Just in Case Box:
GUIDELINES

September 2016

The District Nurses | hospice @HOME

Contents

Context

In June 2012, the Australian Government announced a $325 million investment in Tasmania's health system. Through the Tasmanian Health Assistance Package (THAP) a number of significant investments were made to further develop and support Tasmania's health system to meet future challenges which included $63.2m over 4 years to strengthen end of life choices in Tasmania. Components of that investment included the Better Access to Palliative Care (BAPC)[1].

The objective of the BAPC Program is to expand the existing capacity of the Tasmanian health system to deliver multidisciplinary, home based end of life services for people with life limiting illnesses[2]. hospice@HOME, a partner in the BAPC, provides packages of wrap around care to offer individually tailored services to meet a client's specific needs enabling them to remain at home for their end of life or to remain at home for as long as possible[3].

Since its beginning in 2014, hospice@HOME has observed that when patient's need terminal care, they can experience new or worsening symptoms outside of standard hours when access to subcutaneous medications and care support in the community is difficult. In 2014-2015, 60% of hospice@HOME patient's who died in hospital were admitted for terminal care. The reasons for this are complex, but with hospice@HOME patient's receiving an unprecedented amount of terminal home care support, it has been identified that access to terminal medications and care support is a contributing factor. The UK[4], Canada[5] and to a greater or lesser degree in the majority of other states and territories in Australia[6-10] use standardised systems and processes of anticipatory prescribing to provide easy and timely access to terminal medications. The implementation of 'Just in Case' boxes aims to reduce the number of hospice@HOME patient's requiring hospital transfers for terminal care when their preference is to die at home.

These Guidelines have been developed to support General Practice to implement the Australian and New Zealand Society of Palliative Medicine (ANZSPM) *Framework for Palliative Care in Community Based Aged Care Patient's*[11] through facilitating easy access to terminal medications and 24/7 care support for patient's who are terminal and wish to die in their own home.

Vision, Aims, Objectives and Scope

Vision

To provide all Tasmanians who are assessed as having a life limiting illness and are expected to die within 12 months, the choice to die in their own home regardless of their location, socio-economic status, ethnicity, gender or culture.

Aims

1. To reduce the number of terminal symptom related hospital transfers and deaths for hospice@HOME patient's who express a preference to die at home;
2. To support General Practitioners to implement the ANZSPM *Framework for Palliative Care in Community Based Aged Care Patient's* through easy access to terminal medications and care support.

Objectives

- To ensure that hospice@HOME patient's have control of their preferences in the last few days of life and to facilitate home deaths as a choice if that is preferred.
- To reduce inappropriate and avoidable service utilisation across the health sector – particularly in relation to potentially avoidable hospital admissions, emergency department presentations, and emergency admissions with patient's who are terminal.
- To contribute to the national and international community terminal care evidence base.

Scope

hospice@HOME patient's who are receiving palliative care from their primary care providers and have expressed a preference to die at home. The scope does not extend to Residential Aged Care Facilities (RACF).

Service Delivery Principles

The Just in Case Box is developed and delivered in a manner that is consistent with the following guiding principles:

Patient Controlled Care

The Just in Case Box is based on the development of positive relationships with patient's, their families and carers*.

Engagement

Stakeholders, service delivery organisations (both public and private) and patient's are given the opportunity to influence the design and delivery of the Just in Case Box.

Access and equity

The Just in Case Box is cost effective, accessible, and meets the needs of those with physical and mental health limitations while recognising the diversity of cultural, urban, regional and remote needs.

Accountability

The initiative is open to regular and transparent performance monitoring, clinical governance, assessment of risk, review and evaluation.

Sustainability

The Just in Case Box is developed with consideration of the ongoing sustainability of services.

Governance

The Just in Case Box is scrutinised at all levels internally and externally. The governance oversight is the role of The District Nurses Executive Team that consists of the Chief Executive, Chief Financial Officer, Director of State-wide Operations and the Director of Care. Quality and Safety will also be governed through The District Nurses Medication Advisory Committee which includes a General Practitioner and Community Pharmacist for multidisciplinary oversight. Additionally, each patient who receives a Just in Case Box will also be scrutinised through an external Mortality Review involving all the patient's' participants of care. Finally, an external reference group will provide independent observation of the Just in Case Box for further transparency.

