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**Paediatric End of Life managed Care Network (PELiCaN)**

Guideline for the use of Just in Case boxes for children receiving end of life care.

*This document has been produced by the Paediatric End of Life Care Network (PELiCaN), Service Development sub-group with kind permission and contribution from The Managed Service Network for Children and Young People with Cancer. Thank you for your assistance in the development of this guidance.*

NOTE: This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient’s case notes at the time the relevant decision is taken.

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**1.** **Purpose and Scope**

This guideline applies to the use of Just in Case boxes for children and young people with a life-limiting condition requiring end of life care in NHS Scotland. It was initially developed by the MSN for Children and Young People with Cancer Palliative Care Steering Group in 2018 and has been reviewed, updated, and adapted by the Paediatric End of Life Care Managed Clinical Network (PELiCaN) for use in all life limiting conditions.

The purpose of this guideline and supporting documents is to improve timely access to appropriate symptom management medication if a child experiences distressing or escalating symptoms as they approach end of life. It aims to support the ability to offer a range of locations for the preferred place of care and death as is appropriate to each child’s specific circumstances. Facilitating timely access to specialist symptom management has the potential to enhance patient care and aid the prevention of unnecessary crises and unscheduled hospital admissions.

**2. Aims of Guidance**

The aims of this guideline are to:

* Assist practitioners who are involved in setting up a Just in Case Box for children requiring end of life care within NHS Scotland.
* Assist practitioners who are administering medication from a Just in Case Box.
* To support safe and accountable practice when providing symptom management for those patients who require prescribed medication administered from a Just in Case Box.
* It aims to offer flexibility and recognizes the diverse practices among centres, allowing for tailored approaches to symptom management prescribing.

**3. Patient Selection**

In conjunction with the wider multidisciplinary team, the Lead Clinician will advise of suitability for a Just in Case box in recognition of a child approaching end of life. Early intervention of requesting and supplying the box is preferable to have medications readily available at home on the onset of distressing symptoms.

**4. Informing GP and Emergency Key Information Summary e-KIS**

The GP should be asked to upload the presence of the Just in Case box in the child’s house to e-KIS and stipulate what medications are contained within the box. This should routinely take place as part of the discharge planning for end of life care at home.

**5. Informing Child and Parents / Carers about the Just in Case Box**

* The family and patient (where appropriate) should receive an explanation of the purpose of the Just in Case Box. This may be done by the Lead Clinician and/or Palliative Care Team member and/or Community Nurse and/or Clinical Nurse Specialist.
* Where appropriate certain items from the Just in Case box may be administered by parents as long as they have received training on how to administer (training and governance of parent/carer administration is out with the scope of this guidance).
* Provide the family with a copy of the Parent’s Information Sheet (Appendix 1)*,* which provides information about the Just in Case Box.
* Allow time to fully discuss the need for a Just in Case box before initiating the supply of the required medication.

**6. Criteria for patient exclusion from having a Just in Case Box**

* Risk assessment and management should be undertaken on a case-by-case basis. This might include situations where there is a history or suspicion of drug misuse among carers or visitors to the house.
* If the patient is excluded from having a Just in Case Box, alternative arrangements should be discussed, agreed, implemented, and documented.

**7. Reassessment of a patient’s suitability for inclusion in the scheme**

A patient’s symptom management needs may change over time. The lead clinician must be responsible for ensuring a patient’s suitability for use of a Just in Case box if their condition improves or plateaus.

**8. Type of box to use**

Individual Health Boards/ organisations will have their own stock of suitable box for use. A toolbox, first aid box or similar may provide a suitable method of storage provided it is large enough to contain all the medicines, consumables and paperwork required. Other methods of storage such as the use of a pharmacy Envopak bag may be considered if these are more readily available. Locking the box is not routinely recommended unless there is a very robust system in place to ensure all staff who may need to access the box can do so. Organisations may wish to consider the use of tamper resistant seals (e.g. Envopak seals or cable ties) to enable staff visiting the home to easily check if the contents have been tampered with.

