

# **End of Life Care in Advanced Kidney Disease**

Information for GPs & District Nurses

Renal Unit  
Gloucestershire Hospitals NHS  
Foundation Trust

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Version 1**

# **End of Life Care in Advanced Kidney Disease: Supportive Care for Renal Patients**

## **Background**

Part II of the Renal National Service Framework (2005) recognises that some patients will decide not to undergo dialysis treatment and will instead receive non-dialysis or supportive therapy. The National Service Framework (NSF) for Renal Services was the first national framework to talk about death and dying. In 2009 NHS Kidney Care and the National End of Life Care Programme published “End of Life in Advanced Kidney Disease- A Framework for Implementation”. It is an important step in ensuring that people with advanced kidney disease receive the very best care in the last years, months and days of their lives.

In this leaflet we aim to provide

- Information on established renal failure/discussing future care with patients
- Dietary information for conservatively managed patients
- Triggers for Cause of Concern Register and linking with palliative care/Gold Standards Framework registers in GP practices
- Referral pathway for renal patients to Specialist Palliative Care
- Management of uraemic symptoms for conservatively managed patients
- Guidance on end of life care for patients with renal impairment

## **What is Established Renal Failure (ERF)?**

Chronic kidney disease means that both kidneys have been damaged irreversibly. The chemical waste products and toxins that are normally removed by the kidneys build up in the blood causing the symptoms of kidney failure. At very low levels of kidney function (usually less than 15% of normal) dialysis or kidney transplantation is required to relieve symptoms and to preserve life. This level of kidney function is known as End Stage Renal Disease (ESRD)/CKD Stage 5.

For people with ESRD, dialysis treatment is usually life saving, improving symptoms and quality of life. However, the treatment is demanding and time-consuming and it is often necessary for the patient to make lasting lifestyle changes. These changes include modification to diet and fluid intake. Patients who choose to have haemodialysis usually begin by attending the Cotswold Dialysis Centre or Severn Dialysis Centre at Gloucestershire Royal Hospital for their dialysis treatment three times per week. Understandably, these changes and demands can prove a physical and psychological burden to the patient and their family/carers. Dialysis treatment only replaces some functions of the kidney. It cannot reverse the effects of the patient's other co-morbid conditions and in some cases may not improve the patient's quality of life. In such situations it is important for all concerned to have a clear view of the likely advantages and disadvantages of undertaking dialysis treatment. This should take account of the patient's particular problems, circumstances and concerns. Reaching this point usually involves a good deal of discussion

over a period of time between the patient, their relatives and carers and the Renal Team at Gloucester.

If dialysis is not started, established renal failure will eventually lead to death. Supportive care for renal patients recognises that:

- Patients with multiple co-morbidities may not benefit from dialysis
- Patients may choose not to have dialysis
- Some patients may choose to stop dialysis and wish to die at home
- These patients should be on the GP practice's supportive care register

**As stated in the Renal NSF a 'no-dialysis' option is not a 'no treatment' option.**

The patient and their family will receive continued support from the Renal Multidisciplinary Team working in conjunction with yourselves and social workers as appropriate and where needed Specialist Palliative Care. The patient will receive symptom management including treatment of anaemia with iron supplements/erythropoietin and optimisation of the management of co-morbid conditions to improve quality of life.

### **Recognising the Pre terminal phase and end of life care**

The symptoms associated with ESRD vary. Symptoms such as nausea and vomiting, anorexia, insomnia, anxiety, depression and lethargy with decreasing performance status may be present for months. Severe symptoms usually only arise within the last two weeks of life. Introducing Palliative Care at an early stage for those patients who have chosen not to have dialysis can result in better symptom control and can help the passage into end of life care. Discussion early in the course of disease about a person's wishes for end of life care should aid in decision making and should be recorded to help all those involved in the patient's care know what the wishes are for an individual. A 'Cause for Concern' support register identifies patients 'deteriorating despite dialysis' and those patients deteriorating during conservative management, as potentially approaching the end of life phase (Appendix 1). It promotes a consistent and proactive approach in supporting patients and staff to facilitate communication and advance care planning.

