NHS
Gloucestershire

End of Life Care in Advanced Kidney Disease

Information for GPs & District Nurses

Renal Unit
Gloucestershire Hospitals NHS Foundation Trust

Renal Unit
Gloucestershire Hospitals NHS Foundation Trust
Gloucester
GL1 3NN
Version 2

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 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 (CKD) 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 lifesaving, 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 dialysis usually begin by attending the dialysis centres for their dialysis treatment or have dialysis at home. 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 situation, 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. 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.

Advance Care Planning

Advance care planning early in the course of disease facilitates choice and shared decision-making about all aspects of treatment and care. This can help patients and clinicians to plan ahead for any deterioration or crises. It should include realistic conversations about what may or may not work in any situation – enabling prevention of avoidable admissions and futile interventions. This can extend to a person's wishes for end of life care. It should be recorded and shared with other health and social care professionals involved in the patient's care in order that these wishes may be honoured. Consider liaising with specialist palliative care if needed.

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 Specialist 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:	03004 226768
Renal Support Team:	03004 226761/6890
Renal Dieticians:	03004 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

030004 226847

Appendix 1

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

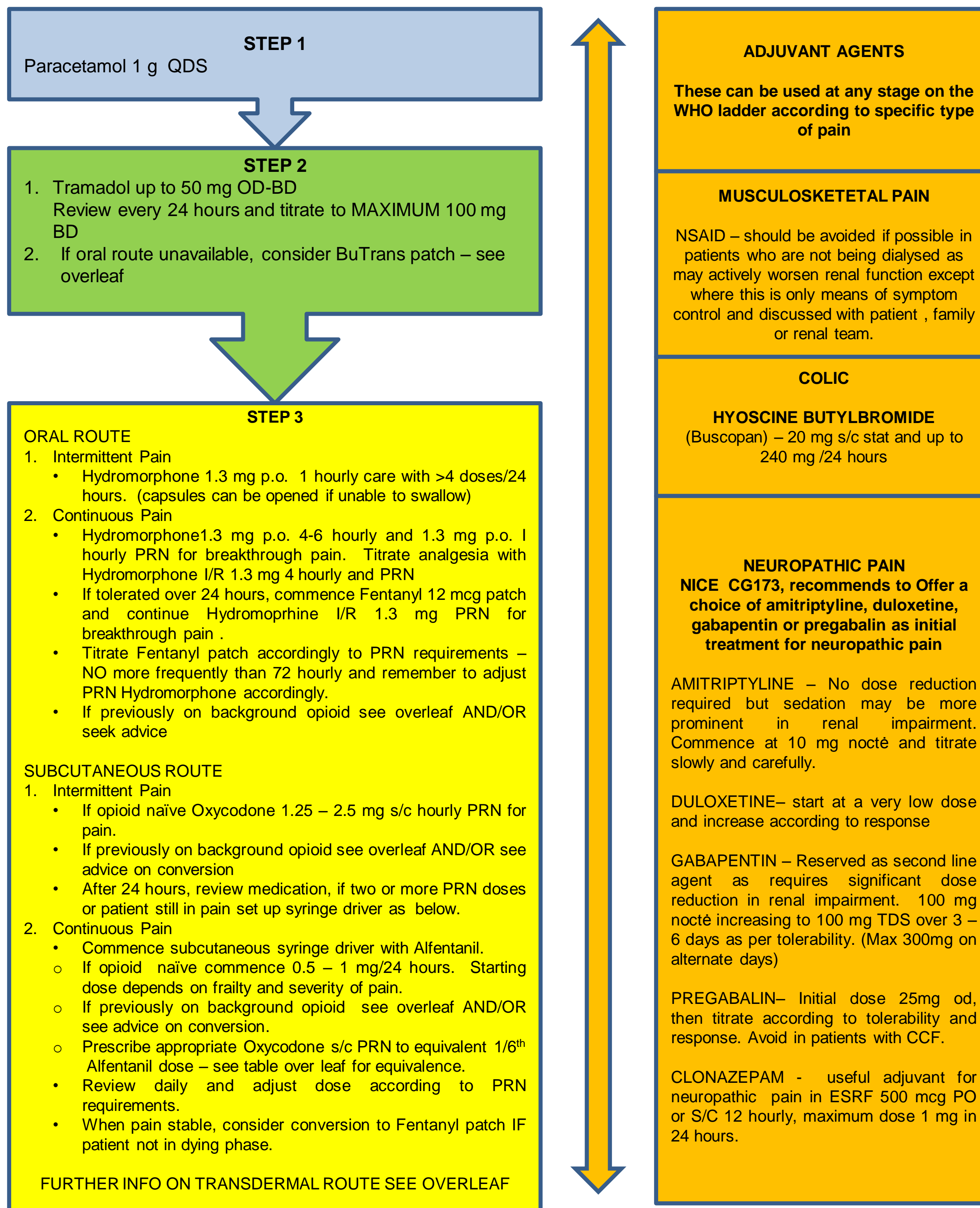
Cause for Concern Patient Assessment

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

Problem	Comments	Date assessed	Signature
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 2
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 oxycodone	s/c oxycodone	s/c diamorphine	s/c alfentanil
30mg	15mg	7.5mg	10mg	1mg

