

# WELSH HEALTH CIRCULAR

WHC (2006) 030



Llywodraeth Cynulliad Cymru  
Welsh Assembly Government

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**Title:** End of Life Care – All Wales Care Pathway for the Last Days of Life

**For Action by:** NHS Trusts, Local Health Boards and Health Commission Wales

**Action required:** See *paragraph(s)* : 5, 6 and 8

**For Information to:** See distribution list attached

**Sender:**

John Sweeney, Director, Community, Primary Care and Health Services Policy Directorate  
Health and Social Care Department

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**Enclosure(s):** Generic Adult Pathway

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## Dear Colleague

### Summary

1. This Welsh Health Circular formally endorses the *All Wales Care Pathway for the Last Days of Life*, following the Minister for Health and Social Services' commitment to ensure that health care encompasses the needs and wishes of those at the end of life. Integrated planning and provision of health services is a key aim of the Welsh Assembly Government. Historically, high quality end of life care has largely been available only to those patients (predominantly cancer sufferers) referred to palliative care services. The purpose of this Welsh Health Circular is to highlight the importance of the continuation of patient care through to the very end of life, irrespective of physical or mental health conditions. A key element of patient need and those of their families is good 'end of life' care.

### Background

2. The quality of care provided to a dying patient has a lasting effect on the families and carers. It is a major cause of bereavement problems in relatives, which can have a lasting effect on long term health. Many complaints concerning the care of dying patients relate to poor communication between professionals and families, a lack of access to services out of hours, inadequate knowledge and skills of staff and inappropriate facilities.
3. It is extremely important that all health care professionals, regardless of specialty, consider the wishes of their patients in terms of end of life care and that it features as part of the basic care provided to patients. The *All Wales Care Pathway for the Last Days of Life* is already being widely used across Wales and is considered to be an endorsement of best practice. This Pathway now needs to be adopted and endorsed throughout Wales to ensure that all patients nearing the end of life receive the care and support appropriate for them. As it stands the Pathway is adult focussed. Work is currently underway to develop *Standards for children and young peoples' palliative care*, which will encompass the issues relating to end of life care. In the light of these Standards the Pathway will need to be adapted to encompass the specific needs of children and young people.

### Implementation

4. The *All Wales Care Pathway for the Last Days of Life* must be considered and put into practice along side and in conjunction with key health publications such as *A Strategic Direction for Palliative Care Services in Wales* and NICE guidance on *Improving Supportive and Palliative Care in Adult Cancer Patients*, to ensure that the wishes of the recently deceased and their recently bereaved, are accounted for. The recent *Needs Assessment for Palliative Care* also provides valuable information which will need to be taken into account to help inform LHB palliative care commissioning plans.
5. Trusts and Local Health Boards need to give a clear steer to all their staff highlighting the importance of the care of the dying and encourage initiatives which improve that care. The *All Wales Care Pathway*, will assist your staff in this area as well as access to training available on certificate level courses.
6. We must ensure that there is an integration of care of the dying into healthcare provision and planning. All revisions to current National Service Frameworks and the development of future

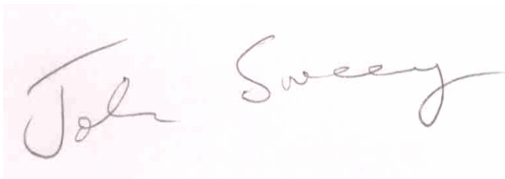
quality requirements issued by the Welsh Assembly Government will in future endorse the *All Wales Care Pathway for the Last Days of Life*.

7. You in turn as Commissioners and Providers of care must also endorse this Pathway and ensure that staff are conversant with its requirements and fully equipped to provide the level of consistent care appropriate to patients and their bereaved in last few days of life. Similarly, we expect Local Health Boards and Health Commission Wales as Commissioners to work closely with all their partners, including the voluntary sector to meet such needs in the most effective and efficient way.

### **Agreed Funding**

8. The immediate funding issues are fairly minimal. As you are aware all NHS Trusts and Local Health Boards in Wales will provide £575 each in support of implementation of the *All Wales Care Pathway for the Last Days of Life* in 2006-07. These organisations should now consider making this recurrent. A further £7,000 will be provided centrally out of the residual element of the Welsh Assembly Government Palliative Care Funding to initiate the process for an all Wales audit of this pathway.

Yours sincerely

A handwritten signature in black ink that reads "John Sweeney". The signature is written in a cursive style and is positioned above the printed name and title.

