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**Example policy and procedures:** *Supporting carers/families to help manage breakthrough symptoms safely using subcutaneous medicines in the home*

VERSION 5 – JULY 2024

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#### Disclaimer

TheExample policy and procedures*: Supporting carers/families to help manage breakthrough symptoms safely using subcutaneous medicines in the home* is intended as a guide for clinical services to help them develop or review their own policies and procedures.

While the Brisbane South Palliative Care Collaborative has exercised due care in ensuring the accuracy of the material (at the date of publication) contained in the example policy and procedures, it is only a general guide to developing appropriate policies and procedures.

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| --- |
| Overview **Purpose of this policy and procedures document**  The purpose of this document is to provide an Example policy and procedures: *Supporting carers/families to help manage breakthrough symptoms safely using subcutaneous medicines in the home*.Clinical services can use this document to develop or review their own policies and procedures.  This document outlines example policy and procedures for providing high quality palliative care by teaching carers/families how to help manage breakthrough symptoms safely using subcutaneous medicines.  This document is a component of the resources developed as part of a National Palliative Care Project called caring@home.  This project aims to improve the quality of palliative care service delivery across Australia by providing resources that will support people to be cared for, and die at home, if that is their choice.  The policy and procedures described here are supported by resources developed by the project. These resources are available at [**www.caringathomeproject.com.au**](file://PA-CL3_SC_DATA7/DATA7/Caring@Home%20Project/Education%20activities/Policy/www.caringathomeproject.com.au)**.**  **How to use this document**  This document is a resource for clinical services to inform the development of policy and procedures for supporting the carers/families of a palliative patient, to help manage breakthrough symptoms safely using subcutaneous medicines in the home. It is not meant to be prescriptive. A clinical service may adapt the content of the policy and procedures to meet their identified needs. This document is applicable to all jurisdictions across Australia and should be used in combination with other caring@home resources.  **How was this document developed?**  This document was developed using best practice guidelines regarding home-based palliative care as identified in the literature. Guidelines include:   * [Guidelines for the Handling of Palliative Care Medicines in Community Services, Version 2, 2020](https://www.caringathomeproject.com.au/Portals/13/Documents/NPS-Palliative-Care-Guidelines-v25-jg260620-ACC.pdf) * [National Palliative Care Strategy 2018](https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018) * [Nursing and Midwifery Board of Australia Nursing Standards for Practice](https://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/Professional-standards.aspx) * [National Palliative Care Standards 5.1 ed, 2024](https://palliativecare.org.au/national-palliative-care-standards/) * [Palliative Care Therapeutic Guidelines, Version 4, 2016](https://tgldcdp.tg.org.au/guideLine?guidelinePage=Palliative+Care&frompage=etgcomplete) |

## Terms/definitions

|  |  |
| --- | --- |
| **Anticipatory prescribing** | Anticipatory prescribing is designed to enable prompt symptom relief when the person develops distressing symptoms. It is based on the premise that although each person is different, many acute events that occur at the end of life can be predicted and management measures put in place in advance. |
| **Breakthrough symptoms** | Even with regular medicines, sometimes symptoms can unexpectedly get worse. When this occurs, it is called a “breakthrough symptom” and may require an extra dose of medicine. |
| **Carer** | A person who provides personal care, support and assistance to another person who needs it because they have a disability, medical condition (including terminal or chronic illness) or mental illness, or they are frail and aged. An individual is not a carer merely because they are a spouse, de facto partner, parent, child, other relative or guardian of an individual, or live with an individual who requires care. A person is not considered a carer if they are paid, a volunteer for an organisation or caring as part of a training or education program. |
| **caring@home** | [caring@home](http://www.caringathomeproject.com.au/) is a national project funded by the Australian Government that aims to improve the quality of palliative care service delivery across Australia by developing resources that support people to be cared for, and die at home, if this is their choice. |
| **Family** | The family is defined as the people identified by the person as a family. This may include people who are biologically related, however it may not. People who joined the family through marriage or other relationships, such as kinship, as well as the chosen family, street family for those experiencing homelessness, and friends (including pets) may be identified by the person as family. |
| **Palliative care** | Care provided for a person of any age who has a life-limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life. |
| **Prescriber** | A health professional authorised to write prescriptions and medication orders and give directions (verbal or written) about administration and supply of prescription-only medicines. |
| **Registered nurse** | A registered nurse is a person with appropriate educational preparation and competence for practice, who is registered with the Australian Health Practitioner Regulation Agency (AHPRA) to practise nursing in Australia. |
| **Sharps container** | A sharps container is used for disposing of needles and syringes that are generally classified as “sharps” within State and Territory waste management legislation. |
| **Subcutaneous cannula** | A subcutaneous cannula is a thin plastic tube that is inserted under the person’s skin. |
| **Subcutaneous medicine** | Subcutaneous medicine is medicine given via a small plastic tube placed under the person’s skin. |
| **Unused medicines** | Unused medicines are medicines dispensed to a patient that are no longer in use including all patient medicines after the person’s death. |