Consumer and Community Participation

To maintain a service that is relevant and responsive to the needs of the person by ensuring effective mechanisms are in place for consumers, stakeholders and the community to participate in service development and to provide feedback.

*Family/carer refers to any person or people who undertake an unpaid role in providing support to the patient and whom the patient identifies as their care givers.

Just in Case Box Guideline

Description

The Just in Case Box is more than just a package of prescribed medications and related medical supplies. Patient's who are prescribed a Just in Case Box by their General Practitioner also receive the clinical and non-clinical care during the last days of life through tailored "end of life packages" with additional support provided through 24/7 telehealth and/or video link to a Registered Nurse via a Samsung Galaxy Tablet. Carers also receive a comprehensive and individualised, one on one education session, provided by trained Registered Nurses, to learn about the safe management of end of life medications using the Caring Safely at Home resources. Additionally, this is fully supported by collaborative and coordinated liaison with the General Practitioner and the patient's other health care providers with frequent reporting and communication to ensure continuity of care.

When should a Just in Case Box be ordered?

The decision regarding when a Just in Case Box goes into the home should be part of the development of the patient's overall plan of care. The development of the plan should involve the patient, the patient's family and/or carers, and the patient's primary care providers.

Patient Eligibility

1. The patient is known and admitted to hospice@HOME;
2. The patient has a management plan that is based on the patient's wishes and clinical condition[11];
3. Medical Goals of Care have been completed (Appendix 1);
4. The patient has expressed a preference to die at home and this has been documented in the Medical Goals of Care (Limitation of Medical Treatment).

Process for Ordering the Just in Case Box

1. The decision to order the Just in Case Box is made collaboratively between the patient, family/carer, the GP and hospice@HOME.
2. The patient's GP completes the Just in Case Box Request (and PBS prescription for the pharmacy), checking the medications of choice (Appendix 2).
3. It is recommended that the GP completes or has completed the GP Palliative Care education from CareSearch (www.caresearch.com.au) which is accredited by RACGP and Australian College of Remote and Rural Medicine (ACRRM).
4. The request form is made readily available on the hospice@HOME website, Medical Director and Best Practice.
5. The request form is completed and faxed to the participating pharmacist in the region where the patient resides (north, northwest or south) and hospice@HOME.
6. The form must include patient identification numbers and Medicare number.
7. The Just in Case Box can be picked up by the family/carer or hospice@HOME can arrange alternative transport.
8. hospice@HOME educates the patient and family/carer about the Just in Case Box. This education, using the Queensland Health, *Caring Safely at Home - palliative care education for caregivers*[7], includes the purpose, precautions, safe storage and directions for it to be used.
9. The Just in Case Box can be used by any nurse*, paramedic or physician who is involved in the care of the patient.

Accessing the Just in Case Box

It is appropriate to use the Just in Case Box when;

- The patient has symptoms that cannot be managed at home by the medication already accessible to the patient and without the Just in Case Box, an ambulance, a visit to the emergency department or admission to hospital would be required.

Contraindications to Ordering the Just in Case Box

A Just in Case Box is contraindicated for a patient's home when:

- The patient is under the age of 18 and/or requires specific dose calculations;
- There is no person in the home who can be responsible for the Just in Case Box.
- There is a clinical improvement and the care plan is re-assessed by a physician[11].

*Nurse in this document means any Registered Nurse who is providing direct care for the patient and their family/carer.

Process for Administration of the Just in Case Box

- When the patient displays symptoms that require the use of the Just in Case Box, the nurse and/or family/carer must contact the patient's GP via agreed methods to discuss the patient's status and receive orders to be documented on the medication chart (Appendix 3).
- The GP can access Decision Assist Phone Advisory Service (24 hours, 7 days a week) on 1300 668 908 for specialist advice if needed.
- The nurse or GP administers the medication as ordered and documents as per usual protocol. Local policies, procedures and standards apply.
- The patient's family/carers can use it with support from 1800HOSPICE nurse (available 24 hours, 7 days a week) after completing the Caring Safety at Home one on one education.
- Family/carers must contact 1800HOSPICE with each symptom change to be supported and assisted by a nurse.
- 1800HOSPICE will fax (or email) the patient's GP a copy of the phone template and hospice@HOME will follow up with all primary care providers the following day.