**9. Recommended medications**

The Lead Clinician will decide what medicines to include in the box after discussion with other members of the multi-disciplinary team. It is recommended that the guidance on drug choice and dosage is accessed from the Association of Paediatric Palliative Medicine (APPM) master formulary available at [www.appm.org.uk](http://www.appm.org.uk).

The contents of the box should be tailored to the individual patient, an example of a standard prescription template of the drugs listed below, is available in Appendix 2 for prescribing these drugs via hospital pharmacies.

**Analgesics**

Oral Morphine Solution 10mg/5mL x 1 bottle

Morphine Sulfate Injection10mg/mL x 10 ampoules

**Anxiolytics/Anti-epileptics**

Midazolam Oromucosal Solution 10mg/mL solution 1 x 5mL bottle

Midazolam Injection10mg/2mL x 10 ampoules

Phenobarbital injection 200mg/mL x 10 ampoules

**Anti Emetics**

Cyclizine Injection 50mg/mL x 10 ampoules

Metoclopramide Injection 5mg/mL x 10 ampoules

Levomepromazine Injection 25mg/mL x 10 ampoules

**Anti Secretory**

Hyoscine Hydrobromide 1mg/72hour x 2 patches

Glycopyrronium Injection 200micrograms/mL x 10 ampoules

**Diluent**

Water for Injections 10mL x 10 ampoules

Appendix 3 offers a standard template for Haematology and Oncology patients. If other medications are required, a blank example template (Appendix 4) is also available where requirements are different for individual patients.

For example, Dexamethasone 3.3mg/mL injection (or alternative strength stocked locally), tranexamic acid 500mg/5mL oral solution/mouthwash and adrenaline 1 in 1000 injection may be considered when indicated for individual patients.

**10. Supplying the medication**

Medications contained within a Just in Case box must be prescribed for an individual patient. The prescribed medication will be dispensed by a community pharmacy or hospital pharmacy depending on local procedures.

**11. Equipment to be kept in Just in Case Box**

In addition to medication, there is equipment which should be stored in the Just in Case box. There is a checklist in Appendix 5 that can be used when filling the box.

**12. Safe storage of the boxes in the home**

The storage of boxes should prioritize safety, ensuring they are kept out of reach of children. When nursing staff deliver the boxes to households, it's crucial for them to engage in discussions with caregivers and identify suitable storage locations.

A label could be placed on the box advising to keep out of reach of children.

**13. Stock control and recording of Controlled Drug (CD) medications in the home environment**

Each Health Board locality has a responsibility to be compliant with controlled drug (CD) legislation and guidelines. If a patient’s Just in Case box contains controlled Drugs a Controlled Drug Stock Monitoring Form(s) should be completed whenever CD’s are handled by staff (either received from pharmacy, or administered during visit).

A Controlled Drug Stock Monitoring Form must be completed for every preparation e.g. if there are 5mg and 10mg ampoules, these must be written on separate forms.

No lines should be left in between entries on the form. All CDs that are administered must be recorded on the medication Kardex and Controlled Drug Stock Monitoring Form(s). See Appendix 6 for an example form.

**Appendix 1- Just in Case Box Parent/Carer Information Leaflet**

****A printable copy of this leaflet is available on the PELiCaN website.

**Paediatric Just in Case Box**

**Information for parents and carers**

**What is a Just in Case box?**

A Just in Case box contains a small supply of prescribed medicines, which is kept in your home in case it is needed to treat any symptoms your child might experience.

Sometimes it can be difficult to obtain these medicines in a hurry, especially at night or at the weekends, so it is helpful to have them available - just in case.

The box contains everything necessary for the nurse or doctor to administer the medicines in your home. Often the medicines are not needed, but if they are ready in the house it can prevent delay in relieving symptoms.

**Type of Medicine and what it is used for**

* Painkiller for pain and this may also be used to reduce feelings of breathlessness
* Medicine for anxiety, restlessness or seizure
* Anti-sickness medicine for nausea and vomitting
* Medicine to dry up excessive secretions in the throat

If any of the medicines are needed, the box contains just enough to last until more can be obtained. The medicines to be replaced are supplied in the usual way from your GP, community pharmacy or via the hospital.