**John Sweeney**  
**Director, Community, Primary Care and Health Services Division**

NAME  
ADDRESS

SURGERY  
GP/Consultant

DOB

## Care Pathway for the last days of life

(based on the Royal Liverpool University Hospitals' ICP for the dying patient)

The Care Pathway is intended as a guide in providing care for the patient and their family in the last days of life.

As a multi-disciplinary document it will replace existing medical and nursing notes during this period of care.

Each professional is encouraged to exercise their own professional judgement.

Any variances to the care suggested in the Pathway should be recorded.

### INSTRUCTIONS FOR USE

- 1 Initial Assessment** should be completed as the patient is entered onto the Pathway. The Doctor completes page 2 {yellow sheet}. The nurse completes page 3 and 4 {green sheet}.
- 2 Ongoing Assessment.** Page 5 to be completed by the nurse when visiting and page 6 every 24 hrs. New sheets of pages 5 and 6 {blue} should be used each day.
- 3 Variance** occurs if the Pathway is not followed as expected. Any variance should be recorded on the pink sheet. An answer in *Italics* is a variance.  
N.B. a variance is not wrong but it is important to record to help with audit.
- 4 Multi-disciplinary Communication Sheet** {white sheet}. Allows scope to record anything not covered by the Pathway. Its use should be encouraged to record communication with the patient and family.

Option of discharge/transfer has been considered

Y[ ] N[ ]

### CRITERIA FOR ICP - DO NOT PUT ON PATHWAY UNLESS

Patient will be dying and at least two of the following:

Bedbound [ ]  
Semi-Comatose [ ]  
Only able to take sips of fluid [ ]  
No longer able to take tablets [ ]

G.P has been informed of situation

Y[ ] N[ ]

<b>CPR has been discussed with relatives and agreed to be inappropriate</b>	Y[ ]	N[ ]
<b>Patient Not for CPR YES</b>	[ ]	
<b>** Advanced Directive of Living Will</b>	Y[ ]	N[ ]
<b>** Discussed with relatives, Macmillan / Marie Curie services available</b>	Y[ ]	N[ ]

NAME  
DOB  
D No.

Date.....  
Time.....

**DOCTORS ASSESSMENT**

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**Diagnosis**

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**PHYSICAL CONDITION**

	Y	N		Y	N
Conscious	[ ]	[ ]	Able to swallow	[ ]	[ ]
Aware	[ ]	[ ]	Nausea / Vomiting	[ ]	[ ]
Confused	[ ]	[ ]	Constipation	[ ]	[ ]
Agitated	[ ]	[ ]	Pain	[ ]	[ ]
Distressed	[ ]	[ ]			
Dyspnoea	[ ]	[ ]	Continent	[ ]	[ ]
Respiratory Tract Secretions	[ ]	[ ]	Catheterised	[ ]	[ ]
			Other state		

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**MEDICAL MEASURES** If a box in *italics* is ticked explain action / inaction on variance sheet.

**Goal: Current medication assessed and non essentials discontinued**

Appropriate oral drugs converted to subcutaneous route via syringe driver  
Yes [ ] No [ ]

**Goal: PRN written up for list below - as per Protocol**

Pain	- Analgesia	Yes [ ]	No [ ]
N&V	- Anti-Emetic	Yes [ ]	No [ ]
Agitation	- Sedative	Yes [ ]	No [ ]
Respiratory Tract Secretions	- Anticholinergic	Yes [ ]	No [ ]
Syringe driver		Yes [ ]	No [ ]

**Goal: Discontinue inappropriate interventions**

Blood Tests	Yes [ ]	No [ ]
Antibiotics	Yes [ ]	No [ ]

Doctors signature \_\_\_\_\_

Date \_\_\_\_\_

Print name \_\_\_\_\_

On call GP informed Yes [ ] No [ ]

(yellow)

NAME  
DOB

Date.....