Assessment of Symptoms and the Need for Medications in the Just in Case Box

All nurses and physicians are accountable for their own decisions and actions and for maintaining competence of their practice according to their professional registration body.

Turnaround Time to Delivery or Pick-up

It is important to anticipate the needs of the patient and to place the Just in Case Box in the patient's home in a timely manner. All completed paperwork and prescriptions must be received before the pharmacy can process the request for a Just in Case Box. It is anticipated that Just in Case Boxes will be ready the day after the request is received.

Disposal of the Just in Case Box and of Unused Medications

The Just in Case Box is for the use of the designated patient only. Legislation requires that any medications and/or supplies remaining in the kit that have been ordered for the patient as part of the Just in Case Box, must be disposed of and destroyed after the designated patient has died. The nurse must ensure that the family/carers are aware that any unused medications and sharps containers must be disposed of. The family/carers can return the Just in Case Box and any other medications that need to be destroyed to their nearest pharmacy.

The reason that the remaining medications and supplies cannot be used by another patient is to protect the safety of the public. Ensuring patient safety outweighs the relatively small financial loss incurred by discarding unused medications.

Appendix 1 – Medical Goals of Care

MEDICAL GOALS OF CARE (GOC) PLAN

TASMANIAN HEALTH SERVICE
❑ North ❑ North West ❑ South

PT ID										

Family Name: <PtSurname> D.O.B. <PtDoB>

Other Names: <PtFirstName> SEX

Address: MARITAL

<PtAddress> REL.

This form is to communicate the medical decision for appropriate treatment goals of care for this patient. Chose A, B, C or D. If changes are made, this form must be crossed through, marked void and a new form completed.

DIAGNOSIS:

NO LIMITATION OF TREATMENT:	**Hospital**	**Community**
A.The goal of care is CURATIVE or RESTORATIVE. **Treatment aim is PROLONGING LIFE** ❑ For CPR and all appropriate life-sustaining treatments ---------->	CODE BLUE	For full resuscitation

LIMITATION OF MEDICAL TREATMENT:

❑ Patient has an advanced care directive and / or has requested the following treatment limitations:

Please specify:

B. The goal of care is CURATIVE or RESTORATIVE with limitations: ❑ **NOT FOR CPR** but is for all respiratory support measures --------> ❑ **NOT FOR CPR or INTUBATION** but is for other active management ------- ----------> *Specific notes:*	For CODE BLUE and MET calls For MET calls Not for CODE BLUE	For treatment and transfer to hospital
C. The goal of care is PALLIATIVE. **Treatment aim is quality of life** ❑ **NOT FOR CPR OR INTUBATION** ----------> *Specific notes:*	MET call ❑ YES MET call ❑ NO	Contact GP for planning
D. The goal of care is COMFORT DURING THE DYING PROCESS ❑ **NOT FOR CPR or INTUBATION** ---------->	For terminal care NOT for CODE BLUE NOT for MET	

Reason for limitation of medical treatment:	❑ medical grounds	❑ patient wishes
Discussed with:	❑ patient	❑ person responsible
DOCTOR'S NAME: <DrName>	**DESIGNATION**:	Family GP
SIGNATURE:	**DATE:**	<TodaysDate>
GP/Consultant responsible:	GP/Consultant informed	❑ YES ❑ NO

This form is endorsed for ambulance transfer, and for the home or care facility.

Abbreviation key: CPR = cardio-pulmonary resuscitation GP = general practitioner MET = medical emergency team

Procedure for completing a Goals of Care (GOC) Form

MEDICAL ASSESSMENT

A clinical evaluation of the patient's situation to one of the three goals of care categories: curative / restorative, palliative or dying (terminal). The following may be helpful to ask, especially if limitations are being considered
(after MJA 2005; 183:230-1):

1. Is the diagnosis correct?
2. Does the patient have capacity and not wish to have certain or all treatments, or if lacking capacity, has an advance directive or person responsible stating this?
3. Is medical treatment likely to prolong life or improve quality of life? Does the treatment carry a far greater risk of complications than possible benefits?
4. Has sufficient time elapsed to be reasonably confident that there is no reasonable prospect of substantial improvement or recovery?
5. Should another medical opinion be obtained?
6. Has the patient or the person responsible been advised of the above? Have they had a chance to express their opinions?
7. Has the patient's general practitioner been involved?

