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CYMRU – WALES
palliative care

All Wales Guidance:
Care Decisions for the Last Days of Life

Version 11 June 2021

An evidence based good practice guide to support healthcare professionals delivering individualised holistic care to those in the last days and hours of life

This document forms part of the patient's confidential clinical record

Important note:
If the patient is **NOT** in the last days or hours of life, Care Decisions Guidance should **NOT** be used.

The full set of All Wales Care Decisions Guidance v11 consists of:

Document A - Main Care Decisions Guidance document (4 pages)
Document B - Patient Symptom Assessment Chart
Document C - Community PRN Medication Administration Record
Document D - Individual Case Review sheet (for evidencing care provided)
Document E - Symptom Control Guidance

Additional Care Decisions Supplements and Appendix are available:

- Covid-19 Symptom Control Supplement
- Diabetes Management Supplement
- Appendix: Considering diversity in delivering person-centred care

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Bwrdd Iechyd Prifysgol Bae Abertawe Swansea Bay University Health Board
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Care Decisions for the Last Days of Life

Context of the All Wales Care Decisions Guidance (CDG):

- **Delivering the best care in the last days (or hours) of life is everybody's business.** People in Wales die in many different places: in acute or community hospitals; in their own, a relative or friend's home; in residential or nursing care homes; in hospices, prisons etc. There is an equal need to deliver the best care possible, whatever the setting. The main 4 page Guidance document (Document A) leads you through the important points to consider for each individual person. The aim is to support and empower you, as a healthcare professional, no matter what your role or specialism, to be able to deliver high quality care in the last days of life. Where further support or advice is needed, specialist palliative care services (including out of hours) are available 24/7 within each Health Board area across Wales.
- The CDG reflects the need for **individualised person-centred care.** CDG advocates that every opportunity should be taken to discuss, with the dying person (where clinically possible) and with those important to them, care preferences, needs, goals and wishes, as well as to make shared decisions about their care.
- The **CDG is evidence based good practice guidance** developed, regularly reviewed and updated by specialists in Wales. (NICE guidance: Care of dying adults in the last days of life, NG31 (2015); The Five Priorities of Care: Leadership Alliance Care of the Dying Patient, One Chance to get it Right Report (2014)).

Targeted use:

- This guidance applies to **adults where death is anticipated or expected in the next few days or hours**.

Prior to commencing guidance use:

- It is recommended that, wherever possible, medical and nursing staff should carry out a joint clinical assessment. A senior clinician should be involved in initial decision-making.
- The term 'patient' is used for ease, but represents people dying in all settings.

General points:

- The Main 4 page Guidance (Document A) can be used with the other Care Decisions supporting documents (e.g. Symptom Control Guidance, Symptom Assessment Chart) as required.
- Prescribe all medications in the appropriate prescription charts, as used locally.
- Completing the Main Guidance document can act as an effective communication tool for teams and can prevent duplication of work such as repeated conversations, which may be distressing for patients. If discussions, decisions and the care given are not recorded in the Guidance (or elsewhere) there is **no evidence or record** that these took place. Using the Guidance can also show that you are working together as a staff team, demonstrating respect and that a person's dignity and wishes are taken seriously.
- People's needs and wishes e.g. beliefs, preferred language, can change when they know they are dying.
- The CDG 'Considering Diversity Appendix' can help guide you further in delivering person-centred care.
- Complete and return a Case Review sheet for all patients. This also evidences the care given.

Using the Main Guidance Document A:

- The Main Guidance document acts as a prompt to support and guide you to deliver the best care possible. It does not replace clinical judgement. Summarise the priorities and decisions of the patient, those important to them and the clinical team in the relevant sections. Briefly document the agreed individual plan of care and, if needed, write more fully in the patient's clinical record. Ensure the senior clinical decision maker signs page 4. Record all further decisions and progress in the patient's clinical record.
- This document should be filed in the current section of the patient's clinical record.

Who should complete what sections of the main Guidance document:

- Individual teams should agree which particular sections are completed by doctors or nurses depending on their local circumstances. In general, doctors may lead on completing pages 1, 2 and 4, with nurses leading the completion of page 3.

Name:

Date of Birth:

Address:

NHS Number:

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All Wales Guidance: Care Decisions for the Last Days of Life

This document forms part of the patient's confidential clinical record. (See context for its use on the previous page.)

Mae'r ddogfen hon ar gael yn y Gymraeg hefyd. / This document is also available in Welsh.

Clinical assessment:

Do the clinical team agree that the patient is in the last days of life? Yes ☐ No ☐

Document changes that make the team think that this person is now dying:

Important:

If the patient is **NOT** in the last days of life, Care Decisions Guidance should **NOT** be used - see page 4.

Have reversible causes of deterioration been considered? Yes ☐ No ☐

Comments:

What is the main medical condition likely to be responsible for this deterioration?