If you are admitted to hospital or hospice, please let the staff know that you have the box in the house.

**How do I look after my Just in Case box?**

The medicines in the box have been specifically prescribed for your child and should not be given to anyone else. Keep them in a safe place out of reach and sight of children. They do not need to be kept in a fridge, but should be kept in a cool, dry place away from direct heat and light.

If the box is no longer needed please talk to your nurse about organising its return

**Any questions?**

If you have any questions about the Just in Case box, please talk to your Paediatric Palliative Care Clinical Nurse Specialist, Paediatric Oncology Outreach Nurse Specialist (POONS), Community Children’s Nurse (CCN), CHAS at Home Nurse or other health professional.

**Contacts**

Clinical Nurse Specialist – Phone Number:

POONS – Phone Number:

CCN – Phone Number:

CHAS contact – Phone Number:

GP – Phone Number:

Community Pharmacy – Phone Number:

Other Health Professional – Phone Number:

**Appendix 2 - Example: Prescription Form Standard Drugs**

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Note: Some centres may use this template as a prescription for pharmacy supply, others may be required to prescribe on locality prescription sheets.

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| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Just in Case Box Prescription -** Prescribers should refer to the APPM master formulary for information on appropriate doses | | | | | | | | | |
| **Hospital Name:** |  | | | | Screened by: (pharmacist) | | |  | |
| Please supply for: | Name: | | | | Weight (kg): | | | Date of Birth: | |
| Address: | | | | Allergies: | | | CHI No: | |
| This supply is made on the understanding that a clear direction of the dose to be administered is given by a clinician responsible for the patient’s care (e.g. Consultant, Doctor or Independent Prescriber) on the patient’s symptom management plan | | | | | | | | | |
| **Drug** | | **Route** | **Strength** | | | **Quantity** | | | **Directions** |
| Oral Morphine solution | | PO/NG/PEG/NJ/ PEJ | 10mg/5mL | | | 1 x 100mL bottle | | | Dosing instructions and directions should be added as per Symptom Management Plan or equivalent |
| Morphine Sulfate injection | | SC/IV | 10mg/mL | | | 10 (ten) ampoules | | |
| Midazolam oromucosal solution | | Buccal/nasal | 10mg/mL | | | 1x 5mL (five millilitres) bottle | | |
| Midazolam injection | | SC/IV | 10mg/2mL | | | 10 (ten) ampoules | | |
| Phenobarbital injection | | CSCI | 200mg/mL | | | 10 (ten) ampoules | | |
| Cyclizine injection | | SC/IV | 50mg/mL | | | 10 ampoules | | |
| Metoclopramide injection | | SC/IV | 5mg/mL | | | 10 ampoules | | |
| Levomepromazine injection | | SC/IV | 25mg/mL | | | 10 ampoules | | |
| Hyoscine Hydrobromide patches | | Transdermal | 1mg/72hrs | | | 2 patches | | |
| Glycopyrronium injection | | SC/IV | 200 microgram/mL | | | 10 ampoules | | |
| Water for injections | | SC/IV | 10mL | | | 10 ampoules | | |
|  | | | | | | | | | |
| **Prescriber’s Name:** | |  | | | | | | | |
| **Prescriber’s signature:** | |  | | Date: | | |  | | |
| Dispensed by/checked by: | |  | | Date: | | |  | | |

**NOTE FOR SCHEDULE 2 and 3 CONTROLLED DRUGS:**

* CD prescriptions require: total quantity in both words and figures (illustrated above), handwritten prescribers signature, form of drug (i.e solution, injection etc.) and dose (i.e give over 24h in CSCI is not a dose however three ampoules to be given over 24 hours is); consult BNFc (Controlled drugs and drug dependence section) for guidance
* On GP10 or HBP prescription pads, controlled drugs are typically prescribed separately from all other medicines due to specific CD requirements; refer to individual Health Board prescribing policies as this may also be required in some tertiary centres (they are listed above in the same prescription for illustration purposes only)

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Note: Some centres may use this template as a prescription for pharmacy supply, others may be required to prescribe on locality prescription sheets.