# Part One: Policy

[Name of clinical service] is committed to providing quality palliative care to people who wish to be cared for, and die at home, if possible, by supporting families and carers tohelp manage breakthrough symptoms safely using subcutaneous medicines.

## Purpose

This policy has been written to provide health professionals working in the community with a safe framework to use when teaching families and carers to help manage breakthrough symptoms using subcutaneous medicines. This policy facilitates safe and effective symptom control, patient choice, family/carer involvement and honours preferred place of care and death.

## Policy statement

The aim of modern palliative care is to support palliative patients to live and die in a manner that aligns with their personal lives, in the setting of their choice, with symptom control and a pattern of care that is supportive of patients’ family/carers. Palliative patients consistently nominate home as their preferred place of care; however, without the support of at least one carer, such as a family member, this is difficult. In part, this is because symptoms in palliative patients are prone to rapid and unpredictable escalation; severe symptoms can emerge at any time and, if not optimally treated, can necessitate transfer to inpatient settings.[[1]](#footnote-2)

This policy is supported by caring@home resources that specifically aim to improve symptom management for home-based palliative patients. The resources provide education for nurses and training materials for families and carers to partner in providing care in the final weeks of a person’s life through safe administration of subcutaneous medicines to alleviate breakthrough symptom distress. In this model of care, community-based services can support families/carers, who volunteer, by integrating them into the multidisciplinary team and providing them with best-practice education and skills to help manage breakthrough symptoms safely by giving subcutaneous medicines as required.

## Guiding principles

Principle 1: Respecting Patient Preferences

* People should be supported to be cared for and die in the place of their choice.

Principle 2: Support and Appreciation for Families and Carers

* The important role of the dying person’s family and carers in providing physical, emotional, social and spiritual support and care is appreciated and respected.
* Supporting the person’s family and carers by working with them to understand the level of care they are willing and able to provide is essential to quality palliative care.
* For the family/carer, the voluntary nature of the role and the ability to stop managing breakthrough symptoms using subcutaneous medicines at any time must be acknowledged.
* Bereavement support is considered important to families/carers should they be involved in breakthrough symptom management.

Principle 3: Open Communication and Cultural Sensitivity

* The process of initiating the use of subcutaneous medicines to help manage breakthrough symptoms must be openly discussed with the person (if appropriate) and the family/carer in the context of death and dying, respecting the person’s specific spiritual, religious and cultural needs.

Principle 4: Multidisciplinary Team Support

* Families/carers are to be supported to help manage breakthrough symptoms safely using subcutaneous medicines within a safe and supportive environment and after appropriate training and support. All members of the multidisciplinary team are to support families/carers being able to give subcutaneous medicines to help manage breakthrough symptoms.

Principle 5: Giving Attention to Vulnerable Populations

* Special attention is paid to the needs of people who may be especially vulnerable or at risk, for example, Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse communities.