### **Symptoms patients may experience**

There are a variety of symptoms that patients with ESRD may experience. Attached is some information regarding these symptoms and suggested treatment options (Appendix 2) both in the pre-terminal phase and later in the days leading up to the patient's death (Appendix 3). If you find symptom control difficult please get further advice from your local Palliative Care Team (Appendix 4).

### **Ongoing support from the Renal Team**

Patients whose end-stage renal disease is being managed without dialysis (**Conservative treatment**) will usually remain under the care of a renal physician and attend outpatient clinics. The Renal Multidisciplinary which includes Palliative Care Team will support them and will plan to visit them at home and liaise with the patient's General Practitioner and District Nurse Team. Home visits maybe undertaken where appropriate.

### **Useful Telephone Numbers**

Renal Ward:	08454 226768
Renal Support Team:	08454 226761/6890
Renal Dieticians:	08454 226847

## **Dietary Advice for Conservative Management**

Even if you have opted for no active treatment of your kidney failure such as dialysis, you are still able to access a dietician at any point for help or advice. You may have been seeing a dietician regularly up until now and this can still continue as you wish.

If you have been following special diets, you may choose to stop these, or alternatively, you may prefer to continue with them as you find this easier. The dietician can discuss this with you on an individual basis and provide guidance for you and your family.

As your kidneys deteriorate, there may be some symptoms you experience which can be helped by changing your diet and your dietician can provide you with information on this.

The most important thing is that you decide what you want to do about your diet.

Please see below for our contact details:

Renal Dieticians  
Dept of Nutrition & Dietetics  
Gloucester Royal Hospital  
Great Western Road  
Gloucester  
GL1 3NN

08454 226847

Email: [renal.dietetics@glos.nhs.uk](mailto:renal.dietetics@glos.nhs.uk)

## **Cause of Concern Register (CfC)**

1. Poor appetite and weight loss >10% (6months)
2. Serum albumin <25 mg/dl
3. Total dependency for transfers
4. Unplanned dialysis
5. ≥2 non elective admissions in 3months
6. Active malignancy
7. Increased hypotensive episodes
8. Increasing dialysis intolerance

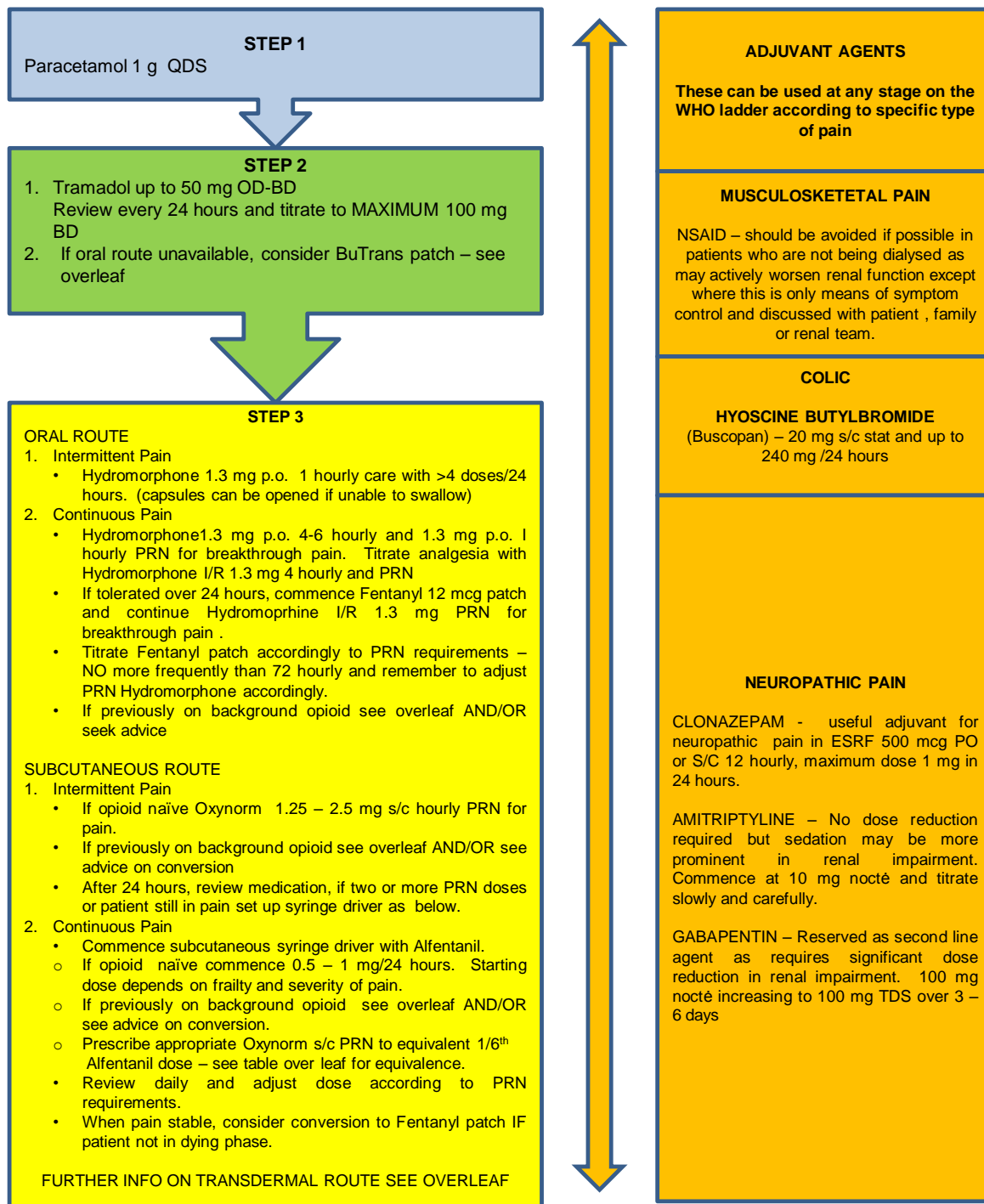
### **Cause for Concern Patient Assessment**

