

30<sup>th</sup> June 2025



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## **Committee for Health Inquiry on Access to Palliative Care Services**

[Committee.Health@niassembly.gov.uk](mailto:Committee.Health@niassembly.gov.uk)

Dear Chair,

Thank you once again for your interest and commitment to Palliative Care in Northern Ireland. As the Palliative Care Inquiry draws to a close, we appreciate the time you have taken to listen to specialists in the region. As the Regional Palliative Medicine Group for Northern Ireland (RPMG), we are writing in response to the correspondence from the Minister for Health dated 10<sup>th</sup> June. As you are aware, the Minister had written following your approach to the Department of Health (DoH) regarding the need for a 'Northern Ireland Regional Last Days Care Bundle' or 'Individualised Care Plan'. We feel it may be helpful to the Health Committee for us to provide some clear background and address some of the issues.

The RPMG is composed of all the Palliative Medicine Consultants, Senior Registrars and Staff Grades from across Northern Ireland working to improve Palliative and End-of-Life services for our communities. We volunteer our time and expertise to write and review regional guidance and policy. We provide representation to the Clinical Engagement Group within the Palliative Care in Partnership (PCiP) structure. We are active nationally through our work with the Association for Palliative Medicine, the National Clinical Leads Group for Palliative Medicine and Hospice UK.

Following concerns regarding the Liverpool Care Pathway (LCP), the 'More Care, Less Pathway' independent review by Baroness Neuberger was published in 2013. The review made strong recommendations, including to phase out the LCP and replace it with 'individualised end-of-life care plans' to reduce the harm caused by the overmedicalisation of end-of-life care to patients and families. The review also recommended that the individualised care plan was to be monitored by the 'national audit for care at the end of life' (NACEL) which NI has spuriously implemented giving us false reassurance of compliance. It is unclear why the DoH cherry picked which elements to implement.

These individualised end-of-life care plans will improve care by providing clear guidance, clarifying senior clinician responsibilities and strengthening communication between staff, patients and families. They are strongly recommended by national guidance - NICE NG31 (2015). Their implementation coupled with associated training have helped in recognising dying, communicating clearly, and delivering symptom management at the end of life.

Unlike the rest of the UK, since 2013 the DoH has persistently ignored these recommendations and have failed, in our view, in giving any clear evidence why it believes that it knows better than the rest of the UK where individualised end-of-life care plans have been the norm for more than 10 years.

In light of the over-medicalisation of normal dying that we have continued to observe causing real distress to patients, families and staff, we sought to encourage the DoH to reconsider its decision which contradicted the actions taken by their counterparts in the rest of the UK.

- 1) Drawing on existing individualised end-of-life care plans being used across England (*Appendix 1*), we invested our own time and expense in developing a draft care plan for NI (*Appendix 2*) ready for iteration with clinical colleagues to create a definitive NI version
- 2) We submitted this to the Clinical Engagement Group in December 2019 representing all multidisciplinary professions.
- 3) With growing frustrating at the lack of a response and clear governance process within the PCiP, RPMG representatives met with the Chef and deputy Chief Medical Officer in February 2023. We were told that the CMO would take the lead on this issue directly from the PCiP.
- 4) A response was received on 27<sup>th</sup> September 2023 (*Appendix 3*), stating that the true reason that the department had failed to take this forward was lack of money. The response also implied proper processes had not been followed and could be under the umbrella work on Advance Care Planning (ACP) and ReSPECT, both of which have also been created but failed to be implemented over the last 5 years.
- 5) This decision was taken despite every NI Palliative Medicine Consultant and member of the Clinical Engagement Group being in favour of NI adopting individualised care planning documentation.

The development and implementation of a Northern Ireland Regional Last Days Care Bundle or Individualised Care Plan in hospitals is an obvious gap in provision of palliative care in NI. The baseline Scoping Audit will not cover this gap or other documentation and resource gaps. This highlights once again the need for clinical leadership (*such as a national clinical lead in palliative care as per all other nations absent in NI*) in focusing work and effort on projects which will provide real benefit to the people of NI.

