

**CARIAD – Carer administration of as-needed subcutaneous medicines for breakthrough symptoms at home.**  
**Information sheet for patients and carers**

**It is important to note that this information sheet is for both patients and carers, which can be read together or separately.** Although some sections may only apply to the patient or the carers, we encourage you to read through all of the information.

Seriously ill people often want to spend their last days of life at home being cared for by family or friends. This information sheet is about how carers, who are looking after a very ill person at home, can be taught to give extra (top-up) doses of medication under the skin to the person they are caring for when they experience ‘breakthrough’ symptoms (that is, symptoms not controlled by their regular medication). This will be in addition to the care they are already receiving.

**Why is this important?**

People who are seriously ill and nearing the end of their life may want to be cared for in their own homes. As their illness gets worse they may find it difficult to take medicines by mouth – either because they are experiencing nausea and 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. Once it is in place it can be used to give the person medication under the skin **without** using needles – this is sometimes called a **subcutaneous injection**.

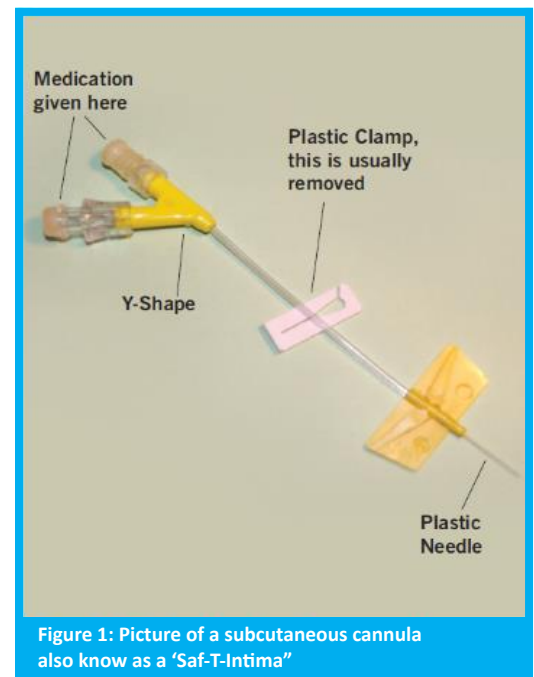


Figure 1: Picture of a subcutaneous cannula also know as a ‘Saf-T-Intima’

If a person is on regular medications, a syringe pump is often connected to the cannula to give medications throughout the day and night to keep symptoms controlled. The person may experience some symptoms even when this is in place – these are called breakthrough symptoms and the most common are pain, nausea, anxiety/agitation, noisy ‘rattly’ breathing and breathlessness. When this happens, a family member/friend is advised to call a healthcare professional, usually a district nurse. The nurse will visit and give the patient an extra dose of medication using the cannula that is already in place. Your healthcare team will check the cannula regularly and change it when needed.

These are sometimes called “**as-needed**” medications. It may take some time for the nurse to arrive, prepare and give the medication.

Teaching carers to learn how to do this instead of having to wait for a nurse to attend is a method that has been used successfully in parts of Australia for many years, and more recently in the UK. As part of the CARIAD Package, those acting as a carer will be trained by a healthcare professional to recognise breakthrough symptoms and prepare and give no-needle medications to manage these symptoms. The carer will receive ongoing support and training as necessary.

### What is involved?

#### *For the Patient*

The healthcare team will ask you who you would like to act as your carer or carers:

- You can have up to two carers to take on this role.
- This person(s) should be a family member or friend who is involved in your day-to-day care, but not anyone who is being paid to provide care for you.
- Your chosen carer(s) should live close-by or be temporarily living with you

We will approach the carer(s) you have identified and ask them to read through this information sheet. We will explain what this would involve for them and that they are not under any obligation to take on this role.

Your chosen carer(s) will be trained to give you subcutaneous medications for breakthrough symptoms and will record information about your breakthrough symptoms in a daily diary.

We will contact your GP and district nursing team to let them know you are being cared for in this way.

You will receive your regular healthcare visits and medication as normal. All that will change is who gives the medication for breakthrough symptoms.

#### *For the Carer*

You will be trained by the nurses to recognise breakthrough symptoms, prepare and give no-needle medications at home. The training given to you is very important, in order to make sure that the patient is given the correct care for breakthrough symptoms. Therefore, you should not train anyone else who is helping to look after the patient. If you are unavailable for any reason (or if there are two carers and both are unavailable), the healthcare team should be contacted to give the patient any as-needed medication. Once trained, you can also choose to



call the healthcare team and wait for them to give the medication, or you can give the medication yourself and ask the nurse to check on the patient later.

Everyone who chooses the CARIAD Package will be able to access support via the usual route for their area. Regular visits from the patient's healthcare team will continue as usual.

*Additional information for both patients and carers*

We do not expect there to be any problems but the healthcare team will monitor you regularly. If the healthcare team believe the patient's care would be better provided in a different way, it will be discussed with both the patient and the carer(s).

Carers will keep a diary of symptoms and medication given. If the patient is able, they will help the carer(s) fill the diary in by answering questions about their breakthrough symptoms and how long it takes for them to improve. After the patient's death, the healthcare team will keep contact with the carer(s).

It is important for you to know that it is completely legal for carers to give symptom-relieving medications as long as they are supported to do so.

The person(s) caring for the patient will be able to give medications for breakthrough symptoms when the patient is very ill and near the end of their life. This might mean that the time when the patient dies is near to when the carer has last given medication. It is very important for those involved to know that these two things are not related and the medication has not ended their life.

If the patient is admitted to a hospital at any stage, the medical team there will handle the management of all the medications (including those for breakthrough symptoms). The carer(s) should not give any no-needle medication if the patient is in the hospital.

If at any time any of you have questions regarding this intervention, please contact your healthcare team.