**Name****Hospital No:****Consultant:**

<b>Problem</b>	<b>Comments</b>	<b>Date assessed</b>	<b>Signature</b>
Poor appetite and weight loss >10% (6months)			
Serum albumin <25 mg/dl			
Total dependency for transfers			
Unplanned dialysis			
Increased hypotensive episodes			
Increasing dialysis intolerance			
≥ 2 non elective admissions in last 3 months			
Active malignancy			

## Appendix 3 PAIN

Management of pain should be based on likely cause according to clinic assessment and should follow the principles of the WHO analgesic ladder modified for ESRF patients with eGFR <30



**IN ALL CASES IF ONGOING PAIN DESPITE THE ABOVE MEASURES CONTACT SPECIALIST PALLIATIVE CARE TEAM FOR ADVICE**

Approximate 24 hour Equivalent Doses									
Oral morphine	Oral Oxynorm		s/c Oxynorm		s/c Diamorphine		s/c Alfentanil		
30 mg	15 mg		7.5 mg		10 mg		1 mg		
Approximate PRN Oxynorm for Alfentanil via syringe driver									
Alfentanil over 24 hours via driver	1 mg	2 mg	3 mg	4 mg	6 mg	8 mg	10 mg	12 mg	15 mg
Oxynorm s/c PRN	1 mg	2.5 mg	4 mg	5 mg	7.5 mg	10 mg	12 mg	15 mg	20 mg

#### TRANSDERMAL ANALGESIA

Fentanyl patch are safe to use in patients with ESRF. Buprenorphine (BuTrans) patches have limited data but appear to be safe in renal impairment and provide a low dose Transdermal opioid (equivalent to step 2 WHO measures) for patients with stable pain and ESRF.