**Nursing Assessment**

**COMFORT MEASURES.**

**Goal: To promote patient comfort**

Pressure areas assessed	Yes [ ]	No [ ]
Assessed need for: special mattress	Yes [ ]	No [ ]
Assessed condition of mouth	Yes [ ]	No [ ]
Assessment of wounds	Yes [ ]	No [ ]

Action taken on any of above assessments

**Consider the environment:** comfort, safety, temperature, ventilation.

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**COMMUNICATIONS**

**Goal: Ability to communicate assessed**

Languages spoken\_\_\_\_\_ Preferred language\_\_\_\_\_

Barriers to communication\_\_\_\_\_

**Goal: Identify and address patients fears and anxieties**

Patient recognises that they are dying Yes [ ] No [ ] Don't Know [ ]

Fears identified\_\_\_\_\_

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**RELIGIOUS / CULTURAL REQUIREMENTS**

**Goal: Religious and cultural needs are respected**

Religion identified (please specify)\_\_\_\_\_

If appropriate contact made with Minister Yes [ ] No [ ]

Contact name\_\_\_\_\_ Contact number\_\_\_\_\_

Religious / Cultural needs identified - please state

**BEREAVEMENT PLANNING / FAMILY CARE**

**Goal: Fears and anxieties of relatives identified and addressed**

Family recognise that patient is dying      Yes [ ]      No [ ]      Don't Know [ ]

Plan of care discussed with relative:      Yes [ ]      No [ ]

Fears identified, please state \_\_\_\_\_

\_\_\_\_\_

Nurses signature \_\_\_\_\_

Date \_\_\_\_\_

Print name \_\_\_\_\_



**Complete Daily**

Day

**MOBILITY / SAFETY**

**Goal: Patient safety ensured**  
Supervision required  
Assessed for bed aids as appropriate

**MICTURITION DIFFICULTIES**

**Goal: Patient is comfortable**  
  
Urinary catheter if in retention  
Urinary catheter or pads, if general weakness creates incontinence

**COMMUNICATION**

**1 PATIENT**

**Goal: Patient becomes aware of situation as appropriate**  
If appropriate, patient is given opportunity to express concerns  
Patient is informed of procedures  
Touch, verbal communication is continued

**2 FAMILY / OTHER**

**Goal: Family / Other are prepared for the patient's imminent death**  
Check understanding  
Inform of measures to make patient comfortable  
opportunity given to express fears and concerns

**DAILY REVIEW BY TEAM** If a box in *italics* is ticked explain action / inaction on variance sheet.

**Goal: All appropriate medications given as prescribed**  
Non essential medication discontinued Yes [ ] No [ ]

**Goal: Inappropriate interventions discontinued** Yes [ ] No [ ]

**RELIGIOUS SUPPORT**

**Goal: Religious rituals / support have been performed**  
Before dying Yes [ ] No [ ] N/A [ ]  
Whilst dying Yes [ ] No [ ] N/A [ ]

Named nurse signature \_\_\_\_\_  
Repeat this page every 24 hrs





NAME

DATE and TIME OF DEATH

**CARE AFTER DEATH**

GP informed of Death Y[ ] N[ ] Time.....

**DEATH CERTIFIED**

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Signature of Certifier

Time

**FAMILY**

**Goal: To prepare, inform and support the patient's family /other, during final stages and immediately after death**

Post mortem discussed if appropriate	Yes [ ]	No [ ]
Contacting Funeral Director explained	Yes [ ]	No [ ]
Information sheet given	Yes [ ]	No [ ]
Family support present	Yes [ ]	No [ ]

**PATIENT**

**Goal: Special needs identified**

Patient had recent administration of radio-isotope: <i>If yes,</i>	Yes [ ]	No [ ]
Nuclear Medicine is informed and guidance followed	Yes [ ]	No [ ]
Family and Funeral Directors informed	Yes [ ]	No [ ]
Patient had infectious disease: <i>If yes,</i>	Yes [ ]	No [ ]
Funeral Directors and home loans informed	Yes [ ]	No [ ]
Patient has religious needs	Yes [ ]	No [ ]

Signature of Nurse .....

**Please inform relevant out of hours agencies (see page 1b for phone number) of patient's demise.**

Variance Sheet Copied and Sent to: Ros Johnstone, Palliative Care Department, Bodfan, Eryri Hospital Caernarfon, Gwynedd LL55 2YE Yes [ ] No [ ]









Name: _____ M <input type="checkbox"/> F <input type="checkbox"/> Address _____ _____ _____ D.o.B. _____ D No _____	CONSULTANT	HOSPITAL
	GP	WARD
	NAMED NURSE	AREA