We would appreciate your support in progressing this area work, and supporting us as clinicians to drive forward other aspects of Palliative Care to make a real and lasting difference to the care we would all want our loved ones to receive.

Yours sincerely,



*Dr Alan McPherson, Chair of RPMG*



*Dr Matthew Doré, Secretary*

Patient name:  
Hospital No:  
NHS No.  
D.O.B:  
  
or affix patient ID sticker here

Brighton and Sussex **NHS**  
University Hospitals  
NHS Trust

## HAVE YOU RECOGNISED YOUR PATIENT MAY DIE IN THE COMING HOURS OR DAYS?

### ENSURE YOU:

HAVE CONSIDERED POTENTIALLY REVERSIBLE CAUSES WHICH MAY BE APPROPRIATELY TREATED

HAVE COMMUNICATED WITH THE PATIENT AND THOSE IMPORTANT TO THEM

AIM TO INVOLVE A SENIOR DECISION MAKER (SpR/CONSULTANT)

DOCUMENT RESUSCITATION STATUS AND TREATMENT ESCALATION PLAN

ASSESS SYMPTOMS AND PRESCRIBE APPROPRIATE MEDICATION

ASSESS NEED FOR CLINICALLY ASSISTED HYDRATION AND NUTRITION

CONSIDER IF DISCHARGE IS FEASIBLE IF PREFERRED PLACE OF CARE IS HOME

CONSULT 'PALLIATIVE CARE' TAB ON TRUST INTRANET FOR FURTHER GUIDANCE

### THEN:

#### DOCTORS

COMPLETE INDIVIDUALISED  
CARE PLAN (ICP) FOR THE  
DYING PATIENT OVERLEAF

#### NURSES

ONCE ICP COMPLETED USE  
SYMPTOM OBSERVATION  
CHART & DAILY CARE PLAN  
FOR THE DYING PATIENT

#### DOCTOR

NAME: \_\_\_\_\_ GRADE \_\_\_\_\_

SIGNATURE: \_\_\_\_\_ BLEEP \_\_\_\_\_

DATE : \_\_/\_\_/\_\_\_\_ TIME \_\_\_\_:\_\_\_\_

#### NURSE

NAME: \_\_\_\_\_ GRADE \_\_\_\_\_

SIGNATURE: \_\_\_\_\_

DATE : \_\_/\_\_/\_\_\_\_ TIME \_\_\_\_:\_\_\_\_

FURTHER GUIDANCE IS AVAILABLE ON PALLIATIVE CARE INTRANET PAGE AND VIA MICROGUIDE APP

BSUH Individualised Care Plan for the Dying Person Version 3.0 – For review Jan 2020 by EOLCSG

- ⇒ **All patients recognised as dying must have pre-emptive medication prescribed PRN for control of common symptoms**
- ⇒ **If PRN not controlling symptoms (≥ 3 doses in any 24 hour period) consult on line guidance and seek advice on whether a regular subcutaneous infusion (syringe pump) is appropriate**

|  |              |    |                         |                             |
|--|--------------|----|-------------------------|-----------------------------|
| Pain/Breathlessness: 1 <sup>st</sup> line <b>Morphine</b>  | 2.5mg        | sc | <i>Pain</i><br>1 hourly | <i>Dyspnoea</i><br>4 hourly |
| 2 <sup>nd</sup> line <b>Oxycodone</b>  | 1.25 – 2.5mg | sc | 1 hourly                | 4 hourly                    |
| (If <u>known</u> severe renal failure eGFR<30ml/min: <b>Alfentanil</b> )<br>*discuss with Palliative Care Team first | 0.2mg        | sc | 1 hourly                | 4 hourly                    |
| Nausea: <b>Haloperidol</b>   | 1.5mg        | sc | 4 hourly                |                             |
| Distress from anxiety: <b>Midazolam</b>  | 2.5-5mg      | sc | 1 hourly                |                             |
| Distress/agitation from delirium: <b>Haloperidol</b>   | 1-2.5mg      | sc | 4 hourly                |                             |
| Respiratory secretions: <b>Glycopyrronium</b>  | 0.2mg        | sc | 4 hourly                |                             |