Approximate **prn** Oxycodone for Alfentanil via syringe driver:									
Alfentanil over 24hrs via driver	1mg	2mg	3mg	4mg	6mg	8mg	10mg	12mg	15mg
Oxycodone s/c prn	1mg	2.5mg	4mg	5mg	7.5mg	10mg	12mg	15mg	20mg

<u>Transdermal analgesia:</u>
Fentanyl patches 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 24hr oral morphine (mg)	4 hourly oral Hydromorphone (mg)	BuTrans Buprenorphine Patch (mcg/hr)	Fentanyl patch strength (mcg/hr)	Alfentanil 24hr 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 patch. Minimum time to titration 72hrs, BuTrans Minimum time to titration 7 days. Titrating more quickly is likely to result in significant side-effects.
3. To convert from syringe pump to Transdermal patch, confirm equivalent dose above. Apply patch and take down syringe pump 6hours 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 pump (see action card on Transdermal patches in the dying phase).

<u>Patient with ESRF in the dying phase:</u> Refer to action cards on care for patients with ESRF – eGFR<30mls/min in the last days of life

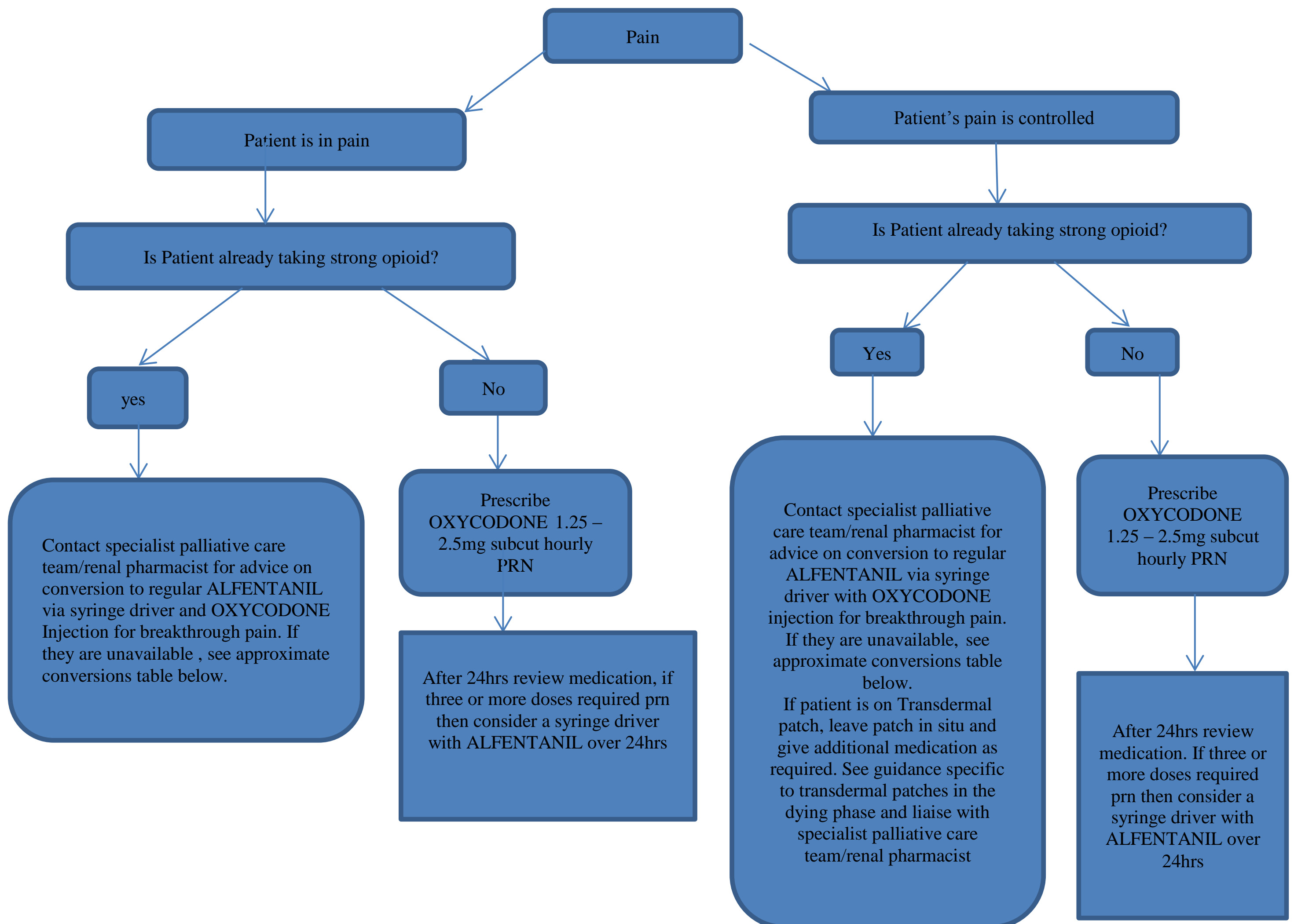
Management of Other Symptoms

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 PO 6mg once daily increasing to three times a day if needed. (Higher doses may cause drowsiness). If vomiting 6.25mg SC stat. Metoclopramide 5mg QDS +/- erythromycin 250mg BD for gastric stasis
Anaemia	Decreased production of the hormone erythropoietin by the kidneys, which stimulates the bone marrow to produce red blood cells	Iron supplementation may also be necessary (iv or oral). Aim for haemoglobin 100-120g/L Erythropoietin Stimulating Agents (ESA) injections
