two day made me feel good:	ys (48	3 hc	ours	s) be	eing	ab	le to	o pr	ovi	de (	care o	r company for
	0	1	2	3	4	5	6	7	Q	9	10	
Rarely or never												Always
Rarely or never  10. Over the past two despirituality:	ays (4	18 h						orte	ed b	y m	ny out	
10. Over the past two day	ays (4	18 h						orte	ed b	y m		Always look on life, faith or Completely
10. Over the past two daspirituality:  Not at all	ays (4	18 h	2	3	4	5	6	orte	ed b	y m		look on life, faith or
10. Over the past two daspirituality:	ays (4	1 1 fe h	2 nas	3 mea	4 anir	5 ng:_	6	7	8 :	9		look on life, faith or
10. Over the past two dispirituality:  Not at all  11. Presently I feel that	ays (4 0 my li	1 1 fe h	2 2 2	3 mea 3	4 anir 4	5 ng:_ 5	6 6	7 7 ant	8 dec	9 9	10 10	look on life, faith or  Completely  Very much meaning
10. Over the past two dispirituality:  Not at all  11. Presently I feel that  Very little meaning or questions 12 and 13, i	0 my li 0 f you answ	1 fe h dia er f	2 2 1 no	3 3 t mea	4  anir 4  ake	5 5 imp	6 6	7 7 ant	8 : 8 dec	9 9 cisio	10 10 ns or	Completely  Very much meaning  need health care in the
10. Over the past two despirituality:  Not at all  11. Presently I feel that  Very little meaning or questions 12 and 13, is ast two (2) days, please of	o my li o f you answ	1 fe h diaaer f	2 2 I no for t	3 3 tt mothe l	4  anir 4  ake	5 5 impfew	6 6 oort:	7 7 ant	8 decoyou	9 9 way	10 10 ns or	Completely  Very much meaning  need health care in the
10. Over the past two dispirituality:  Not at all  11. Presently I feel that  Very little meaning or questions 12 and 13, in the past two displays, please of the past two displays.	o my li o o o o o o o o o o o o o o o o o o	1 1 dia er f	2 2 2 I no for t	3 3 tt mohe l	4  anir 4  ake last agi	5 5 impfew reecc 5	6 6 v tim	7 7 ant nes	8 deceyou	9 9 way	10  10  ns or l.  / deci:	Completely  Very much meaning  need health care in the  sions were made for  Completely

	0	1	2	3	4	5	6	7	8	9	10			
Very comfortable														Stressful
5. Over the past two deople most important					ove	erall	, I fe	elt i	my	inte	ractio	ons with	the c	other
Very comfortable	0	1	2	3	4	5	6	7	8	9	10			Stressful
6. Over the past two d	ays (4	48 ŀ	nou	rs) ı	my f	fina	ncia	al si	tua	tior	has	been sti	ressfu	l:
Not at all	0	1	2	3	4	5	6	7	8	9	10		C	ompletely

Questionnaire: 1

Page: 26

CARiAD Carer Diary Control v2 July 2017

#### **QOLLTI-F: Quality of Life During Serious Illness – Family Carers**

Please read these instructions before answering the questionnaire.

There are no right or wrong answers. Honest answers will be most helpful.

This questionnaire includes a series of statements that we would like you to respond to by choosing a number from 0 to 10.

These numbers extend from one extreme answer (for example, 'not at all') to its opposite (for example, 'completely'). Please choose or circle the number between 0 and 10 that best represents how you feel.

Note that sometimes the best situation is at the 0 end of the scale, and sometimes the best situation is at the 10 end of the scale.

We are interested in learning about your OVERALL quality of life, so please consider any issues that affect you, even if they are not related to your caregiving role.

A blank in a sentence refers to the person you are caring for, but please do not write any name to keep this confidential.