Guidance for Transdermal Patches:

1.Estimated opioid dose equivalences are as table below:

Total 24 hr morphine (mg)	4 hourly oral Hydromorphone	BuTrans Buprenorphine Patch (mcg/hr)	Fentanyl Patch strength (mcg/hr)	Alfentanil 24 hr dose via syringe driver
5-10	-	5	-	
15-20	-	10	-	
30	1.3	10	12	1
60	1.3	15	25	2
90	1.3	-	25	3
120	2.6	-	50	4
180	3.9	-	75	6
240	5.4	-	100	8
300	6.7	-	125	10
360	8.0	-	150	12
420	9.3	-	175	14
480	10.6	-	200	16

2. They MUST be titrated in a timely fashion to ensure steady state has been reached i.e. Fentanyl Durogesic MINIMUM time to titration 72 hours, BuTrans MINIMUM time to titration 7 day. Titrating more quickly is likely to result in significant side effects.
3. To convert from syringe driver to Transdermal patch, confirm equivalent dose above. Apply patch and take down syringe driver 6 hours after applying patch.
4. In the dying phase, where patients are already established on patches, the patch should be left in situ and additional analgesia given via syringe driver (see action card on Transdermal patches in the dying phase).

#### PATIENT WITH ESRF IN THE DYING PHASE

Refer to action cards on care for patients with ESRF – eGFR <30 in the last days of life.