## Principles of service provision

* Registered nurses[[2]](#footnote-3) administering any medicines, assisting with administration, or supporting families/carers to give medicines must exercise professional judgement, apply knowledge and recognise their professional accountability according to the organisation’s mandatory training requirements and the requirements of the Nursing and Midwifery Board of Australia’s Registered nurse standards for practice - effective 1 June 2016.[[3]](#footnote-4)
* Registered nurses are responsible for recognising any limitations in their knowledge and competence and must decline any duties they do not feel able to perform in a skilled and safe manner in accordance with the Nursing and Midwifery Board of Australia’s Registered Nursing Standards for Practice - effective 1 June 2016.3
* Clinical services are responsible for using best-practice principles with families/carers who are taught to give subcutaneous medicines including:
  + Using a closed, needle-free technique, with a subcutaneous cannula and luer lock syringes to maximise patient, family/carer and staff safety and reduce the incidence of needle stick injury.
  + Unless clinically contraindicated, two subcutaneous cannulas should be inserted to ensure that, in the case of one cannula becoming blocked, the patient can still have timely access to symptom control medicines. This is particularly important if a nurse is not immediately available to change the subcutaneous cannula.
  + If the patient has a continuous subcutaneous infusion via one of the cannulas, breakthrough medicines should be administered via the second subcutaneous cannula rather than using the second arm of the cannula connected to the infusion device.
  + Flushing the subcutaneous cannula with 0.9% sodium chloride 0.5mL after subcutaneous medicines are given. Some subcutaneous medicine doses are delivered in small volumes therefore flushing the cannula after the last medicine dose ensures the patient receives the complete dose of prescribed medicine.
* Registered nurses teaching families/carers to help manage breakthrough symptoms with subcutaneous medicines need to complete the caring@home education for nurses or equivalent.
* Registered nurses must assess whether a carer is competent to safely prepare and give subcutaneous medicines. Registered nurses have a legal obligation to ensure that carers taught to prepare and give subcutaneous medicines are competent to do so. Competency can be demonstrated using the *Training checklist and carer/family post-training competency assessment* checklist (see Appendix 1).
* Registered nurses will ensure the carer has been trained using the caring@home resources and have access to ongoing support both in person and via a 24-hour on-call procedure.
* All adverse incidents are to be reported by existing internal reporting arrangements.
* Registered nurses should use their clinical judgement to critically assess each individual situation and intervention when appropriate.
* All employees practise in accordance with specific policies and procedures, linked to continuous quality improvement and risk management programs of their employment organisation, to allow safe and effective medicine management.

## 

## Relevant resources

### caring@home resources

To support implementation into routine clinical practice, caring@home has developed resources at three levels:

1. Clinical services
2. Health professionals
3. Carers/Families

|  |  |  |
| --- | --- | --- |
| **Level** | **Resource** | **Description** |
| **Clinical services** | National Core Community Palliative Care Medicines List | The National Core Community Palliative Care Medicines List (the List) identifies four medicines for use by home-based palliative patients in the terminal phase who require urgent symptom relief |
| Guidelines for the handling of palliative care medicines in community services (Version 2) | These guidelines can be used by community service providers to inform the development of detailed protocols and procedures tailored to the requirements of individual services |
| Example policy and procedures: Supporting carers/families to help manage breakthrough symptoms safely using subcutaneous medicines in the home (Version 5) | This document may be used by community service providers to develop and/or review relevant documentation within their own organisation’s policy and procedure framework |
| **Health professionals** | palliMEDS App | This app familiarises primary care prescribers and community pharmacists with eight palliative care medicines used for management of terminal symptoms |
| PELP Palliative and End-of-Life Prompts | A framework to support identification of the emergent clinical needs of the patient and to optimally manage the dying process |
| Online education modules | The online education aims to educate nurses about how to teach carers/families to manage symptoms at home, including safely using subcutaneous medicines |
| Managing palliative care symptoms: A guide for health professionals | To assist health professionals to support families who are caring for a person who chooses to die at home if this is possible |
| Introducing caring@home resources PowerPoint | This presentation may be used when introducing the caring@home resources to your service |
| Conducting education for a carer PowerPoint | This presentation can be used to conduct face-to-face education sessions with nurses rather than requiring nurses to complete the online education modules developed as a part of the caring@home resources |
| **Families/carers** | caring@home resources for families and carers include:   * The Community Palliative Care Resources Box * Resources for Aboriginal and Torres Strait Islander Families packaged as the Palliative Care Clinic Box * Standard resources plus translation of some of these resources into 9 commonly spoken languages in Australia.   See pages 11 and 12 for detail about these resources | |