IMPLEMENTATION

1. Tick the box on the form that best describes the goals of care for the patient at this time.
   - A. **CURATIVE or RESTORATIVE** – if no treatment limitations are required tick box A. Refusal of a single treatment, such as blood products, in the context of otherwise full active treatment should be documented in the first line under limitations of medical treatment.
   - B. **CURATIVE or RESTORATIVE** with limitations – If in hospital, limitations to code blue or MET calls can be further documented. If in the community, the patient is for active treatment and transfer to a hospital if appropriate.
   - C. **PALLIATIVE** – The treatment aim is quality of life. If in hospital limitations to MET calls can be further documented. If in the community the GP can be contacted for further direction in management.
   - D. **DYING** – The treatment aim is comfort while the patient is dying. The prognosis is hours to days.
2. The details of the GOC discussions should be clearly documented in the patient's current progress notes.
3. The ultimate responsibility for treatment decisions including cessation of life-prolonging medical treatment and deployment of palliative and terminal care is a medical one and not the responsibility of the patient or person responsible.
4. The GOC form should not be completed by an intern.
5. The completed GOC form is filed in the current admission record, in the alerts section.
6. If the GOC change, the old form should be crossed out, marked VOID and a new form signed.
7. On discharge, a copy of the form can be sent with the patient or to the GP with the discharge summary if appropriate.
8. On discharge, the GOC form is scanned into the alerts section of the Digital Medical Record.
9. The Tasmanian Ambulance Service will recognise and act in accordance to the GOC form.
10. General practitioners or specialists may complete a GOC plan for ongoing care in the community and this form can be sent with the patient to the hospital if required.
11. Day patients who are low risk are not required to have a GOC form completed.

Appendix 2 – Just in Case Box Request Form – PART 1

Date:

Patient Name:
Address:
DOB:
Indentifying Number:
Medicare Number:

Just in Case Box Request – PART 1

This is a request for a Just in Case Box to be activated when terminal symptoms require urgent intervention to facilitate a comfortable death at home. The Registered Nurse must obtain a valid medication order when the Just in Case Box is required. This document is not a prescription.

Contact _____ ***(name)***, who is the patient's primary care provider, on

_____ ***(insert contact number)*** when the patient's symptoms require the use of the Just in Case Box. The primary care provider can be contacted:

- ❑ At any time of day or night
- ❑ During daytime hours only (7 days a week), for afterhours GP access contact 1800HOSPICE
- ❑ During working hours only (Mon-Fri only), for afterhours GP access contact 1800HOSPICE

NB: PBS prescriptions must be completed in conjunction with this request form.

Just in Case Box eligibility Checklist

- ❑ The patient is known and admitted to hospice@HOME;
- ❑ The patient has a management plan that is based on the patient's wishes and clinical condition;
- ❑ The patient has a Medical Goals of Care;
- ❑ The patient has expressed a preference to die at home which is documented on the Medical Goals of Care (Limitation of Medical Treatment).

Once both sides of the document are complete, please fax request form to the participating pharmacy in your region and hospice@HOME

Hospice@HOME (24 hours)	Ph: 1800 4677423	Fax: (03) 6273 3002
Capital Chemist, Newtown (South) Capital	Ph: (03) 6286 0001	Fax: (03) 6286 0002
Capital Chemist, Kings Meadows (North)	Ph: (03) 6344 3658	Fax: (03) 6344 7337
Terry White, Four Ways (North West)	Ph: (03) 6424 4233	Fax: (03 6424 5741

Just in Case Request Form – PART 2

Patient Name:
Address:
DOB:
Indentifying Number:
Medicare Number:

****PBS prescriptions must also be completed and sent to the pharmacy**
*****Directions for use can be obtained by calling Decision Assist on 1300 668 908 (24 hours)**

AGITATION, ANXIETY or SEIZURE

- ☐ Clonazepam liquid (oral drops) 2.5mg/ml
- ☐ Clonazepam injection 1mg/ml
- ☐ Midazolam injection 5mg/ml

DELIRIUM

- ☐ Haloperidol injection 5mg/ml

EXCESS PULMONARY SECRETIONS

- ☐ Hyoscine butylbromide (Buscopan) injection 20mg/ml

NAUSEA

- ☐ Metoclopramide injection 10mg/2ml

PAIN and/or SHORTNESS OF BREATH ****CHOOSE ONLY ONE OPIOID**

- ☐ Morphine sulphate injection 10mg/ml AND 30mg/ml
- ☐ Hydromorphone injection 2mg/ml
- ☐ Fentanyl citrate injection 100mcg/2ml