- **If patient on existing regular opioids or other symptom control medication consult on line guidance for conversions and advice on starting a regular subcutaneous infusion (syringe pump)**
- Review and discontinue non-essential medication. For essential medication which cannot be taken orally (e.g. anti-epileptics) see online guidance
- **FOR COMPLEX SYMPTOM MANAGEMENT / TREATMENT RESISTANT SYMPTOMS CONSULT PALLIATIVE CARE TEAM OR A PHARMACIST**

#### Prescribing guidance

See “palliative medicine”+“care of the dying” – sections 14 & 15 online prescribing guidelines

Hospital Palliative Care Team (M-F 9-5)

ext 3021 Bleep: 8420

RSCH (OOH) = Martlets Hospice -

01273 964164

PRH (OOH) = St Peter & St James Hospice -

01444 471598

Medicines Information Service ext.

8153 / 8566



**FURTHER GUIDANCE IS AVAILABLE ON PALLIATIVE CARE INTRANET PAGE AND VIA MICROGUIDE APP**

BSUH Individualised Care Plan for the Dying Person Version 3.0 – For review Jan 2020 by EOLCSG

## INDIVIDUALISED CARE PLAN FOR A DYING PERSON

**Goal:** To facilitate dying with dignity and comfort for the patient while providing carers with support. To ensure sensitive communication about the deterioration in the patient's condition  
**PLEASE REVIEW THIS PLAN DAILY**

Patient name:  
Hospital No:  
NHS No.  
D.O.B:  
or affix patient ID sticker here

### PRIORITY 1: RECOGNISE

*Which members of the MDT have been involved in the recognition of dying phase and what is the condition(s) now thought to be irreversible and contributing to the dying phase?*

### PRIORITY 2: COMMUNICATE

*Document who the patient identifies as most important to them and their contact details. Share understanding of expectations of dying phase eg symptoms, timeframe and document here.*

### PRIORITY 3: INVOLVE

*Make sure the patient knows which senior clinicians are leading their care. Involve the dying person and those important to them in decisions about treatment and care including food, drink and physical symptoms.*

### PRIORITY 4: SUPPORT

*Identify, explore and respect the needs of those the dying person identifies as important to them and meet them as far as is possible.*

*Contact details provided and plan to meet again:*

## PRIORITY 5: PLAN & DELIVER AN INDIVIDUALISED CARE PLAN


- 1) **Goals of care** (eg dignity and alleviation of symptoms)
- 2) **Clinical interventions** (eg NEWS2, symptoms observation chart, blood sugar readings, MET calls)
- 3) **Management of physical symptoms** (eg individualised symptom plan)
- 4) **Management of broader holistic needs** (psychological, spiritual, cultural, religious and practical (eg parking permits or visiting times) needs)
- 5) **Management of hydration and nutrition** (eg assessment of ability to eat and drink, at risk oral fluids/food to person's thirst, need for clinically assisted hydration and/or nutrition)
- 6) **Other individualised care goals**
- 7) **Preferred place of care**

PLEASE REVIEW THIS CARE PLAN DAILY

## CLINICIAN AGREEING ABOVE INDIVIDUALISED CARE PLAN

Signature \_\_\_\_\_ Name \_\_\_\_\_ Grade \_\_\_\_\_ Date \_\_\_\_\_ Time \_\_\_\_\_