(Date: / /)												
1. Over the past two day hospital, other) was the						ndei	red	if th	ne p	olac	e	was staying (home,
Never	0	1	2	3	4	5	6	7	8	9	10	Always
2. Over the past two day	s (4	8 h	ours	s) I I	nad	the	pri	vac	y I	war	ited.	
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
3. Over the past two day	s (4	8 ho	ours	s) th	ie c	ond	litio	n o	f		was	distressing to me.
Not often	0	1	2	3	4	5	6	7	8	9	10	Always
4. Over the past two day	s (4	8 h	ours	s) th	ne a	mo	unt	of o	con	trol	I have	e over my life was:
Not a problem	0	1	2	3	4	5	6	7	8	9	10	A huge problem
5. Over the past two day	s (4	8 h	ours	s) I I	nad	tim	e to	o ta	ke (	care	of my	yself.
Never	0	1	2	3	4	5	6	7	8	9	10	Always
Page: 27	ıest	tior	nna	ire	: 2	_	)			CAF	RiAD Car	er Diary Control v2 July 2017

6. Over the past two day	rs (4	8 ho	ours	s) I v	was	abl	e to	th	ink	clea	arly.	
Not often	0	1	2	3	4	5	6	7	8	9	10	Always
7. Over the past two day	rs (48	8 h	ours	s) p	hysi	call	y I f	elt:				
Extremely poor	0	1	2	3	4	5	6	7	8	9	10	Extremely good
8. Over the past two day	rs (48	8 h	ours	s) ei	mot	ion	ally	I fe	lt:			
Extremely poor	0	1	2	3	4	5	6	7	8	9	10	Extremely good
9. Over the past two day made me feel good:	rs (48	8 ho	ours	s) b	eing	ab	le to	o pı	ovi	de (	care o	or company for
Rarely or never	0	1	2	3	4	5	6	7	8	9	10	Always
10. Over the past two da spirituality:	ays (4	48 ł	nou	rs) l	l wa	s co	mf	orte	ed b	y n	ny ou	tlook on life, faith or
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
11. Presently I feel that I	my li	ife ŀ	nas	me	anir	ng:_			:			
Very little meaning	0	1	2	3	4	5	6	7	8	9	10	Very much meaning
For questions 12 and 13, if past two (2) days, please o												need health care in the
12. Over the past two da	ays (4	48 H	iou	rs) l	agı	reed	l wi	th t	he	way	y dec	isions were made for
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
13. Over the past two da	ys (	48 H	nou	rs) t	the	qua	lity	of	hea	lth	care	we received was:
Unsatisfactory	0	1	2	3	4	5	6	7	8	9	10	Extremely good
CARiAD Carer Diary Control	v2 Jul	ly 20	17			(		Qı	ıes	tio	nnai	re: 2

Very comfortable	0	1	2	3	4	5	6	7	8	-	9	10			Stressful
.5. Over the past two opeople most important					ove	erall	, I f	elt ı	my	in	ter	actions	with t	he ot	her
Very comfortable	0	1	2	3	4	5	6	7	8	9	9	10			Stressful
.6. Over the past two	days (4	18 H	nou	rs)	my	fina	ncia	al si	tua	iti	on	has be	en stre	ssful:	
Not at all	0	1	2	3	4	5	6	7	8	9	9	10		Co	mpletely

#### **QOLLTI-F: Quality of Life During Serious Illness – Family Carers**

Please read these instructions before answering the questionnaire.

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We are interested in learning about your OVERALL quality of life, so please consider any issues that affect you, even if they are not related to your caregiving role.

A blank in a sentence refers to the person you are caring for, but please do not write any name to keep this confidential.

name to keep this confide	iiiiai	•										
(Date://)												
1. Over the past two day hospital, other) was the						ndei	red	if th	ne p	lac	e	was staying (home,
Never	0	1	2	3	4	5	6	7	8	9	10	Always
2. Over the past two day	ys (4	8 ho	ours	s) I I	nad	the	pri	vac	уIv	war	ited.	
Not at all	0	1	2	3	4	5	6	7	8	9	10	Completely
3. Over the past two day	ys (4	8 h	ours	) th	ie c	ond	litio	n o	f		_ was	s distressing to me.
Not often	0	1	2	3	4	5	6	7	8	9	10	Always
4. Over the past two day	ys (4	8 h	ours	) th	ne a	mo	unt	of o	con	trol	I have	e over my life was:
Not a problem	0	1	2	3	4	5	6	7	8	9	10	A huge problem
5. Over the past two day	ys (4	8 h	ours	s) I I	nad	tim	ne to	o ta	ke d	are	of m	yself.
Never	0	1	2	3	4	5	6	7	8	9	10	Always
CARIAD Carer Diary Control	v2 Ju	ly 20	17			(	_	Qı	ıes	tio	nnair	Page: 30