Shortness of breath	Anaemia Pulmonary oedema Acidosis	Correct anaemia with ESA High dose diuretic i.e. Furosemide 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:** Zero AQS cream, Eucerine cream, Eucerine lotion **Antihistamine**: Chlorphenamine, Cetirizine, loratidine, Hydroxyzine (at night) **Gabapentinoids**: Gabapentin 100mg daily or post dialysis (up to 300mg daily) or pregabalin 25mg OD or after dialysis (may be limited by side effects) Treat iron deficiency
Lack of appetite	Uraemia Depression	Seek advice from renal dieticians. Small, regular meals of whatever patient likes. Reassurance to family re patient's decreased appetite. Metoclopramide 5mg QDS+/- erythromycin 250mg BD if early satiety/gastroparesis Anti-depressants. Citalopram 10mg od or mirtazapine 15-30mg 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 Pramipexole 88microgram od, titrate to maximum 1.1mg od. Rotigotine 2mg daily and titrate to response.
Cramps	Specific cause unknown	Quinine Sulphate 200-300mg nocte

Symptoms	Possible causes	Treatment / Management
Insomnia	Multiple causes	Review medication, Manage insomnia / sleep hygiene Night sedation e.g. Zopiclone 3.75mg 1-2 at night(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.

Appendix 3: MANAGEMENT OF PAIN FOR PATIENTS IN LAST DAYS OF LIFE WITH e GFR<30



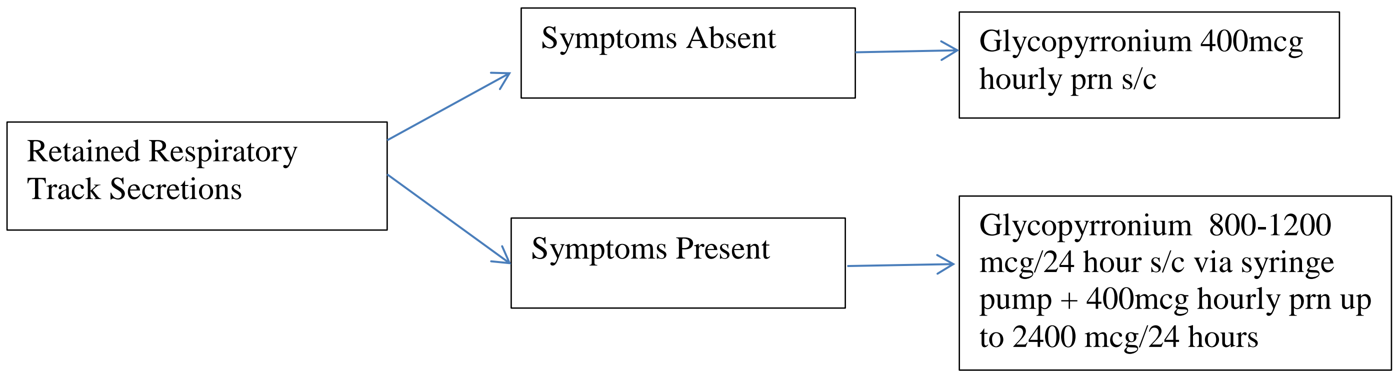
PRN dose of OXYCODONE injection should be 1/6 of 24hr equivalent does in driver e.g ALFENTANIL 2mg s/c via driver will require 2.5mg OXYCODONE Injection s/c PRN