|   |   |  |
|---|---|--|
| <p>Brighton and Sussex <br/>University Hospitals<br/>NHS Trust</p> | <p><b>ACTION AND<br/>EVALUATION OF<br/>SYMPTOMS</b></p> | <p>Patient name:<br/>Hospital No:<br/>NHS No.<br/>D.O.B:<br/><br/>or affix patient ID sticker here</p> |
| <p><b>SYMPTOM</b><br/>(What symptom?)</p>   | <p><b>ACTION</b><br/>(What did you do?)</p>             | <p><b>EVALUATION</b><br/>(Did your action help? If not, what other<br/>action have you taken?)</p>     |
| <p>Signature: _____<br/>Date/Time: _____</p>  | <p>Signature: _____<br/>Date/Time: _____</p>            | <p>Signature: _____<br/>Date/Time: _____</p>   |
| <p>Signature: _____<br/>Date/Time: _____</p>  | <p>Signature: _____<br/>Date/Time: _____</p>            | <p>Signature: _____<br/>Date/Time: _____</p>   |
| <p>Signature: _____<br/>Date/Time: _____</p>  | <p>Signature: _____<br/>Date/Time: _____</p>            | <p>Signature: _____<br/>Date/Time: _____</p>   |
| <p>Signature: _____<br/>Date/Time: _____</p>  | <p>Signature: _____<br/>Date/Time: _____</p>            | <p>Signature: _____<br/>Date/Time: _____</p>   |
| <p>Signature: _____<br/>Date/Time: _____</p>  | <p>Signature: _____<br/>Date/Time: _____</p>            | <p>Signature: _____<br/>Date/Time: _____</p>   |

## DAILY NURSING CARE PLAN FOR THE DYING PERSON

PREFERRED NAME \_\_\_\_\_

DATE \_\_\_\_/\_\_\_\_/\_\_\_\_

Patient name:

Hospital No:

NHS No.

D.O.B:

or affix patient ID sticker here

### GOAL : MEDICATION NEEDS REVIEWED BY DOCTORS & ADJUSTMENTS MADE AS NECESSARY

|       |  |  |
|-------|--|--|
| DAY   |  |  |
|       |  |  |
| NIGHT |  |  |
|       |  |  |

### GOAL : HOLISTIC ASSESSMENT COMPLETED & NEEDS OF PATIENT AND PEOPLE MOST IMPORTANT TO THEM MET (EMOTIONAL, SPIRITUAL, CULTURAL, PRACTICAL)

|       |  |  |
|-------|--|--|
| DAY   |  |  |
|       |  |  |
| NIGHT |  |  |
|       |  |  |

### GOAL : MOUTH CARE DELIVERED AND ORAL HYGIENE MAINTAINED

|       |  |  |
|-------|--|--|
| DAY   |  |  |
|       |  |  |
| NIGHT |  |  |
|       |  |  |

### GOAL : ORAL HYDRATION IS MAINTAINED & ASSISTANCE PROVIDED TO DRINK AS ABLE/DESIRED

|       |  |  |
|-------|--|--|
| DAY   | Oral hydration estimate: None <input type="checkbox"/> , <500ml <input type="checkbox"/> , 500-1000ml <input type="checkbox"/> , 1000-1500ml <input type="checkbox"/> >1500ml <input type="checkbox"/> |  |
|       |  |  |
| NIGHT | Oral hydration estimate: None <input type="checkbox"/> , <500ml <input type="checkbox"/> , 500-1000ml <input type="checkbox"/> , 1000-1500ml <input type="checkbox"/> >1500ml <input type="checkbox"/> |  |
|       |  |  |

### GOAL : ORAL NUTRITION MAINTAINED & ASSISTANCE PROVIDED TO EAT AS ABLE/DESIRED

|       |  |  |
|-------|--|--|
| DAY   |  |  |
|       |  |  |
| NIGHT |  |  |
|       |  |  |

### GOAL: MICTURITION/CATHETERS & BOWEL/STOMA CARE: COMFORT & DIGNITY MAINTAINED. APPROPRIATE CATHETER CARE AND URINARY SYMPTOMS MAINTAINED

|       |  |  |
|-------|--|--|
| DAY   |  |  |
|       |  |  |
| NIGHT |  |  |
|       |  |  |

### GOAL: HYGIENE, SKIN INTEGRITY AND COMPLICATIONS OF BEING IN BED: COMFORT AND DIGNITY MAINTAINED, APPROPRIATE PRESSURE AREA CARE ADDRESSED

|       |  |  |
|-------|--|--|
| DAY   |  |  |
|       |  |  |
| NIGHT |  |  |
|       |  |  |

IF GOALS NOT MET DURING SHIFT PLEASE DOCUMENT WHY AND WHAT ACTION HAS BEEN TAKEN  
CONTINUE DOCUMENTATION OVERLEAF IF REQUIRED

## EVALUATION OF CARE GIVEN

[illegible]



# **THE INDIVIDUALISED PLAN OF CARE FOR PATIENTS IN LAST DAYS OF LIFE**

LOGO?