Person centred focus - patient understanding and priorities:

Patients should be given opportunities to discuss and plan their individualised care.

Is the patient aware that they are deemed to be in the last days of life? Yes ☐ No ☐ *OR*

Patient is unable (for clinical reason) to discuss* ☐ Patient states they do not want to discuss* ☐

Document any discussions with the patient about their awareness of dying (so others can build on/avoid duplication).

Record <u>what matters most to them</u> including any priorities, needs or concerns they have/are known to have had, taking into account their capacity to make decisions. *

**Involve and discuss, as appropriate, with those important to the patient – see page 4*

Important holistic information about the patient:

Note any key medical, nursing, social or other important information which may affect, or needs to be taken into account, when providing individual patient care. These may include: disability e.g. hearing, sight, mobility; language; race, culture, religion and belief; sexual orientation; gender identity, their important relationships; anxiety, mental health; and any caring roles they usually undertake. *For more practical guidance about these see the Care Decisions 'Considering Diversity Appendix'.*

NB It is statutory duty that Welsh speakers are enabled to speak their mother tongue. Welsh language preferred ☐

Patient's preferred place of care:

Where is the preferred place of care for this patient in the last days of life?

Is this currently being achieved? Yes ☐ No ☐ No preference or unable to express ☐

If no, why not?

Name: Date of Birth: Address: NHS Number:

Completing HCP (initials)……
Date……

Advance Care Planning (ACP) and Future Care Planning (FCP):

Refer to national/local guidance

Has the patient expressed wishes and preferences in an Advance Care Plan? Yes ☐ No ☐ Don't know ☐
If yes, how have these views been taken into account?

Has the patient completed an Advance Decision to Refuse Treatment (ADRT)? Yes ☐ No ☐ Don't know ☐
Is there a registered Lasting Power of Attorney (LPA) for Health and Welfare? Yes ☐ No ☐ Don't know ☐
Is there a Future Care Plan (FCP) in place? Yes ☐ No ☐ Don't know ☐

Has the patient expressed a decision on the organ donor register? (Can check on: 03000 20 30 40) Yes ☐ No ☐
Has the patient opted in ☐ or opted out ☐ or have they nominated an appointed representative ☐ ?

If the patient **hasn't opted out** please discuss tissue donation with patient / next of kin. If tissue donation is a possibility please refer to national Referral Centre for tissue donation on 0800 432 0559.
Action:

Medical management plan:

Document agreed medical management plan, particularly with regard to ACP/FCP, further investigations, escalation of care and interventions which may be considered.

Hydration decisions:

Document any discussions and decisions regarding hydration (including the risk/benefit of oral fluids and/or the use of parenteral fluids) with the patient / those important to them.

Nutrition decisions:

Document any discussions and decisions about nutrition (including artificial feeding via PEG/NG tube) with the patient / those important to them.

CPR Status – Natural Anticipated and Accepted Death (NAAD):

Refer to All-Wales DNACPR policy

Document any discussion with patient and those important to them about allowing natural death to occur, and complete appropriate forms (refer to fuller entries in patient record if necessary).

Name:

Date of Birth:

Address:

NHS Number:

Completing HCP (initials)……
Date……

Cultural, spiritual and religious support for patient and those important to them:

Consider the individual needs of the patient and those important to them. The Diversity Appendix offers practical advice. Discuss any particular priorities which may affect individual patient care. Document actions to be taken:

Individual plan of care — Update existing nursing care plans and risk assessments Refer to Symptom Assessment Chart

Focus on measures to increase patient comfort. Stop interventions no longer providing symptomatic benefit.
Document decisions on the following:

- Monitoring of vital signs (e.g. NHS Early Warning Scores in hospital setting)
- Regular blood tests
- Monitoring blood sugar levels*
- Other:
- Investigations or appointments
- Management of Implantable Cardiac Device*

Update existing nursing care plans and risk assessments in line with the above decisions.
In particular, address the following important aspects of care in the last days of life:

- Mouth care
- Skin
- Bladder/bowel
- Communication
- Environment - Privacy/Single room
- Symptom assessment
- Anticipatory medication
- Blood sugar level management*
- Hydration
- Nutrition

Symptom Control

- Rationalise current regular medication.
- Assess the patient for symptoms likely to occur in the last days of life (including pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation, and noisy respiratory secretions).
- Document findings on the Symptom Assessment Chart.
- Prescribe anticipatory medication with individualised indications for use, dosage and route of administration.
- Refer to the Care Decisions Symptom Control Guidance, if needed.

*Refer to local/national guidance such as:

- Care Decisions Diabetes Management Supplement or EOLC Diabetes UK Clinical Care Recommendations (2018)
- All Wales Operational Document for Deactivation of ICD (guidance) (2019)

Ongoing review — Update existing nursing care plans and risk assessments

Continue to monitor **at least daily** for signs and symptoms, for example pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation, and noisy respiratory secretions. Liaise with senior clinician if any concerns.