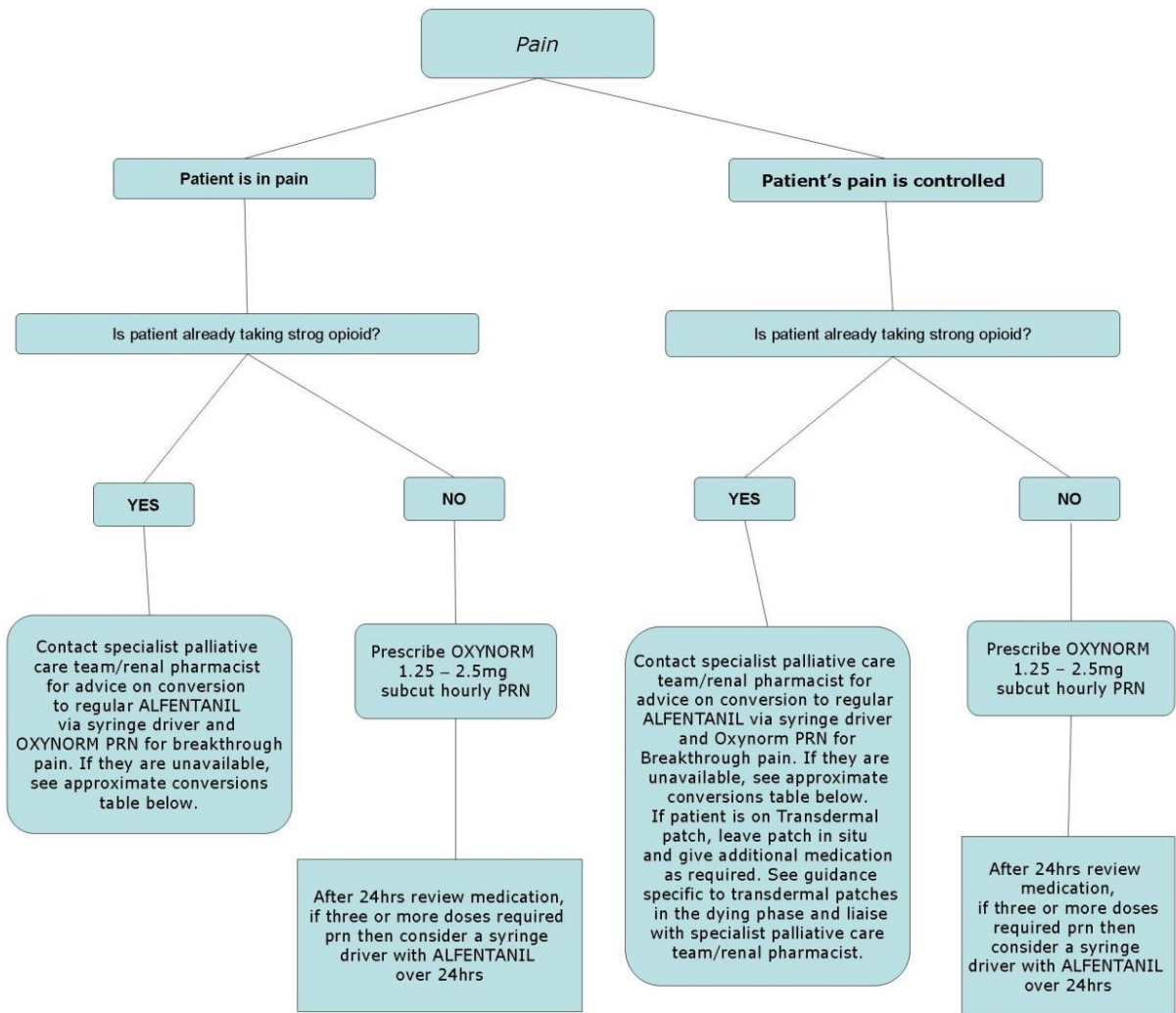


## Management of Other Symptoms

In order to manage the following symptoms appropriately the patients should have when required medications prescribed and available

Symptoms	Possible causes	Treatment / Management
Nausea and Vomiting	Identify cause and treat appropriately Commonly caused by uraemic toxins.	If usual anti emetics ineffective try levomepromazine 6mg once daily increasing to tds (Higher doses may cause drowsiness). If vomiting 6.25mg sc stat.
Anaemia	Decreased production by the kidneys of the hormone erythropoietin (ESA) which stimulates the bone marrow to produce red blood cells	ESA injections Iron supplementation may also be necessary (usually iv). Aim for haemoglobin 10-12g/dl
Shortness of breath	Anaemia Pulmonary oedema  Acidosis	Correct anaemia with ESA High dose diuretic i.e. Frusemide 80-500mg per day, higher doses divided morning and lunchtime. Correct acidosis with sodium bicarbonate 1-2g tds/qds
Pruritis / Itchy skin Symptomatic relief	Uraemia  Iron deficiency	Emollient: Diprobase cream, 50:50 liquid +WSP ointment, double base gel Antihistamine e.g. Chlorphenamine, Cetirizine, loratidine, Hydroxyzine (at night) Treat iron deficiency
Lack of appetite	Uraemia  Depression	Seek advice from renal dieticians. Small, regular meals of whatever patients likes. Reassurance to family re patients decreased appetite. Anti depressants. Citalopram 10mg od adjust according to symptoms and tolerability
Restless legs	Specific cause unknown, common in renal failure.	Clonazepam 500 micrograms nocte Ropinirole 0.25mg daily, increasing to 4mg daily
Cramps	Specific cause unknown	Quinine Sulphate 200-300mg nocte

<b>Symptoms</b>	<b>Possible causes</b>	<b>Treatment / Management</b>
Insomnia	Multiple causes	Review medication, Manage insomnia / sleep hygiene Night sedation e.g. Zopiclone 3.75mg 1-2 nocté(Advise intermittent use) Treat depression.
Dry mouth	Uraemia, medication, exclude oral thrush	Stimulate saliva, Salivix pastilles
Lethargy Low mood Depression	Common in renal patients Loss of independence, anxiety Uncertainty / reliance on carers Facing own death / mortality	Correct anaemia as above. Where appropriate provide spiritual support. Psychological interventions and/ or anti depressants Manage poor sleep if present.
Constipation	Reduced dietary and fluid intake / Immobility / Analgesia and other medication.	Review diet Senna 2-4 tablets bd, Fybogel, Sodium Docusate 100mg bd up to 500mg/24hrs, Laxido 1-2 sachets daily, adjust according to frequency of bowel action.
Loss of sexual function	Anaemia Depression Lethargy Peripheral neuropathy Hormonal abnormalities	Correct anaemia Psychological intervention Psycho sexual counselling / Review need for medication Consider pharmacological intervention.



PRN dose of OXYNORM should be 1/6 of 24hr equivalent dose in driver e.g. ALFENTANIL 2mg s/c via driver will require 2.5mg OXYNORM s/c PRN