### caring@home resources for families and carers

### 

### [National Palliative Care Standards 5.1 ed, 2024](https://palliativecare.org.au/national-palliative-care-standards/)

The National Palliative Care Standards (5th ed) have been updated following consultation with the palliative care community and other stakeholders. The Standards clearly articulate and promote a vision for compassionate and appropriate specialist palliative care. The Standards recognise the importance of care that is person-centred and age appropriate. In particular, they point to the requirement for specific attention to the needs of people who may be especially vulnerable or at risk.

### [Therapeutic Guidelines: Palliative Care Version 4, 2016](https://tgldcdp.tg.org.au/guideLine?guidelinePage=Palliative+Care&frompage=etgcomplete)

A practical and up-to-date Australian palliative care text for all healthcare professionals, particularly those working in primary care, is vital. The revised 4th edition continues to provide good advice from expert clinicians on a range of practical issues, including symptom management, communication guidance and support for deprescribing.

### [Nursing and Midwifery Board of Australia Professional Standards](http://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/Professional-standards.aspx)

Nurses and midwives must be registered with the Nursing and Midwifery Board of Australia (NMBA) and meet the NMBA's professional standards to practise in Australia.

Professional standards define the practice and behaviour of nurses and midwives and include:

* Codes of conduct
* Standards for practice
* Codes of ethics.

# Part Two: Procedures

## Step 1. Training for staff: Nurse information and education

Sustainable and ongoing staff training processes are implemented to ensure all nurses who will be teaching families and carers to give medicines have an understanding and knowledge of the caring@home resources.

The primary resources are the modules -

* Module 1: Understanding the caring@home resources and their benefits
* Module 2: Conducting one-on-one carer/family training

PowerPoint presentations have been developed for group learning.

Other educational resources are listed in the policy section.

## Step 2. Implementing

### Identify the carer/s

The appropriate health professional must:

* Identify when a person receiving palliative care is approaching their end of life in a timely manner.
* Identify the person’s and family’s/carer’s wishes for place of care through open discussion in the context of supporting a home death.
* Identify if the family/carer would like more than one carer to be trained to manage subcutaneous medicines.
* Use clinical judgement to determine the suitability of carers to give subcutaneous medicines to help manage breakthrough symptoms. The *Assessment of carer preparedness to administer subcutaneous medicines checklist* (See Appendix 2) may help to inform decision making.
* Use professional judgment to decide which caring@home resources would be most appropriate for the carer/s to use: the Community Palliative Care Resources, Standard version, the version for Aboriginal and Torres Strait Islander families or translated versions (nine languages available).
* Determine the carer/s’ willingness to give subcutaneous medicines by explaining the procedure for managing breakthrough symptoms, explaining why symptom management is important and explaining the role of the carer in helping to manage breakthrough symptoms safely by using subcutaneous medicines. If carer/s is/are not willing, alternative care to ensure patient symptom control needs to be explored.
* Identify additional potential supports to support the primary carer if the carer is willing to take on the role.
* Leave resources (as considered appropriate by the health professional) with carer/s after the initial discussion about giving subcutaneous medicines.
* Clearly explain to the carer/s that they can discontinue helping to manage breakthrough symptoms with subcutaneous medicines at any time, should they wish to, and that alternative care to ensure adequate symptom control will be provided.

### Liaise with the multidisciplinary team

* Inform all relevant health stakeholders of the carer/s’ decision to volunteer to give subcutaneous medicines to help manage breakthrough symptoms and communicate this according to organisational guidelines.
* If appropriate, send a letter to the prescriber indicating that training has occurred (See Appendix 3).
* Discuss anticipatory prescribing with the person’s prescriber and plan to ensure prescriptions and medicine supplies are available when needed. The prescriber will be required to prescribe anticipatory medicines and all relevant information must be communicated to them.