- Carry out regular symptom review, and discuss with senior colleagues if needed.
- Maintain frequent two-way communication with the patient (if they are able) and those important to them, taking into account that patient priorities may change over time.
- Discuss patient progress (and any changes) with the multi-disciplinary team.
- Consult your local Specialist Palliative Care Team for further advice if required.

Name:

Date of Birth:

Address:

NHS Number:

Completing HCP (initials)……
Date……

Understanding and priorities of those important to the patient:

With the patient's consent, those important to the patient should be given opportunities to discuss and help plan the patient's care. Offer information (including written material) about the role they can play to be involved and support care at this time.

Do those important to the patient understand the patient is dying? Yes ☐ No ☐ *OR*

Patient has no important people/does not want anyone informed ☐

Name of key individual to be involved / kept informed:

Relationship to patient:

Document discussion held with those important to the patient. Consider the following:

What support do they have? What are their needs and concerns at this time?

Are they aware how to access facilities, practical help or additional support, at home, in hospital or other setting?

Are they aware of bereavement support available, if needed?

If at home, do they know what to do when the person dies? **Document agreed plan:**

Verification of expected death:

Can verification of death be carried out by a suitably trained healthcare professional (other than a GP or hospital doctor) according to the management of an 'expected death'? Yes ☐ No ☐

Medical Examiner / Coroner:

Will the death meet the statutory regulations to refer to the coroner Yes ☐ No ☐

Document reason and discussions with team and those important to the patient:

If referring to coroner/medical examiner, have you let next of kin know? Yes ☐ No ☐ N/A ☐

Does next of kin know what will happen after death? Yes ☐ No ☐

(NB. For cultural/religious reasons, urgent death certificates and particular care of body may be needed by some families.)

IMPORTANT:

- If the clinical situation improves and the patient is **no longer deemed to be in the last days of life,** then the clinical team should discuss an alternative medical management plan. Care Decisions guidance should **no longer be used**. This should be indicated by drawing a line through each page, signed and dated.
- Please complete and return a Case Review sheet for each patient after death.

Identify responsible healthcare professionals:

<u>Healthcare professional (HCP) completing the document:</u>

Print Name: Signature: Date:

Role:

<u>Senior clinical decision maker consulted and plan agreed:</u>

Print Name: Signature: Date:

Role:

Name:

Date of Birth:

Address:

NHS Number:

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Care Decisions for the Last Days of Life

Patient Symptom Assessment Chart

Use this chart to record patient symptoms at the time of your assessment (required at least daily).
Mark each symptom 'score' in the appropriate section:

KEY: 0 = None, 1 = Mild, 2 = Moderate, 3 = Severe, 4 = Overwhelming

****Contact senior clinician to review medication if symptoms severe and/or persisting****

Year: ( ) dd/mm														
Use 24 Hour Clock	**Time**													
Pain *If patient unable to verbalise, observe facial expressions, body language and guarding.*	4													
	3													
	2													
	1													
	0													
Distress / Anxiety / Delirium / Restlessness / Agitation	4													
	3													
	2													
	1													
	0													
Breathlessness	4													
	3													
	2													
	1													
	0													
Noisy respiratory secretions	4													
	3													
	2													
	1													
	0													
Nausea (score 0 if unrousable)	4													
	3													
	2													
	1													
	0													
Vomiting	**Yes**													
	No													
Dry mouth	4													
	3													
	2													
	1													
	0													
Add other symptoms below to monitor e.g. seizures, wound care														
	4													
	3													
	2													
	1													
	0													
	4													
	3													
	2													
	1													
	0													
Initials														

Name:

Date of Birth:

Address:

NHS Number:

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Care Decisions for the Last Days of Life

Patient Symptom Assessment Chart

Use this chart to record patient symptoms at the time of your assessment (required at least daily).
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****Contact senior clinician to review medication if symptoms severe and/or persisting****

Year: ( ) dd/mm													
Use 24 Hour Clock	**Time**												
Pain *If patient unable to verbalise, observe facial expressions, body language and guarding.*	**4**												
	3												
	2												
	1												
	0												
Distress / Anxiety / Delirium / Restlessness / Agitation	**4**												
	3												
	2												
	1												
	0												
Breathlessness	**4**												
	3												
	2												
	1												
	0												
Noisy respiratory secretions	**4**												
	3												
	2												
	1												
	0												
Nausea (score 0 if unrousable)	**4**												
	3												
	2												
	1												
	0												
Vomiting	**Yes**												
	No												
Dry mouth	**4**												
	3												
	2												
	1												
	0												
Add other symptoms to monitor below e.g. seizures, wound care													
	4												
	3												
	2												
	1												
	0												
	4												
	3												
	2												
	1												
	0												
Initials													

COMMUNITY MEDICATION ADMINISTRATION RECORD

DRUG ALLERGIES & SENSITIVITIES	PLEASE CIRCLE AS APPROPRIATE: NONE KNOWN YES SIGNED…… DATE…….. NAME……
Drug / Allergen:	Description of Reaction:

This section must usually be completed prior to administration of any medicine. Refer to local policies for further guidance.