#### Approximate 24 hour Equivalent Doses:

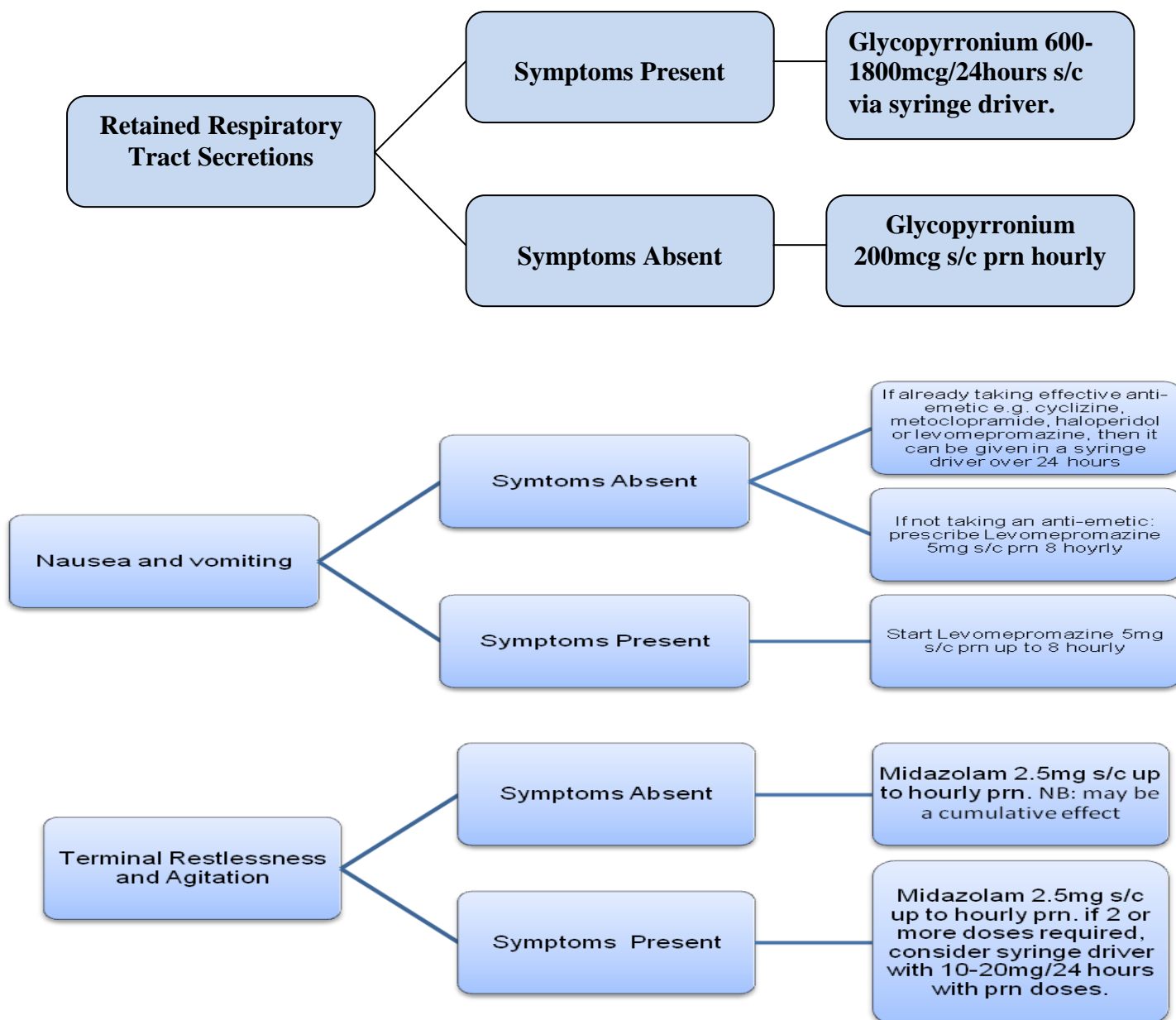
oral Morphine	s/c Morphine	s/c Diamorphine	oral Oxynorm	s/c Oxynorm	oral Hydromorphone	s/c Alfentanil
30mg	15mg	10mg	15mg	7.5mg	2mg	1mg

#### Approximate PRN doses for breakthrough pain with Alfentanil Syringe Driver

Alfentanil (mg) over 24hrs	1	2	3	4	5	6	8	10	12	14
Oxynorm (mg) s/c hrly PRN	2	4	6	8	10	12	16	20	24	28
Hydromorphone (mg) oral hrly PRN	1.3	1.3	1.3	2.6	2.6	3.9	5.2	6.5	7.8	9.1