**SYRINGE DRIVER**

<b>G.P./Consultant</b>											
<b>GRASEBY M.S.16A. BLUE RATE SET = mm per hr</b>				<b>GRASEBY M.S. 26 GREEN RATE SET = mm per 24 hrs</b>							
<b>COMMENCED BY.(Nurse/Doctor)</b>						<b>Signature</b>			<b>Signature</b>		
<b>DATE</b>											
<b>TIME SET UP / CHANGED</b>											
<b>RATE SET AND CHECKED</b>											
<b>SOLUTION CLEAR</b>											
<b>PRIMED NEW LINE</b>											
<b>CONNECTIONS SECURE</b>											
<b>NEEDLE SITE EXAMINED. ENTER RATING AND ACTION TAKEN (see * below)</b>											
<b>LIGHT FLASHING</b>											
<b>SPARE BATTERY AVAILABLE</b>											
<b>BREAKTHROUGH ANALGESIA PRESCRIBED (see guides no)</b>											
<b>COMMENTS</b>											
<b>SIGNATURE</b>											

\* = RATING:- 1 = CLEAN 2 = RED 3 = INFLAMED

ACTION TAKEN =

e.g. NEEDLE SITE CHANGE

## **Guidelines for Symptom Control**

**Syringe Drivers** are not always necessary, but are extremely useful if patient:

- nauseous or vomiting
- unable to swallow
- too weak for oral drugs
- unconscious
- has poor oral absorption

**All** the drugs in the guidelines are compatible in mixtures in a syringe driver.

Precipitation may occur with higher concentrations of Cyclizine.

Water for injection to be used to dilute all drugs except methotrimeprazine (use 0.9% sodium chloride)

### **Pain**

Is the patient able to swallow medication?

If **yes**:- Continue oral s/r morphine + 1/6th dose for breakthrough pain

If **no** Convert to SYRINGE DRIVER

Calculate 24hr intake of Morphine.

Divide total by 3 to get the equivalent dose of Diamorphine s/c over 24hrs.

E.g. patient on 60mg MST bd and had 2 doses of 30mg Oramorph

$$\text{total } (60 * 2) + (30 * 2) = 180\text{mg}$$

$$\text{Equivalent dose of Diamorphine} = 180/3 = 60\text{mg}$$

**Also** needs breakthrough dose prescribing of 1/6th of syringe driver  
i.e. 10mg Diamorphine in this example.

If not previously on strong opioid:

Bolus Diamorphine 2.5-5mg s/c

Syringe driver 10-20mg s/c Diamorphine over 24 hrs

PRN Medication - 2.5-5mg s/c Diamorphine

To calculate subsequent dose of Diamorphine:

Add the dose of Diamorphine given in the previous 24hrs.

I.e. Syringe driver plus prn doses..

Increase the syringe driver dosage accordingly.

At the present time (May 2005) Diamorphine may be difficult to source, Morphine is available in 10 and 30mg per ml ampoules and can be used with other drugs in a syringe driver. To convert from oral Morphine to sub cut Morphine divide by 2. In the above examples there would be 90mg of Morphine in the syringe driver and 15mg as a breakthrough dose.

**If pain persists** consider other causes of distress: bone pain, neuropathic pain, anxiety, fear, full bladder.

## **Nausea and Vomiting**

PRN medication on all treatment sheets: Cyclizine 50mg s/c bolus 6hrly

If nauseous or vomiting:

Cyclizine 150mg s/c via syringe driver over 24hrs.

If problem persists:

1. Add Haloperidol 5mg to syringe driver over 24hrs
2. Replace above drugs with Methotrimeprazine 25mg over 24hrs
3. Contact Palliative Care Team

If bowel obstruction present: contact Palliative Care Team.

## **Restlessness, Agitation, Anxiety**

All treatment sheets to have PRN Midazolam 5-10mg s/c

If patient is restless:

Add 20mg Midazolam to Syringe Driver over 24hrs

Give 5-10mg Midazolam 2hrly PRN

The dosage in the Syringe Driver can be increased if needed in 50% increments to a maximum of 100mg

## **Noisy Breathing due to Respiratory Tract Secretions**

All treatment sheets to have Hyoscine Hydrobromide 0.6mg s/c 4 hrly written up.

If present give:

Hyoscine Hydrobromide 0.6mg s/c bolus

Add Hyoscine Hydrobromide 1.2mg s/c to syringe driver over 24 hrs.

If Symptoms persist increase Hyoscine Hydrobromide to 2.4mg (in 24hrs)

Further details available in Trust Formulary, or BNF pages 12-15

These guidelines are based on:

Changing Gear: National Hospice Council 1998

All Wales Palliative Medicine Guidelines 1998

## **Useful Telephone Numbers**

**Palliative Care Dept.**

**01286 662775**

**Health Authority Nominated pharmacies**

Dr A Fowell and L Minto

Ysbyty Gwynedd

September 1999

*(white)*