HEALTH RECORD/NHS No:_____

SURNAME:_____

FIRST NAME:_____

ADDRESS:_____

_____

DATE OF BIRTH:_____

CONSULTANT/GP:_____

DISTRICT NURSE TEAM: _____

DETAILS OF SUPPLEMENTARY CHARTS
TICK APPROPRIATE BOX

SYRINGE PUMP ☐ OTHER (Please specify) ☐

If starting a syringe pump, use the 'All Wales Continuous Subcutaneous Infusion Medication Administration Record'.

REGULAR MEDICATION THAT IS STILL REQUIRED

ENTER DOSE AGAINST TIME REQUIRED. USE ONE ROUTE ONLY FOR EACH ENTRY	REGULAR MEDICINE	MONTH	YEAR
DATE →	DATE		
DATE →	MEDICINE (Approved Name)	SPECIAL INSTRUCTIONS	PRESCRIBER'S SIGNATURE
ROUTE →			
SPECIFY TIME IF REQUIRED / DOSE / SIGN / DOSE CHANGE			
Morning			
Midday			REWRITE CHART
Evening			
Bedtime			
DATE →	MEDICINE (Approved Name)	SPECIAL INSTRUCTIONS	PRESCRIBER'S SIGNATURE
ROUTE →			
SPECIFY TIME IF REQUIRED / DOSE / SIGN / DOSE CHANGE			
Morning			
Midday			REWRITE CHART
Evening			
Bedtime			

DATE	**Oxygen** (if required)	SPECIAL INSTRUCTIONS (Refer to local guidelines). Flow rate and delivery device: Target oxygen saturation (if appropriate): **Or**, indicate that oxygen use is for comfort measures only	PRESCRIBER'S SIGNATURE

QUICK REFERENCE GUIDE: COMMONLY USED AS-REQUIRED MEDICINES AND DOSES:

INDICATION	MEDICINE	DOSE	FREQUENCY	ROUTE
Pain / breathlessness (if opioid-naïve)	Morphine	2.5mg	2 hourly	SC
Agitation (anxiety)	Midazolam	2.5 or 5mg	2 hourly	SC
Agitation (delirium)	Haloperidol Levomepromazine	2.5mg 6.25 or 12.5mg	4 hourly up to 6 hourly	SC SC
Nausea / Vomiting	Cyclizine Haloperidol Levomepromazine	50mg 1mg-1.5mg 6.25mg	4 hourly (max 150mg/24hours) 4 hourly 4 hourly (max 25mg/24hours)	SC SC SC
Noisy resp. secretions	Hyoscine hydrobromide Glycopyrronium	400 micrograms 200 micrograms	4 hourly (max 2.4mg/24hours) 4 hourly (max 1.2mg/24 hours)	SC SC

COMMUNITY MEDICATION ADMINISTRATION RECORD

PATIENT'S NAME…….. **HEALTH RECORD No. …….**

Important note 1: For some symptoms the same medicine is used in a different dose. If this is the case, please make a separate entry.
*** Important note 2:** It is good practice to indicate a maximum dose in 24 hours. This aids timely clinical review if frequent as-required doses are needed. The maximum dose indicated should include both as-required and regular medication (e.g. medication via CSCI).

AS REQUIRED MEDICINES				DATE	TIME GIVEN	DOSE/ ROUTE	GIVEN BY	DATE	TIME GIVEN	DOSE/ ROUTE	GIVEN BY	DATE	TIME GIVEN	DOSE/ ROUTE	GIVEN BY
INDICATION **Pain / Breathlessness**	MEDICINE (Approved name)														
DOSE	ROUTE	FREQUENCY	MAX DOSE IN 24 HRS *												
PRESCRIBER'S SIGNATURE			DATE												
INDICATION **Agitation (Anxiety)**	MEDICINE (Approved name)														
DOSE	ROUTE	FREQUENCY	MAX DOSE IN 24 HRS *												
PRESCRIBER'S SIGNATURE			DATE												
INDICATION **Agitation (Delirium)**	MEDICINE (Approved name)														
DOSE	ROUTE	FREQUENCY	MAX DOSE IN 24 HRS *												
PRESCRIBER'S SIGNATURE			DATE												
INDICATION **Nausea / Vomiting**	MEDICINE (Approved name)														
DOSE	ROUTE	FREQUENCY	MAX DOSE IN 24 HRS *												
PRESCRIBER'S SIGNATURE			DATE												
INDICATION **Noisy resp. secretions**	MEDICINE (Approved name)														
DOSE	ROUTE	FREQUENCY	MAX DOSE IN 24 HRS *												
PRESCRIBER'S SIGNATURE			DATE												
INDICATION **Dry mouth**	MEDICINE (Approved name)														
DOSE	ROUTE	FREQUENCY	MAX DOSE IN 24 HRS *												
PRESCRIBER'S SIGNATURE			DATE												
INDICATION	MEDICINE (Approved name)														
DOSE	ROUTE	FREQUENCY	MAX DOSE IN 24 HRS *												
PRESCRIBER'S SIGNATURE			DATE												

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Please complete and return this sheet for all deceased patients.