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| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Just in Case Box Prescription -** Prescribers should refer to the APPM master formulary for information on appropriate doses | | | | | | | | | |
| **Hospital Name:** |  | | | | Screened by: (pharmacist) | | |  | |
| Please supply for: | Name: | | | | Weight (kg): | | | Date of Birth: | |
| Address: | | | | Allergies: | | | CHI No: | |
| This supply is made on the understanding that a clear direction of the dose to be administered is given by a clinician responsible for the patient’s care (e.g. Consultant, Doctor or Independent Prescriber) on the patient’s symptom management plan | | | | | | | | | |
| **Drug** | | **Route** | **Strength** | | | **Quantity** | | | **Directions (dosing instructions may be added where there is local protocol)** |
| Oral Morphine solution | | PO/NG/PEG/NJ/ PEJ | 10mg/5mL | | | 1 x 100mL bottle | | | To be given as directed by symptom management plan or equivalent |
| Morphine Sulfate injection | | SC/IV | 10mg/mL | | | 10 (ten) ampoules | | |
| Midazolam oromucosal solution | | Buccal/nasal | 10mg/mL | | | 1x 5mL (five mL) bottle | | |
| Midazolam injection | | SC/IV | 10mg/2mL | | | 10 (ten) ampoules | | |
| Cyclizine injection | | SC/IV | 50mg/mL | | | 10 ampoules | | |
| Levomepromazine injection | | SC/IV | 25mg/mL | | | 10 ampoules | | |
| Hyoscine Hydrobromide patches | | Transdermal | 1mg/72hrs | | | 2 patches | | |
| Dexamethasone | | SC/IV | 3.3mg | | | 10 ampoules | | |
| Water for injections | | SC/IV | 10mL | | | 10 ampoules | | |
|  | | | | | | | | | | SC/IV | 10mL | 10 ampoules |
| **Prescriber’s Name:** | |  | | | | | | | |
| **Prescriber’s signature:** | |  | | Date: | | |  | | |
| **Dispenced by/checked by** | |  | | Date: | | |  | | |

**NOTE FOR SCHEDULE 2 and 3 CONTROLLED DRUGS:**

* CD prescriptions require: total quantity in both words and figures (illustrated above), handwritten prescribers signature, form of drug (i.e solution, injection etc.) and dose (i.e give over 24h in CSCI is not a dose however three ampoules to be given over 24 hours is); consult BNFc (Controlled drugs and drug dependence section) for guidance
* On GP10 or HBP prescription pads, controlled drugs are typically prescribed separately from all other medicines due to specific CD requirements; refer to individual Health Board prescribing policies as this may also be required in some tertiary centres (they are listed above in the same prescription for illustration purposes only)

**Appendix 4 – Example: Blank Prescription Form Template**

Note: It is likely that some Health Boards will require the prescription to be written on a local template. This blank template is for example purposes and may be useful when writing a bespoke prescription.

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| **Just in Case Box Prescription -** Prescribers should refer to the APPM master formulary for information on appropriate doses | | | | | | | | | |
| **Hospital Name:** |  | | | | Screened by: (pharmacist) | | |  | |
| Please supply for: | Name: | | | | Weight (kg): | | | Date of Birth: | |
| Address: | | | | Allergies: | | | CHI No: | |
| This supply is made on the understanding that a clear direction of the dose to be administered is given by a clinician responsible for the patient’s care (e.g. Consultant, Doctor or Independent Prescriber) on the patient’s symptom management plan. | | | | | | | | | |
| **Drug** | | **Route** | **Strength** | | | **Quantity** | | | **Directions** |
|  | |  |  | | |  | | | Dosing instructions and directions should be added as per Symptom Management Plan or equivalent |
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| **Prescriber’s Name:** | |  | | | | | | | |
| **Prescriber’s signature:** | |  | | Date: | | |  | | |
| Dispensed by/checked by: | |  | | Date: | | |  | | |