**Assess and review daily on individual basis to maximise overall comfort**

**Document key discussion points in each domain and refer to guidance pages for further details**

## **Priority 1: Recognition of dying**

Predicting dying is difficult. Which members of the MDT have been involved in recognition of the dying phase?

What is the condition(s) that is thought to be irreversible and contributing to the dying phase?

## **Priority 2: Communication, support and shared decision making**

**Involve the dying person and those important to them in decisions**

1. Explore understanding of current medical condition and clarify as necessary.  
Offer to clarify expectations of dying phase eg. symptoms, timeframe, uncertainty

2. What is most important to the patient at this stage?

3. Agree Goals of care – eg. Alleviation of symptoms, dignity, avoidance of medical interventions  
**Reference the following if applicable - Advance care plans; Advance decisions to refuse treatment; Power of attorney for health care; plans re organ/tissue donation**

4. Preferred Place of Death?

5. \*\* Establish **Ceilings of intervention** - Review Hospital Anticipatory Care Plan / Treatment Escalation Plan.  
Document medical interventions no longer appropriate including CPR.

6. Assess and document any social and practical needs–e.g. visiting/facilities/car parking

## THE INDIVIDUALISED PLAN OF CARE FOR PATIENTS IN LAST DAYS OF LIFE

**ENSURE ALL POTENTIALLY REVERSIBLE CAUSES FOR DETERIORATION HAVE BEEN CONSIDERED AND APPROPRIATELY TREATED** e.g. Infection, hypercalcaemia, renal failure, opioid toxicity, recent chemotherapy)

**DISCUSSIONS SHOULD TAKE PLACE BETWEEN THE HEALTHCARE TEAM, PATIENT AND THOSE IMPORTANT TO THEM AND REQUIRE A SENIOR CLINICIAN (CONSULTANT/STr/SAS) AND MULTIPROFESSIONAL TEAM ASSESSMENT**

**DISCUSS AND DOCUMENT RESUSCITATION STATUS AND REVIEW ANY EXISTING ADVANCE CARE PLANS AND ADVANCE DECISIONS TO REFUSE TREATMENT**

**CLEARLY OUTLINE THE GOALS OF CARE AND APPROPRIATE CLINICAL OBSERVATIONS AND MONITORING**

**ASSESS SYMPTOMS AND PRESCRIBE APPROPRIATE MEDICATION AND NEED FOR CLINICALLY ASSISTED HYDRATION AND NUTRITION**

**CONSIDER IF DISCHARGE IS FEASIBLE IF PREFERRED PLACE OF DEATH IS HOME**

**REFER PATIENTS WITH COMPLEX NEEDS TO THE HOSPITAL SPECIALIST PALLIATIVE CARE TEAM**

COMPLETE INDIVIDUALISED PLAN OF CARE (IPC) FOR THE DYING PATIENT OVERLEAF AND THEN DAILY CLINICAL NOTES

THEN:  
DOCTORS                      NURSES

ONCE IPC COMPLETED USE SYMPTOM OBSERVATION CHART & DAILY CARE PLAN FOR THE DYING PATIENT

### Discussed with:

Patient only ☐

Patient plus relative/other ☐

Relative/other only ☐

Face-to-face ☐

Telephone ☐

If not discussed with patient annotate reason:

Names of relatives/other and relationship to patient

Inform re name of

**Senior Clinician responsible for Care**

**Nurse leading care**

### Healthcare professional completing this form:

Please tick to confirm you are up to date with the End of Life mandatory training