	0	1	2	2	1	_	6	7	8	9	10	
Not often		_			_						10	Always
7. Over the past two da	ays (48	3 ho	ours	) pł	hysi	call	y I f	elt:				
Extremely poor	0	1	2	3	4	5	6	7	8	9	10	Extremely good
3. Over the past two da	ays (48	3 ho	ours	) er	mot	ion	ally	I fe	lt:			
Extremely poor	0	1	2	3	4	5	6	7	8	9	10	Extremely good
9. Over the past two da made me feel good:	ays (48	3 hc	ours	s) be	eing	ab	le to	o pr	ovi	de (	care o	r company for
	0	1	2	3	4	5	6	7	8	9	10	
Rarely or never												Always
Rarely or never  10. Over the past two opposite the past two oppos	days (4	18 h		rs) I		s co		orte	ed b	y m	ny out	
10. Over the past two c	days (4	18 h		rs) I		s co		orte	ed b	y m		Always look on life, faith or Completely
10. Over the past two ospirituality:  Not at all	days (4	18 h	2	rs) I	4	s co	6	orte	ed b	y m	ny out	look on life, faith or
10. Over the past two o	days (4 0 t my li	1 1 fe h	2 nas	rs) I	4 anir	5 ng:_	6	7	8 :	9	ny out	look on life, faith or
10. Over the past two ospirituality:  Not at all  11. Presently I feel that  Very little meaning	days (4	1 1 fe h	2 2 2	3 3 tt ma	4 anir 4	5 5 imp	6 6	7 7 ant	8 dec	9 9	10 10 ons or	look on life, faith or Completely
10. Over the past two ospirituality:  Not at all  11. Presently I feel that  Very little meaning or questions 12 and 13,	days (4	1 fe h dia er f	2 2 1 no	3 3 tt me	4  anir 4  ake	s co	6 6	7 7 ant	8 dec	9 9 cisio	10  10  ons or l.	Completely  Very much meaning  need health care in the
10. Over the past two ospirituality:  Not at all  11. Presently I feel that  Very little meaning or questions 12 and 13, ast two (2) days, please	days (4	1 fe h diaaer f	2 2 I no for t	3 mea 3 t me he l	4  anir 4  ake	5 imp	6 6 oort:	7 7 ant	8 deccyou	9 9 way	10  10  ons or l.	Completely  Very much meaning  need health care in the
Not at all  11. Presently I feel that  Very little meaning or questions 12 and 13, ast two (2) days, please  12. Over the past two of	days (4	1 1 dia er f	2 2 2 I no for t	3 3 tt mothe l 3	4  anir 4  ake last agi	5 5 impfew 5	6 6 coort tim	7 7 ant nes	8 decayouu	9 9 way	10  10  ny out 10  10  ns or /. / deci:	Completely  Very much meaning  need health care in the  sions were made for  Completely

	0	1	2	3	4	5	6	7	8	9	10			
Very comfortable														Stressful
5. Over the past two decople most important					ove	erall	, I fo	elt	my	inte	ractio	ons wit	h the	other
Very comfortable	0	1	2	3	4	5	6	7	8	9	10			Stressful
6. Over the past two d	lays (4	48 h	ou	rs) ı	my	fina	ncia	al si	itua	tior	n has	been st	ressfu	ıl:
Not at all	0	1	2	3	4	5	6	7	8	9	10		C	Completely

CARiAD Carer Diary Control v2 July 2017

Questionnaire: 3

Page: 32



CARer-ADministration of as-needed subcutaneous medication for breakthrough
symptoms in home-based dying patients: the CARiAD open pilot RCT

Step-by-step guides



# A step by step guide to opening and drawing up medications from an ampoule.

### **Instructions**

1. Wash your hands with soap and water and dry well.





2. Assemble the equipment in a clean container.



- 3. Attach blunt filter drawing up needle to luer-lock syringes.
  - Take the syringe out of the packet.
  - Put the needle onto the syringe using a twisting action until secure.