**NOTE FOR SCHEDULE 2 and 3 CONTROLLED DRUGS:**

* CD prescriptions require: total quantity in both words and figures, handwritten prescribers signature, form of drug (i.e solution, injection etc.) and dose (i.e give over 24h in CSCI is not a dose however three ampoules to be given over 24 hours is); consult BNFc (Controlled drugs and drug dependence section) for guidance
* On GP10 or HBP prescription pads, controlled drugs are typically prescribed separately from all other medicines due to specific CD requirements; refer to individual Health Board prescribing policies as this may also be required in some tertiary centres (they are listed above in the same prescription for illustration purposes only)

**Appendix 5 – Just in Case Box Dry Stock Checklist**

Items to be put in box by nurse before taking out to the patient’s home. The contents of box may vary slightly due to differences in local practice.

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| **Syringes and Needles**   * 1ml luer lock syringes x 10 * 3ml luer lock syringes x 10 * 5ml luer lock syringes x 10 * 10ml luer lock syringes x 10 * 20ml luer lock syringes x 5 * 30ml luer lock syringes x 5 * Filter straws (red/pink) x 20 * Green needle x 20 * Orange needle x 5 * Syringe caps x 20 | **Subcutaneous Equipment**   * Subcutaneous cannula x 5 * Anti syphon line x 5 * Bionectors x 5 * Water for injections 10ml – 1 box * Sodium chloride for injection 10ml -1 box | **Devices**   * Syringe pump\* used in NHS board x 2 * Lock box for syringe pump x 1 * Key (or equivalent) for lock box * Spare 9-volt batteries for pump x 2 * Light protection bag for pump x 1 * Labels x 10   \*Give consideration to supply of pumps and if one needs to be in home immediately or at a later date |
| **Sundries**   * Tray for drug preparation x 1 * Pre injection skin swabs x 10 * Dry sterile swabs or gauze x 10 * Adhesive remover wipes x 5 * Adhesive film patches x 5 * Sharps box & absorbent sachets * Gloves, aprons and bags for rubbish * Scissors & plasters * Antibacterial hand gel x 1 bottle * Antibacterial/Sterile wipes for equipment | **Paperwork/Prescribing Support**   * Prescription kardex * Administration record * Controlled drug administration record * Controlled drug stock monitor chart * [APPM Guidelines – available online](https://www.appm.org.uk/formulary/) * [BNF-C – should use online version](https://bnfc.nice.org.uk/)  * [Scottish Palliative Care Guidelines (SPCG)](https://rightdecisions.scot.nhs.uk/scottish-palliative-care-guidelines/?UID=2175863472023925155431) * **Continuous Subcutaneous Compatibility Resources**: [SPCG](https://rightdecisions.scot.nhs.uk/scottish-palliative-care-guidelines/?UID=2175863472023925155431), The Syringe Driver: Continuous Subcutaneous Infusions in Palliative Care: Andrew Dickman (paper) and [Medicines Complete Compatibility Checker](https://www.medicinescomplete.com/#/). | **Additional items for consideration dependent on patient’s needs (not essential)**   * Additional equipment for suspected bleed i.e. dark towels, identified box to contain specific medications in this scenario. * Ng tubes x 2 (size appropriate), pH strips and dressings for attachment * Enteral syringes * Catheters (size appropriate) * Dressing packs |

**Appendix 6 - CD Stock recording form**

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**Name and CHI: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Drug name, form and strength: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

* A separate sheet should be completed for each drug, strength and form
* Two signatures are required as a minimum (NHS /CHAS or parent/carer)

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|  | | **Received** | | **Removal** | | **Administered** | | **Confirm balance in home** | |
| **Date** | **Time** | **Received from** | **Quantity** | **Reason** | **Quantity** | **Dose (mg/quantity)** | **Discarded**  **(mg/quantity)** | **Signature(s)** | **Balance** |
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