#### SUPPORTIVE INFORMATION:

- To convert from other strong opioids contact Specialist Palliative Care Team/ Pharmacy for further advice
- If symptoms persist contact the Specialist Palliative Care Team.
- Anticipatory prescribing in this manner will ensure that in the last hours / days of life there is no delay responding to a symptom if it occurs.
- PATIENT SAFETY POINT: 2 different strengths of ALFENTANIL injection may be supplied for the same patient: 500micrograms/ml and/or ALFENTANIL 5 milligrams/ml (INTENSIVE CARE preparation) – PLEASE CHECK LABELLING CAREFULLY BEFORE DRAWING UP



SHORTNESS OF BREATH		
Positioning of patient: a cool fan on the face. Oxygen if hypoxic and reassuring presence of family or staff.	Strong opioid such as oxycodone or fentanyl, used at half to full recommended dose for pain; used as required up to hourly or in syringe driver if repeated doses required.	Midazolam 2.5mg s/c can be given if associated with anxiety or panic attacks.

## Appendix 4

### REFERRAL PATHWAY FOR RENAL FAILURE PATIENTS TO SPECIALIST PALLIATIVE CARE

The long-term nature of renal diseases means that holistic patient centred-support is a huge part of the routine management of renal patients. A lot of this will be done by the patient's renal and primary care teams. For some patients, specialist palliative care input may be required e.g. for troublesome symptoms/complex ethical decision making and end of life care. Patients would usually remain under the renal team with input from the specialist palliative care team and ongoing joint working, although in-patient stay in the county's specialist palliative care unit (Sue Ryder Leckhampton Court) may be needed.

Specialist palliative care (SPC) input may be delivered by:

1. Telephone advice for specific symptom management problems
2. One off assessment from SPC in any care setting.
3. Ongoing support from hospital SPC team/community palliative care services and/or hospice services.

#### WHO TO REFER TO SPECIALIST PALLIATIVE CARE

Most patients will have or be approaching end-stage renal disease, where the focus of care will have changed from curative to palliative and prognosis is limited. Some patients, who have complex specialist needs, may be referred at an earlier stage, from diagnosis onwards.

They may be:

- Managed conservatively (without dialysis)/yet to dialyse with:
  - significant symptom control, psychological or family/social issues
  - be approaching the last few weeks of life
- Experiencing difficulties in deciding whether to have dialysis or choose conservative management, particularly when there are issues of family conflict, impaired capacity, or complex concurrent disease
- Progressing poorly on dialysis and experiencing significant and troublesome symptoms
- Considering discontinuing dialysis

#### HOW TO REFER TO SPECIALIST PALLIATIVE CARE

Any member of staff can refer to the SPC team. Referrals are also accepted from patients or relatives, but all will be discussed with the medical team/GP prior to assessment. Where possible, the patient, and/or carer, should be informed and in agreement with the referral. Patients may be discharged if their condition stabilises.

#### HOSPITAL REFERRALS

- GRH telephone 5179 and speak to the secretary or leave a message
  - CGH telephone 3447 and speak to the secretary or leave a message.
- Staff referring hospital in patients are encouraged to put a written referral (green form) in the medical notes outlining the patient's current clinical problems, understanding of illness and reason(s) for referral.
- Referral letters for outpatients, patients can also be seen on the dialysis unit.

#### TELEPHONE ADVICE

- Dr Cath Blinman: CGH and South Cotswolds Community patients Pager: 07699 752529
- Dr Emma Husbands: GRH and Gloucester/Forest of Dean Community patients Mobile: 07810126133
- Dr Paul Perkins: Cheltenham and North Cotswolds Community patients Mobile: 07788 415034
- Also Hospital Teams GRH – b1p 2391/2125, CGH - b1p1629

#### COMMUNITY REFERRALS

- A single point of access co-ordinates referrals.
- Fax referral form to 08454 225125 (form on intranet)
- Referral letters: Community Palliative Care Team, Beacon House, Gloucestershire Royal Hospital, GL1 3NN.
- Telephone 08454 225370

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## DOCUMENT TITLE – DOCUMENT PROFILE

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ASSOCIATED LEGISLATION AND CODES OF PRACTICE	Hyperlink where possible