- 4 Opening an ampoule:
- a) For a plastic ampoule:
  - Simply twist the top of the ampoule until it is removed.



- b) For a glass ampoule:
  - Hold the ampoule upright with the pointed end at the top.
  - Check all fluid is removed from the neck of ampoule.
  - If not, gently flick the top of the ampoule until the fluid runs back into it.
  - If there is a dot on the ampoule this shows where the weak point in the neck is and where the ampoule should break. Ensure the dot is facing away from you.







## A step by step guide to opening and drawing up medications from an ampoule. (continued)

### **Instructions**

- 4 Opening an ampoule: (continued)
  - Hold the ampoule in one hand, place the ampoule opener on to the
    top of the ampoule using the other hand. With your thumb, push
    the neck of the ampoule away from you to snap the top off. Tip the
    top of the ampoule out of the ampoule opener into the sharps
    container. If it will not come out, dispose of ampoule opener and
    ampoule top together.



- 5. Drawing up medication from an ampoule:
  - Hold the ampoule in your non-dominant hand upside down at a slight angle or in a position that is comfortable for you such as on a table.
  - The medication should not come out of the ampoule if you tip it upside down.
  - Insert the needle into the ampoule.
  - Draw the medication into the syringe by slowly pulling back on the plunger of the syringe.
  - Once fluid is in the syringe, take the needle out of the ampoule.





6. Dispose of the ampoule directly into the sharps container.



7. Point the needle to the ceiling, flicking the syringe with your index finger to get all air bubbles in the syringe to move to the top.

Slowly push the plunger of the syringe upwards until you have the correct dose/amount as instructed by the doctor/nurse.







# 10 step plan for preparing and giving as-needed subcutaneous injections using a blunt needle technique.

Remember, if you have any concerns about any of the steps you can contact your healthcare team using the numbers in your carer diary.

1. Wash your hands with soap and water and dry well.





#### 2. Assemble the equipment in a clean container. You will need:

- Medication(s) ampoule(s) as well as normal saline for flushing.
- Luer-lock syringes.
- Blunt filter drawing up needle(s).
- Alcohol wipe (optional).
- Sharps container.



#### 3. Check the injection site for:

- Redness.
- Tenderness.
- Swelling.
- Leakage.





#### 4. Attach the blunt drawing up needle to the Luer-lock syringe.

- Take the syringe out of the packet.
- Put the needle onto the syringe using a twisting action until secure.



#### 5. Open the plastic or glass ampoule.

 Refer to the guide 'Opening and drawing up from an Ampoule'.





#### 6. Drawing up medication from an ampoule:

- Place the ampoule in a position that is comfortable for you, such as on a table, or turn the ampoule upside down. The medication should not come out of the ampoule when turned upside down.
- Insert the needle into the ampoule.
- Draw up the medication by slowly pulling back on the plunger of the syringe.





## 10 step plan for preparing and giving as-needed subcutaneous injections using a blunt needle technique (continued).

#### 6 Drawing up medication from an ampoule: (continued)

- Once the medication is removed from the ampoule, hold the syringe with the needle pointing upright.
- Flick the syringe with your finger to get all air bubbles to the top,
   then push the plunger up to expel the air bubbles from the syringe.
- Slowly push the plunger of the syringe upwards until you have the correct dose/amount as instructed by the doctor/nurse.
- Dispose of the ampoule directly into the sharps container.





#### 7. Give the injection into the cannula:

- Take the prepared syringe(s) in a clean container, and a sharps container to the person.
- Remove the drawing up needle and dispose of it into the sharps container.
- Place the small blunt needle on the end of the syringe using a twisting motion to secure it.
- Swab the white rimmed cap at the end of the cannula with an alcohol wipe (optional).
- Push the blunt plastic needle into the centre of the white rimmed cap.
- Slowly push the plunger of the syringe until the barrel is empty.
- Remove syringe with needle from the cannula and dispose of it into the sharps container.
- Repeat the process with 0.5mls of normal saline after all medications have been given to flush the line.