This sheet is used to evidence the quality of care provided at the end of life in Wales (with or without the use of Care Decisions guidance).

*Please complete/tick **all answers** that are relevant. *(If no evidence exists, 'No' should be ticked.)*

Last Days of Life Care in Wales: Individual Case Review Sheet

Health Board area:……	**About the deceased:**
Name of org/establishment/ team reporting: ……	☐ Male ☐ Female ☐ Other
Location/base/area team covers (to attribute data):……	**Age:**……
Patient's Care Setting: ☐ Own home ☐ Residential Home ☐ Nursing Home	**Primary diagnosis:** ☐ Cancer
☐ Community Hospital ☐ Acute hospital ☐ SPC IPU / Hospice ☐other……	☐ Non-cancer ☐ Unknown

Priority 1: The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed/revised regularly.

Recognising the dying phase:

- Was the patient seen by a senior clinician in their last days? ☐ Yes ☐ No
- Was it documented that the team agreed the patient is likely to be in the last days or hours of life? ☐ Yes ☐ No

Recognising the patient's needs and wishes in their last days of life:

- Was it documented that the patient was asked about or had already indicated their needs and wishes? ☐ Yes ☐ No
- Was the patient where they preferred to be cared for in the last days of life? ☐ Yes ☐ No
  If not, why not? ……
- Was it documented that arrangements/plans were reviewed and revised as needs changed? ☐ Yes ☐ No

Priority 2: Sensitive communication takes place between staff and the person who is dying and those important to them.

- Was there evidence of sensitive discussions with the patient about their last days of life? ☐ Yes ☐ No
  Was the patient unable to discuss (e.g. Dementia, confused, lacked capacity, no communication) ☐ *Yes*
  Did the patient clearly indicate that they did not want to discuss the issue ☐ *Yes*
- Was there evidence of discussion with those important to the patient regarding last days of life? ☐ Yes ☐ No
  No important people were identified by patient or patient did not want them involved ☐ *Yes*

Priority 3: The dying person, and those identified as important to them, are involved in decisions about treatment and care.

- Was there evidence that opportunities were given to the patient and those important to them to be involved in discussions about treatment and care? ☐ Yes ☐ No ☐ n/a

Priority 4: The people important to the dying person are listened to and their needs are respected.

- Was there evidence that those important to the patient were listened to and their needs respected? ☐ Yes ☐ No ☐ n/a
- Were those important to the patient made aware of the practical support and information available to them (before and after death) e.g. hospital facilities/increased nursing care at home/booklet/sign posting ☐ Yes ☐ No

Priority 5: Care is tailored to the individual and delivered with compassion – with an individual care plan in place.

Was there documented evidence of:

- Holistic individualised care planning being undertaken *(this may include: physical, psychological, spiritual, cultural, religious needs assessment and action planning)* ☐ Yes ☐ No
- Appropriate anticipatory medication, tailored to the needs of the patient, being available ☐ Yes ☐ No
- At least daily monitoring of signs and symptoms, including need for parenteral fluids ☐ Yes ☐ No

Other: Documentation: Were any of the following documents used?

(i) Main Care Decisions Guidance (4 pages) (Document A) ☐ Yes ☐ No
(ii) Symptom assessment chart (Document B) ☐ Yes ☐ No
(iii) Symptom control guidance (flow diagrams) (Document E) ☐ Yes ☐ No

Any further comment on care or if any aspect not fulfilled, why?	**Return completed sheets** to your local audit dept or: ▪ *Email:* CareDecisions@wales.nhs.uk ▪ *Post*: Einir Roberts, Care Decisions Manager, Palliative Care, Bodfan, Eryri Hospital, Caernarfon Gwynedd. LL55 2YE ▪ Fax: FAO Care Decisions Team 03000 851669

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All Wales Guidance: Care Decisions for the Last Days of Life

Symptom Control Guidance

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Introduction

This guideline is an aid to clinical decision-making in managing common symptoms which can occur in people in the last days of life.