### Preparing for one-on-one training with the carer/s

* Assemble clinical equipment required and the relevant caring@home resources for carers (as listed in the policy section of this document) that will meet the needs of the patient and their carer/s.

### Training the carer/s

* Deliver one-on-one training with carer/s as the key strategy for educating carers about managing breakthrough symptoms safely using subcutaneous medicines.
* Create a relaxed and open environment allowing the carer/s space to focus and concentrate on the training. This includes ensuring the person being cared for is settled and comfortable before commencing the training.
* Provide an opportunity for the carer/s to express any fears and anxieties that they may have.
* Use the *Training checklist and carer/family post-training competency assessment* (See Appendix 1) to guide training.
* Assess the carer’s ability to prepare and give subcutaneous medicines using the *Training checklist and carer/family post-training competency assessment* (See Appendix 1).
* File the assessment in the patient’s chart.
* Ensure all relevant contact numbers are available and encourage the carer to report any concerns or phone to ask questions.

### Appropriate support

* Provide a 24-hour on-call phone number that carers can use outside of business hours that is supported by a procedure to manage after-hours emergency situations and carers’ questions about subcutaneous medicine use.
* Conduct home visits according to patient need to support the carer. Assess the effectiveness of care at each contact, review the medicines diary/book and adjust the care plan in liaison with the treating doctor to best meet the needs of the patient.
* Assess the need for further training or support at each contact. Reiterate the role of the on-call service and encourage the carer/s to use the after-hours telephone number for ongoing support.
* Review the supply of medicines at each contact and support the carer/s to restock medicines according to local practices.
* Provide replacement resources if originals are lost or inaccessible.

## Step 3. Safe handling of medicines

Medicine prescription, management, storage, transport, administration and disposal is conducted in accordance with the [Guidelines for the handling of medicines in community services.](https://www.caringathomeproject.com.au/Portals/13/Documents/NPS-Palliative-Care-Guidelines-v25-jg260620-ACC.pdf) Processes comply with state and local policy regulations and workplace policy and procedures.

### Medicine authorisation

* Prescription-only medicine must not be given unless an authorised prescriber has provided an order for this to occur. Each order must be recorded in the person’s medical record according to the policy and procedures of the organisation so that a complete and up-to-date reference record is available to all appropriate health professionals involved in the person’s care. Any changes in dosage, route or frequency must be included in this record.
* Specific guidelines may differ between states - please refer to the medication guidelines specific to your state and workplace policy and procedure regarding medicine management.