#### 8. Check the injection site for:

- Redness.
- Tenderness.
- Swelling.
- Leakage.





#### 9. Record the medication(s) given in the carer diary and check later that they have worked.

#### 10. Safe storage and disposal of medication(s):

- Store medication(s) in a container in a cool place away from children and away from the view of the general public.
- Store sharps container out of reach as directed by your nurse.
- It is important to dispose safely of unused medication(s). Return unused medication(s) to your local pharmacist when they are no longer required.



# 10 step plan for preparing and giving as-needed subcutaneous injections using a no-needle technique.

Remember, if you have any concerns about any of the steps you can contact your healthcare team using the numbers in your carer diary.

1. Wash your hands with soap and water and dry well.





#### 2. Assemble the equipment in a clean container. You will need:

- Medication(s) ampoule(s) as well as normal saline for flushing.
- Luer-lock syringes.
- Blunt filter drawing up needle(s).
- Alcohol wipe (optional).
- Sharps container.



#### 3. Check the injection site for:

- Redness.
- Tenderness.
- Swelling.
- Leakage.





#### 4. Attach the blunt drawing up needle to the Luer-lock syringe.

- Take the syringe out of the packet.
- Put the needle onto the syringe using a twisting action until secure.



#### 5. Open the plastic or glass ampoule.

 Refer to the guide 'Opening and drawing up from an Ampoule'.





#### 6. Drawing up medication from an ampoule:

- Place the ampoule in a position that is comfortable for you, such as on a table, or turn the ampoule upside down. The medication should not come out of the ampoule when turned upside down.
- Insert the needle into the ampoule.
- Draw up the medication by slowly pulling back on the plunger of the syringe.





## 10 step plan for preparing and giving as-needed subcutaneous injections using a no-needle technique (continued).

#### 6 Drawing up medication from an ampoule: (continued)

- Once the medication is removed from the ampoule, hold the syringe with the needle pointing upright.
- Flick the syringe with your finger to get all air bubbles to the top, then push the plunger up to expel the air bubbles from the syringe.
- Slowly push the plunger of the syringe upwards until you have the correct dose/amount as instructed by the doctor/nurse.
- Dispose of the ampoule directly into the sharps container.





#### 7. Give the injection into the cannula:

- Take the prepared syringe(s) and normal saline flush in a clean container to the person.
- Remove the blunt filter drawing up needle and dispose of it in the sharps container.
- Next pick up the cannula, and push the syringe into the blue/yellow area (see picture), using a twisting or screwing motion until the syringe is securely attached to the cannula.
- Slowly push the plunger of the syringe until the barrel is empty.
- Remove the syringe, use a twisting motion to unscrew the syringe.
- Place syringe in bin.
- Repeat the process with 0.5mls of normal saline after all medications have been given to flush the line.

#### 8. Check the injection site for:

- Redness.
- Tenderness.
- Swelling.
- Leakage.





#### 9. Record the medication(s) given in the carer diary and check later that they have worked.

#### 10. Safe storage and disposal of medication(s):

- Store medication(s) in a container in a cool place away from children and away from the view of the general public.
- Store sharps container out of reach as directed by your nurse.
- It is important to dispose safely of unused medication(s). Return unused medication(s) to your local pharmacist when they are no longer required.





CARer-ADministration of as-needed subcutaneous medication for breakthrough
symptoms in home-based dying patients: the CARiAD open pilot RCT
Injection training pack

### Injection training pack



### **Suggested contents:**

- Plastic container with a lid
- Saf-T-Intima inserted into a stoma type adhesive dressing
- Selection of luer-lock syringes (3 and 5 ml)
- Water or Normal Saline ampoules (glass & plastic)
- Ampoule opener
- Blunt filter drawing up needles
- Alcohol wipes (if required)
- Blunt needles for injecting into a cannula (if required)