- **Regular assessment of symptoms remains important.**
  - Assess the patient for symptoms likely to occur in the last days of life (including pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation, and noisy respiratory secretions).
  - **Consider reversible causes of symptoms** e.g. pain or agitation caused by urinary retention or constipation.
- **Management requires an individualised approach to the patient.**
  - An individualised approach may suggest a different medication/dose/strategy being indicated to those listed as 1st line in the guidance.
  - There should also be **consideration of non-pharmacological strategies** in addition to medication to manage symptoms e.g. positioning, environment, reassurance.
- **Medication considerations:**
  - **Prescribe anticipatory (including injectable) medication** with individualised indications for use, dosage and route of administration. Such injectable subcutaneous (SC) medication should be available for use in anticipation of the common symptoms in the last days of life even if these symptoms are not yet present.
  - **Continuous subcutaneous infusion (CSCI)** using a syringe driver/pump is indicated if a patient requires regular symptom control medication but can no longer take this by mouth or if there are concerns about absorption from the oral route.
  - It is good practice to **indicate a maximum dose in 24 hours**. This aids timely clinical review if frequent as-required doses are needed. The maximum dose indicated should include both as-required and regular medication (e.g. medication via CSCI).
  - Where CSCI is required the diluent should be water for injection. Contact pharmacy for advice if drug compatibility is a problem.

Contact your local specialist palliative care team (SPCT) for more advice.

With the OOH service outlined below, support is available 24/7.

Out of Hours Specialist Palliative Medicine Telephone Advice Line:

- **North Wales**: 01978 316800
- **South East Wales** (Marie Curie Hospice): 02920 426000
- **South East Powys** (Royal Glamorgan / Royal Gwent Hospitals): 01443 443443 / 01633 234234
- **South West Wales** & **South West Powys** (Morriston Hospital): 01792 703412 / 01792 702222
- **Mid Powys** (St Michael's Hospice): 01432 852080
- **North Powys** (Severn Hospice): 01743 236565

For more information see:

- Current version of the BNF
- Palliative Care (Adult) Network Guidelines - PANG. Max Watson, Peter Armstrong, Craig Gannon, Nigel Sykes, Ian Back. 2017

Acknowledgements: This document has been developed in accordance with NICE guidance 'Care of dying adults in the last days of life' (2015, NG31, nice.org.uk/guidance/ng31) and e-Learning for Health module 04_23. It describes pragmatic practice.

The management of pain with morphine in the last days of life

Is the patient in pain?

No

Is the patient prescribed regular oral morphine?

No

Prescribe in anticipation of the symptom developing:

- Morphine 2.5mg SC PRN up to 2 hourly

Yes

If the patient can no longer take oral morphine, convert to morphine CSCI:

1. Divide regular 24 hour oral morphine dose by 2 and prescribe as morphine via CSCI over 24 hours
2. Prescribe PRN SC morphine at 1/6th of the 24 hour CSCI dose up to 2 hourly

Yes

Is the patient prescribed regular oral morphine?

No

If the patient can take oral morphine PRN, continue this. In addition, prescribe morphine 2.5mg SC PRN up to 2 hourly.

If two or more PRN doses are given with effect in 24 hours, consider using morphine via CSCI over 24 hours.

Yes

1. Convert oral morphine to morphine CSCI by dividing the regular 24 hour oral morphine dose by 2; then, increase by approximately 20 to 30% (i.e. the equivalent of 2 PRN doses), and prescribe as morphine via CSCI over 24 hours. Stop regular oral morphine!
2. Prescribe PRN SC morphine at 1/6th of the 24 hour CSCI dose up to 2 hourly.

Note:
If the patient is on **another regular opioid**, please see page 3 of 8.

Note:
Caution required in **renal and/or hepatic impairment** – alternative dosing or medication choice may be required – see page 8 of 8.

Is the patient still in pain 24 hours after commencing morphine via CSCI?

Yes

Consider another 30% increase in morphine via CSCI (if pain is opioid-responsive). *Contact the SPCT for advice.*

Other pain management considerations in the last days of life

Diamorphine

- Diamorphine can be useful where large doses of opioid is needed as smaller volume is required.
- To convert oral morphine to SC diamorphine divide by 3:
  E.g. 30mg oral morphine = 10mg SC diamorphine
- All the other prescribing principles remain the same as morphine.

Note:
PRN doses will generally be approximately 1/6th of the total equivalent regular daily opioid dose.

Oxycodone

- Oxycodone may be useful where morphine not tolerated or contraindicated.
- Oxycodone is often favoured over morphine in mild to moderate renal impairment but caution still required.
- Oxycodone is generally contraindicated in moderate to severe hepatic failure.

For converting oral oxycodone to SC oxycodone two different conversions are commonly used. Either:

- Reduce dose by 1/3:
  E.g. 30mg oral oxycodone = 20mg SC oxycodone OR
- Reduce dose by 1/2:
  E.g. 30mg oral oxycodone = 15mg SC oxycodone

Contact the SPCT for advice if needed.