CURRENT MEDICATIONS (attached printed copy if preferred):

ALLERGIES:

Patient's usual pharmacy name:
Address:

Delivery instructions:

- ☐ **Family will contact participating pharmacy to organise pick up themselves**
  Name..... **Phone.....**
- ☐ **Alternative transport to be arranged by hospice@HOME**

Physician name: Prescriber number:

Office phone: Mobile phone: Fax:

Appendix 3 – Just in Case Box Contents

Just in Case Box Contents

BAG 1

1 x Just in Case Box Guidelines

1 x Just in Case Box request form and prescription (complete)

1 x Medical Goals of Care (complete)

1 x Declaration of Life Extinct pack

2 x National Standard Medication Chart[12]

20 x labels for medications[13]

1 x Caregiver Medication Diary

1 x 1800HOSPICE fridge magnet

1 x Incident/Hazard Form

1 x black ball point pen

Prescribed medications

1 x NIKI Pump (in a case with key)

4 Infusion lines (Microbore Extension Sets)

2 x 9V batteries

BAG 2

6 x interlink injection sites

6 x Tegaderm (6cm x 7 cm)

30 x 1ml Luer Lock syringes

20 x 3ml Luer Lock syringes

5 x 5ml Luer Lock syringes

2 x 20ml Luer Lock syringes

20 x combi stoppers

20 x alcohol swabs

10 x 10ml Normal Saline for Injection

10 x 5ml Normal Saline for Injection

20 x blunt drawing up needles

20 x blunt plastic cannula

4 x Safe-T-Intima

1 x sharps container

1 x micropore tape

1 x Plastic container with a lid

Appendix 4 – Decision Assist Medications for Dying Patient's

Just in Case Box Medication[14]

The list of nine medications was developed by a panel of 12 experts, including GPs, pharmacists, nurse practitioners and palliative medicine specialists, under the direction of The Australian & New Zealand Society of Palliative Medicine (ANZSPM)[14]. It represents the latest addition to ANZSPM's resources for General Practitioners under the Federal Government funded initiative, Decision Assist, a program to support GPs and aged care workers to provide palliative care and advance care planning to older Australians.

The new evidence based medication list is appropriate for dying patient's who are unable to swallow, and targets symptoms including pain, dyspnoea, nausea and vomiting, agitation and delirium, and respiratory secretions. Selection criteria for the medications to be considered in the list included cost, simplicity of use, and ease of storage, safety and efficacy[14].

hospice@HOME will provide funding for all Just in Case Box medications including non-PBS items and all consumables.

MEDICATION	CONCENTRATION	PACKAGED as
Clonazepam liquid* (oral drops)	**2.5mg/ml**	**10ml bottle (2.5mg/ml)**
Clonazepam injection*	**1mg/ml**	**box of 5 ampoules**
Fentanyl citrate injection**	**100mcg/2ml**	**box of 5 ampoules**
Haloperidol injection	**5mg/ml**	**box of 10 ampoules**
Hydromorphone injection	**2mg/ml**	**box of 5 ampoules**
Hyoscine butylbromide (Buscopan) injection***	**20mg/ml**	**box of 5 ampoules**
Metoclopramide injection	**10mg/2ml**	**box of 10 ampoules**
Midazolam injection**	**5mg/ml**	**box of 10 ampoules**
Morphine sulphate injection	**10mg/ml AND 30mg/ml**	**box of 5 ampoules**

Notes:

* Non-PBS unless for seizure control

** Not on the PBS

*** Non-PBS unless for colicky pain. Unrestricted via the Repatriation Schedule

Appendix 5 – Contact Numbers

Decision Assist:	1300 668 908	
Hospice@HOME (24 hours)	Ph: 1800 4677423	Fax: (03) 6273 3002
Capital Chemist (South)	Ph: (03) 6286 0001	Fax: (03) 6286 0002
Capital Chemist (North)	Ph: (03) 6344 3658	Fax: (03) 6344 7337
Terry White (North West)	Ph: (03) 6424 4233	Fax: (03) 6424 5741

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