Name

Position

Signature

Date / Time

### Review and endorsement by most senior health care professional:

Signature

Name

Date

## Guidance Notes to help with completion of Individualised plan of care

Ensure each section completed/ document key discussion points in each domain

### Discussion should take place with patient (where possible) and those identified as important to them

- Education and training of staff are crucial to ensuring high quality end of life care and it is therefore essential that all staff involved in looking after patients in the last days of life have completed End of Life Care education and training
- Care after death must also be undertaken with dignity and respect. Staff should be aware of how to access information that can be shared with families about bereavement support.

### Priority 1 - Recognition of dying

- Recognising that someone may be entering the last days of life can be difficult. Using clinical judgement and following an MDT approach will help ensure that the patient and those important to the patient get the best possible care and support.
- There should be open discussion to make the most appropriate plan of care, recognising there may be some degree of uncertainty. Close daily review should consider whether there is continuing deterioration or if there is stabilisation or even temporary improvement.
- Ensure all potentially reversible causes for deterioration have been considered and whether it is appropriate to treat them at this stage in the underlying medical condition / disease e.g. infection, hypercalcaemia, renal failure, opioid toxicity, recent chemotherapy.

### Priority 2 - Communication, Support and shared decision-making

- Communication must be sensitive, clear and honest. Check insight and discuss that death is likely within hours or days. Answer questions and provide information. Communicate any uncertainty with prognosis. Ensure involvement in discussing, developing and reviewing their individualised plan of care.
- **Agree Goals of Care** - ascertain and agree what is most important to the patient at this stage e.g. alleviation of symptoms, dignity, avoidance of medical interventions, preferred place of care and death etc.
- **\*\*\*Establish Ceilings of intervention** - discuss and document what medical interventions the patient would want to avoid or are no longer appropriate.  
e.g. ICU, HDU, dialysis, NIV/ AIRVO, blood tests, IV fluids, antibiotics etc.  
This may already be documented in a **Hospital Anticipatory Care Plan** or **Treatment Escalation Plan** – however check if Goals of Care and Ceilings of Intervention have changed.  
**Resuscitation Status** - discuss and document. Ensure deactivation of ICD if applicable.
- Describe changes that may occur in dying (Cheyne-Stokes breathing, noisy respiratory secretions, mottled skin, loss of consciousness).
- Ensure there is opportunity to state their needs and preferences- psychological spiritual, religious and cultural needs, preference for visitors, patient and visitor facilities.
- Ensure knowledge of the name of the senior doctor in the team (with responsibility for their treatment and care) and the nurse leading their care.
- Reassure there will be regular review to monitor for improvement, deterioration or stability.
- Where relevant - discuss and clarify any need for **referral to Coroner** e.g. Industrial lung disease.

## Priority 3 - Individualised plan of care

- **Clinical monitoring**
  - Review benefit of clinical monitoring including stopping, starting or continuing- NEWS 2, blood tests, blood glucose, fluid balance chart.
  - Explain use of Symptom Observation Chart for adults in last days of life as alternative.
- **Symptom assessment**
  - Assess patient re comfort and dignity: including assessment of pain, nausea & vomiting, agitation, breathlessness, noisy breathing, confusion and dry mouth
- **Medications**
  - Discuss that medication will be reviewed with the aim of discontinuing any medication not providing symptomatic benefit or that may cause harm, and the potential to commence medication aimed at comfort. Review benefit of starting, stopping or continuing medications such as **enoxaparin, antibiotics, statins and oxygen**.
- Use an **individualised** approach to prescribing Anticipatory Medicines and specify their indication. Consider **analgesia, antiemetic, anxiolytic, and anti-secretory medications** - refer to "**RPMG Symptom guidance at end of life**".
- Discuss potential routes of administration including use of syringe pump and discuss potential side effects of medications including drowsiness.
- **Hydration and Nutrition**
  - Support the dying person to drink if they wish to and are able to.
  - Check for any difficulties, such as swallowing problems or risk of aspiration.
  - Discuss the risks and benefits of continuing to drink, and also discuss the risks and benefits of clinically assisted hydration (subcutaneous / Intravenous fluids)
  - Patients may still choose to take sips despite risk of aspiration.