Fentanyl/Buprenorphine patch(es)

- Leave the patch in situ when commencing a CSCI and continue to change at prescribed frequency.
- PRN dose should be roughly 1/6th of the 24 hour opioid dose including both equivalent patch and CSCI doses.
- See BNF "prescribing in palliative care" section for conversion details or *contact the SPCT for advice* if needed.

Alfentanil

- Alfentanil can be used in moderate to severe renal impairment, *but only under the direction of specialist palliative care team.*
- To convert oral morphine to SC alfentanil divide by 30:
  E.g. 30mg oral morphine = 1mg alfentanil

Note:
Where **alfentanil** is used via CSCI the PRN dose will likely be morphine or oxycodone as alfentanil is too short-acting to be suitable for PRN use.

The management of breathlessness in the last days of life

Does the patient feel breathless?

No

Yes

- Reposition the patient, e.g. sit them up in bed.
- Improve air circulation i.e. fan therapy, open windows.
- Give oxygen only if hypoxic.

Does breathlessness persist?

No

Yes

Prescribe in anticipation of the symptom developing:

- Morphine 2.5mg SC PRN up to 2 hourly
  and
- Midazolam 2.5mg SC PRN up to 2 hourly

- Give morphine 2.5mg SC PRN up to 2 hourly
  or
- If already on regular opioids, give appropriate breakthrough dose (at 1/6th of the 24 hour opioid dose up to 2 hourly)

If not sufficiently effective, give midazolam 2.5 SC PRN up to 2 hourly

- If two or more PRN doses for breathlessness are given with effect in 24 hours, increase the medication already given via CSCI, or consider commencing CSCI with morphine and/or midazolam over 24 hours (initial dose guided by PRN use)
- *Contact the SPCT for advice if symptoms not adequately controlled*

Note:
Morphine is used for the **relief of the sensation of breathlessness**.
Midazolam is used for the **anxiety associated with dyspnoea**.

The management of agitation and restlessness in the last days of life

Is the patient restless or agitated?

No

Prescribe in anticipation of the symptom developing:

- For agitation (anxiety): Midazolam 2.5 or 5mg SC PRN up to 2 hourly
- For agitation (delirium): Haloperidol 2.5mg SC PRN up to 4 hourly

Yes

Consider and resolve where possible any underlying causes such as:

- Uncontrolled pain
- Full bladder
- Full rectum
- Breathlessness
- Anxiety and fear

If the patient's distress cannot be otherwise relieved:

1. If **delirium** and psychotic features are predominant (e.g. hallucinations, confusion, restlessness),
   - Give haloperidol 2.5mg SC PRN up to 4 hourly.
   - If two or more PRN doses of medication are given with effect in 24 hours, consider using the medication via CSCI over 24 hours.
   - Levomepromazine 6.25 or 12.5mg SC PRN up to 6 hourly is an alternative to haloperidol.

   If symptoms persist, contact the SPCT for advice. In certain circumstances, the SPCT may advise larger doses than the ones stated above.
2. Where **anguish and anxiety** are prominent,
   - Give midazolam 2.5 or 5mg SC PRN up to 2 hourly.
   - If two or more PRN doses of midazolam are given with effect in 24 hours, consider using midazolam 10mg via CSCI over 24 hours.
   - The CSCI dose of midazolam may need to be increased gradually up to 30mg over 24 hours.

   If symptoms persist, contact the SPCT for advice. In certain circumstances, the SPCT may advise larger doses than the ones stated above.

Note:

Terminal agitation is often a feature of hyperactive delirium and therefore antipsychotics are commonly used first line, either alone or in combination with a benzodiazepine.

The management of noisy respiratory secretions ('rattle') in the last days of life

Does the patient have noisy respiratory secretions?

No

Prescribe in anticipation of the symptom developing:

- Hyoscine hydrobromide 400 micrograms SC PRN up to 4 hourly

or

- Glycopyrronium 200 microgram SC PRN up to 4 hourly

Yes

- Provide explanation and reassurance to those around the patient.
- Consider repositioning the patient
- Continue regular mouth care

Do noisy respiratory secretions persist?

No

Yes

Prescribe either hyoscine hydrobromide or glycopyrronium

1. Hyoscine hydrobromide
   - Give hyoscine hydrobromide 400 micrograms SC and repeat up to 4 hourly if needed.
   - If two or more PRN doses are given with effect in 24 hours, consider using hyoscine hydrobromide 1.2mg via CSCI over 24 hours.
   - If symptoms persist after 24 hours and there are no intolerable side effects, increase to a maximum of hyoscine hydrobromide 2.4mg via CSCI over 24 hours.
2. Glycopyrronium
   - Give glycopyrronium 200 micrograms SC and repeat up to 4 hourly.
   - If two or more PRN doses are given with effect in 24 hours, consider using glycopyrronium 600 microgram via CSCI over 24 hours.
   - If symptoms persist after 24 hours and there are no intolerable side effects, increase to a maximum of glycopyrronium 1.2mg via CSCI over 24 hours.