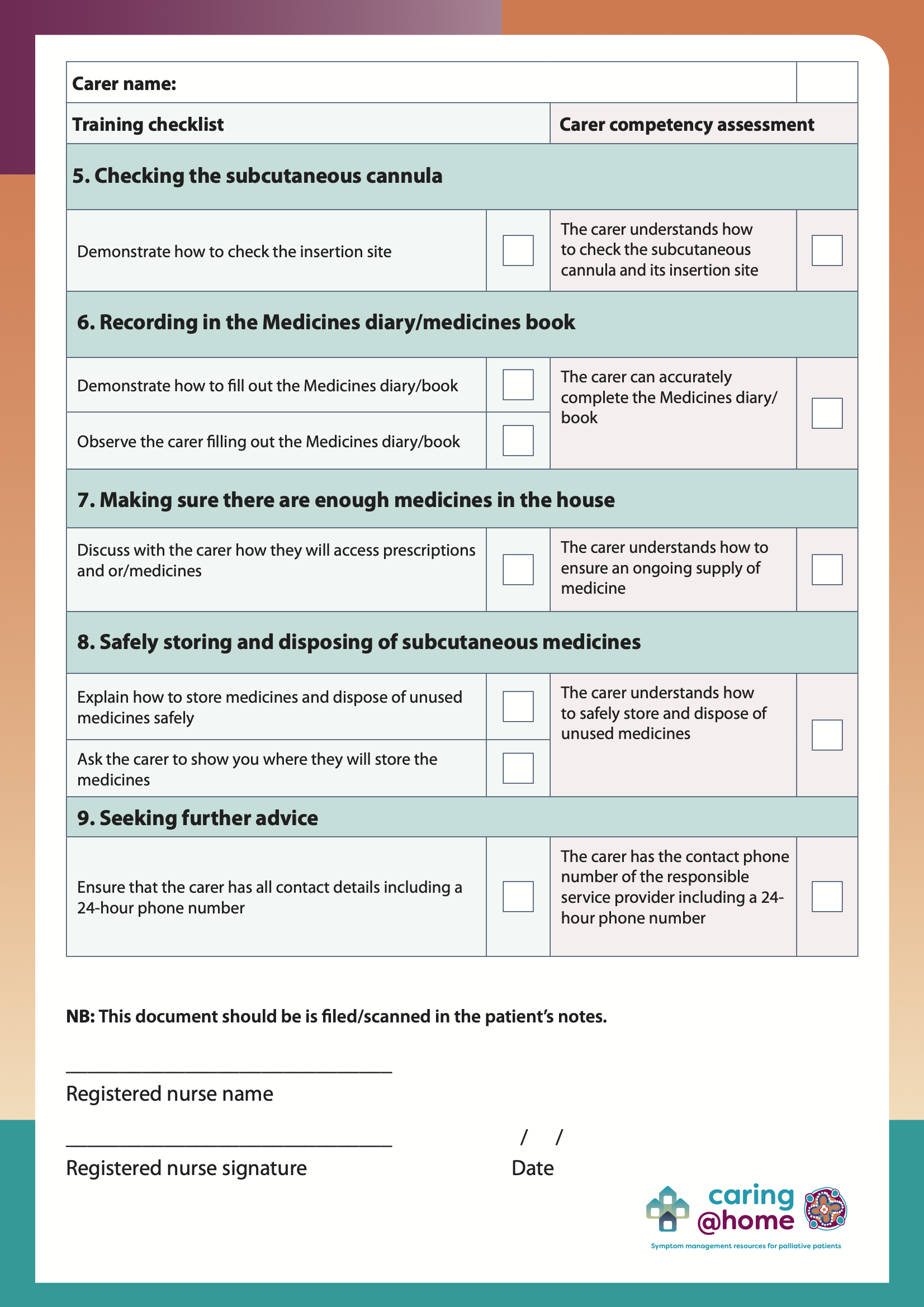
### Storage of medicines in the home

* Educate carer/s about appropriate storage of medicines and emphasise that medicines must be stored in accordance with instructions included on the label and instructions discussed by the appropriate health professional. Inform carers that they are responsible for the safe storage of all medicines within the home environment and provide education to support this process.
* Store pre-prepared subcutaneous medicines in the fridge (or similar) in an appropriate container to decrease risk of microbial contamination. Each syringe must be labelled using a colour-coded label and marked with the following in accordance with national standards[[4]](#footnote-5):
  + - Medicine name
    - Medicine dose
    - Date of preparation
    - Initials of the person preparing the syringe

### Disposal of medicines

* Educate carers that unwanted or unused medicines must be disposed of safely according to state legislation and workplace policy and procedures.

# Appendix 1: Training checklist and carer/family post-training competency assessment



# Appendix 2: Assessment of carer preparedness to give subcutaneous medicines checklist[[5]](#footnote-6)

This checklist can be used by nursing staff to support clinical decision making when determining a carer’s preparedness and ability to manage breakthrough symptoms safely using subcutaneous medicines. This tool does not replace a nurse’s clinical judgment. The carer’s confidence may increase after receiving more information and education. The service provided should explore the support needs of the carer and use this understanding of their individual situation to inform the decision to implement the use of subcutaneous medicines in the home.