### Daily Clinical notes

- Ensure daily review - see prompts on each clinical notes page

Document key discussion points in each domain and refer to guidance pages for further details

### Priority 3: Individualised Plan of Care

#### (A) Clinical monitoring?

eg. NEWS 2, Blood tests, Blood glucose, fluid balance chart, symptom observation chart.

#### (B) Physical Symptoms –current symptoms and plan for management.

#### (C) Medication Review

Which medications are discontinued and which need to be continued?

Assess and prescribe individualised anticipatory meds and document discussion re: *potential side effects*.

Assess oxygen requirements.

#### (D) Management of Hydration and Nutrition

Discuss risks and benefits of options and document agreed plan e.g. IV/SC Fluids, risk feeding. Include plan for management of dry mouth.

#### (E) Psychological, Spiritual, Religious and Cultural needs

Identify, explore and document patient's concerns, beliefs, faith and values.

Consider involving other services e.g. Chaplaincy/social work/counselling.

## Daily clinical notes

**Assess patient daily.**

**Please consider the following in your daily review of patients.**

1. Focus of care – is the patient deteriorating, stabilising or improving? Review levels of intervention/management plan.
2. Symptom management – include review of Symptom Observation chart.
3. Hydration and Nutrition needs – support patient to eat and drink if appropriate.
4. Patient and family concerns – ensure updated on situation. Include review of place of care.

## Daily clinical notes

**Assess patient daily.**

**Please consider the following in your daily review of patients.**

1. Focus of care – is the patient deteriorating, stabilising or improving? Review levels of intervention /management plan.
2. Symptom management – include review of Symptom Observation chart.
3. Hydration and Nutrition needs – support patient to eat and drink if appropriate.
4. Patient and family concerns – ensure updated on situation. Include review of place of care.

\*On Behalf Of Diane Walker\*

DOH Response re. Individualised End of Life Care Plans

Dear Clinical Engagement Group members

Following recent discussion at the CEG meeting on 14 Sept a further request was made to DOH colleagues to provide an update on policy discussions with regards to a regional approach to Individualised End of Life Care Plans. The following response was received yesterday from John Millar at DOH and was subsequently discussed at the regional PCiP Programme Board meeting this morning:

Received 27 September 2023:

It is recognised that RPMG and CEG members are keen to see the introduction of regional, standardised individualised care plans and a briefing paper on this had been forwarded to the Department with an ask for a meeting with CMO and CNO to discuss.

As you know RPMG also wrote separately on the matter to CMO requesting a meeting and this was held on 28 February. Whilst RPMG has met with CMO and DCMO, in line with the original ask from the briefing paper, it will also be important that the views of nursing and other policy colleagues are considered as part of this process. The matter remains subject to consideration in the Department.

There has been no commitment or endorsement at this stage for any new arrangements. It will require a fuller assessment of whether this is needed and that will require wider discussion and consideration through proper process. Unfortunately, other priorities and resourcing pressures have impacted on this.

Any proposals for individualised end of life care plans should be considered within the broad umbrella of Advance Care Planning and work coming out of that, for example the introduction of ReSPECT.

As highlighted to RPMG colleagues in the response issued by Brendan Whittle and Aidan Dawson on 26 May, a number of key issues need to be considered to support any regional end of life care plan include governance, auditing, training and development, funding to support roll out etc. and the Department concurs with this.

As you will be aware, the Department is in an extremely challenging financial position, and we are already looking critically at service delivery priorities. Within this context, it is unlikely that any additional money will be available to take forward new areas of work.

In light of this response, the 'Regional approach to Individualised End of Life Care Plans' (Workstream #17) will remain as a workstream on the PCiP regional work plan but it will not be possible to allocate a timeline to it at this time.

Kind regards  
Diane

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