Note:

It may be helpful to explain to those present that noisy respiratory tract secretions can be a **normal part of dying** as fluid pools in the oropharynx. Consider whether this symptom need treating at all; most patients are unaware of secretions.

If the patient is distressed, follow breathlessness management guidelines.

The management of nausea and vomiting in the last days of life

Does the patient have nausea or vomiting?

No

Is the patient prescribed a regular oral anti-emetic?

No

Prescribe in anticipation of the symptom developing:

- Haloperidol 1mg - 1.5mg SC PRN 4 hourly and/or
- Cyclizine 50mg SC PRN 4 hourly (max 150mg/24 hours).

Yes

- Prescribe this anti-emetic via CSCI over 24 hours.
- Prescribe a PRN anti-emetic e.g. levomepromazine 6.25mg SC PRN 4 hourly (max 25mg/24 hours).

Note:

Considering the **likely cause** of nausea/vomiting to help decide the most appropriate 1st line anti-emetic:

- Toxic/ biochemical causes (e.g. renal failure, opioids, hypercalcaemia) – **haloperidol**
- Vestibular causes/ raised intracranial pressure – **cyclizine**
- Gastric stasis/ functional bowel obstruction – **metoclopramide**
- In **Parkinson's disease,** consider Ondansetron first line (see page 8 of 8)

Levomepromazine is a broad spectrum anti-emetic and is often used second or third line.

Yes

Is the patient prescribed a regular oral anti-emetic?

No

- Consider prescribing an anti-emetic via CSCI over 24 hours. (See examples of common regimes below.)
- Prescribe a PRN anti-emetic e.g. levomepromazine 6.25mg SC PRN 4 hourly (max 25mg/24 hours).
- *If symptoms persist, contact the SPCT for advice.*

Yes

- Prescribe this anti-emetic via CSCI over 24 hours.
- Prescribe levomepromazine 6.25mg SC PRN 4 hourly (max 25mg/24hours).
- If two or more PRN doses are given with effect in 24 hours, consider swapping to levomepromazine 12.5mg via CSCI over 24 hours.
- Prescribe a PRN SC anti-emetic.

Note:

Examples of common anti-emetic regimens for nausea/vomiting in the last days of life:

- Haloperidol via CSCI over 24 hours, Cyclizine or Levomepromazine PRN
- Cyclizine (+/- Haloperidol) via CSCI over 24 hours, Levomepromazine PRN
- Metoclopramide via CSCI over 24 hours, Levomepromazine PRN
- Levomepromazine via CSCI over 24 hours, Levomepromazine and/or Ondansetron PRN

Do not use Cyclizine and Metoclopramide together, as they counter-act each other.

Special considerations in the last days of life

Renal impairment

Pain:

- Oxycodone is often used as an alternative to morphine in mild to moderate renal impairment (though caution is still needed).

Other symptoms:

- Most other symptom control medications can be used in renal impairment with caution as long as there is adequate review.
- Consider starting with lower doses and/or longer dosing intervals.
- Refer to BNF for further information.

End stage renal failure

- *Advice should usually be sought from SPCT or renal specialists.*
- Drug elimination will be significantly slower so symptoms may be manageable with PRNs alone.

Pain:

- Prescribe in anticipation of the pain developing: oxycodone 1 or 2mg SC PRN 4 hourly.
- If CSCI is required, *seek SPCT advice* regarding the best analgesic option.

Other symptoms:

- Prescribe glycopyrronium instead of hyoscine hydrobromide.
- Use lower doses of midazolam, haloperidol and levomepromazine.
- *Seek advice from Pharmacy or SPCT if needed.*

Heart failure

- Heart failure medications may offer significant symptom relief: So, where possible, do not abruptly stop these medications just because the patient is entering their last days of life.
- Opioids and midazolam can be helpful for breathlessness. Dose adjustment is needed if the patient has concurrent renal impairment.
- Avoid cyclizine.
- Diuretics can sometimes be given subcutaneously *– seek advice from the heart failure team or SPCT.*

Parkinson's disease

- If unable to take oral Parkinson's medications consider using a rotigotine transdermal patch starting at 2mg/24 hours.
- Avoid anti-dopaminergic medications e.g. haloperidol, metoclopramide and levomepromazine.
- *Seek advice from Pharmacy, Care of the elderly or SPCT if needed.*

Seizures

- If there is a risk of seizures, prescribe buccal midazolam 10mg PRN.
- If on regular oral anti-epileptic medication(s) and unable to take these, *seek SPCT advice* regarding the best medicine to use via CSCI over 24 hours.

Diabetes management

- For advice on diabetes management in the last days of life, see Supplementary document. Advice is based on 'End of Life Diabetes Care' (Diabetes UK, 2018).
- *Seek advice from Diabetes team or SPCT if needed.*