|  |  |  |
| --- | --- | --- |
| **Questions** | **Yes** | **No** |
| Is the prescriber aware and agreeable to the carer giving the person subcutaneous medicines? |  |  |
| Has the carer demonstrated an understanding of the reasons for the use of subcutaneous medicines? |  |  |
| Is the carer willing to give subcutaneous medicines at home? |  |  |
| Does the carer have any relevant health issues or cognitive impairment that may affect their ability to safely give subcutaneous medicines? | Specify: |  |
| Does the carer have any visual impairment that may affect their ability to safely give subcutaneous medicines? | Specify: |  |
| Is the carer able to understand the resources? | Specify: |  |
| Can the carer read the colour-coded syringe labels and the fridge chart? |  |  |
| Are there any other factors that may affect the carer’s ability to safely give subcutaneous medicines? | Specify: |  |

On a **Scale of 0 – 3** how confident is the carer feeling about their ability to manage breakthrough symptoms safely using subcutaneous medicines?

|  |  |
| --- | --- |
| **Score** | **Level descriptor** |
| 0 | Unwilling/ unable |
| 1 | Less confident |
| 2 | Confident |
| 3 | Very confident |

# Appendix 3: Prescriber correspondence letter[[6]](#footnote-7)

[Clinical service’s name/ logo/ letterhead]

[Patient information]

[Date]

Dear [Prescriber’s name],

It has been identified that the above person requires subcutaneous medicines to help manage breakthrough symptoms at home. As it is the client’s and carer’s wish to remain at home, we have discussed the carer’s willingness to give subcutaneous medicines using the caring@home resources with support from our service.

[name of carer] has been identified as the main carer for this person who will give subcutaneous medicines to help manage breakthrough symptoms.

We have determined that the carer is an appropriate person for this role.

We have provided training to the above carer using the caring@home resources in the context of supporting a home death. The training topics include teaching carers about:

* Recognising and rating breakthrough symptoms
* Knowing what subcutaneous medicine to give for each symptom
* Writing a label, opening an ampoule, and drawing up medicine (if the nurse does not do this)
* Giving medicine using a subcutaneous cannula
* Checking the subcutaneous cannula
* Recording in the medicines diary/book
* Safely storing and disposing of subcutaneous medicines
* Making sure there are enough medicines in the home
* Seeking further advice.

The carer has agreed to:

* Participate in ongoing education and support
* Contact the on-call nursing services if support is required.

The carer understands that you are likely to prescribe medicines in anticipation of common emergent symptoms.

Participating carer confidence to give subcutaneous medicines is assessed regularly during home visits.

The carer is aware that they can change their minds at any time. If choices change, we will contact you to discuss the person’s place of care options.

[Name]

[Designation]

[Signature]

[Date]

[Contact]

1. Israel F, Reymond L, Slade G, Menadue S, Charles MA. [Lay caregivers’ perspectives on injecting subcutaneous medications at home.](http://doi.org/10.12968/ijpn.2008.14.8.30774) *Int J Palliat Nurs.* 2008; 14(8):390-395. [↑](#footnote-ref-2)
2. Other suitably qualified and registered health professionals may be able to teach carers/families to give subcutaneous medicines depending on jurisdictional requirements. [↑](#footnote-ref-3)
3. Nursing and Midwifery Board of Australia. Registered nurse standards for practice - effective 1 June 2016. Melbourne: Nursing and Midwifery Board of Australia. [↑](#footnote-ref-4)
4. Australian Commission on Safety and Quality in Health Care. [National Standard for User-applied Labelling of Injectable Medicines, Fluids and Lines.](https://www.safetyandquality.gov.au/wp-content/uploads/2015/09/National-Standard-for-User-Applied-Labelling-Aug-2015.pdf) Sydney: ACSQHC, 2015. [↑](#footnote-ref-5)
5. Adapted from WA Country Health Service: Medication safety for palliative carers at home procedure. Government of Western Australia. [↑](#footnote-ref-6)
6. Adapted from WA Country Health Service: General Practitioner notification letter. Government of Western Australia. [↑](#footnote-ref-7)