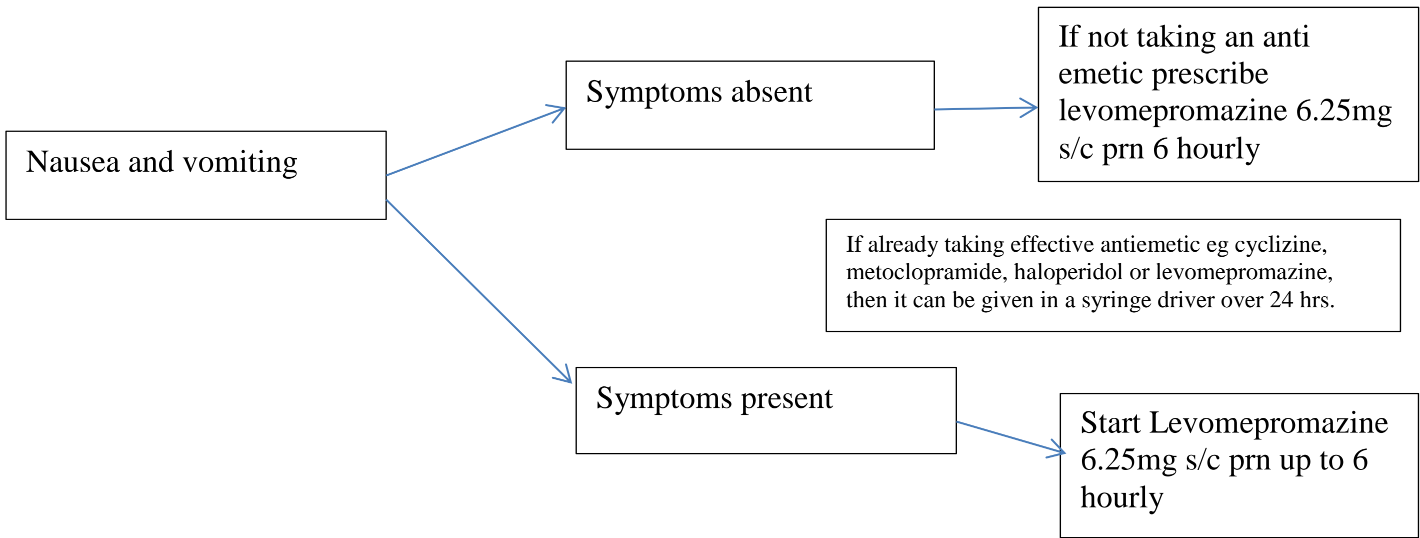
Approximate **24 hour** Equivalent Doses:				
Oral morphine	s/c morphine	s/c oxycodone	s/c diamorphine	s/c Alfentanil
30mg	15mg	7.5mg	10mg	1mg

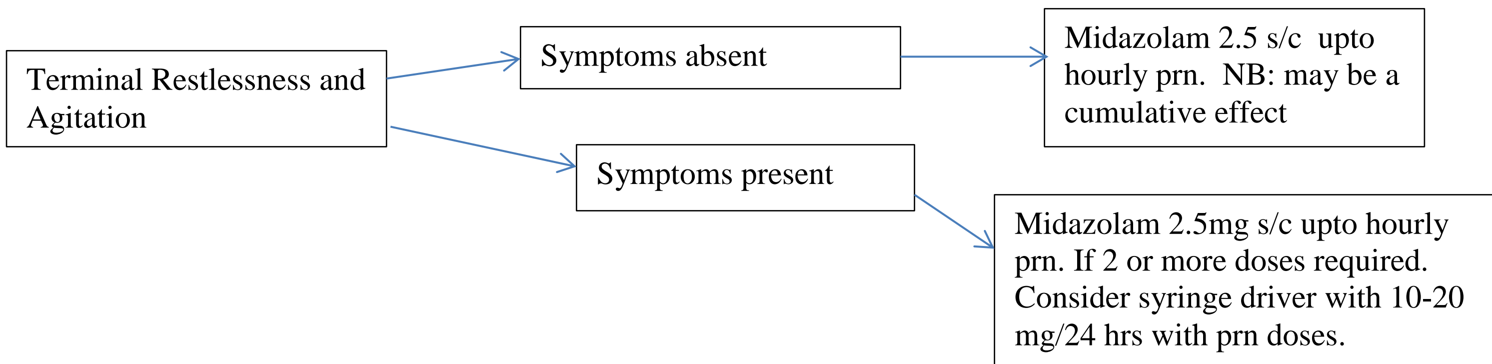
Approximate PRN doses for breakthrough pain with Alfentanil Syringe Driver										
Alfentanil (mg) Over 24hrs	1	2	3	4	5	6	8	10	12	14
Oxycodone (mg) s/c hrly PRN	1	2.5	4	5	6	7.5	10	12	15	17.5
Hydromorphone (mg) oral hlry PRN	1.3	1.3	1.3	2.6	2.6	3.9	5.2	6.5	7.8	9.1

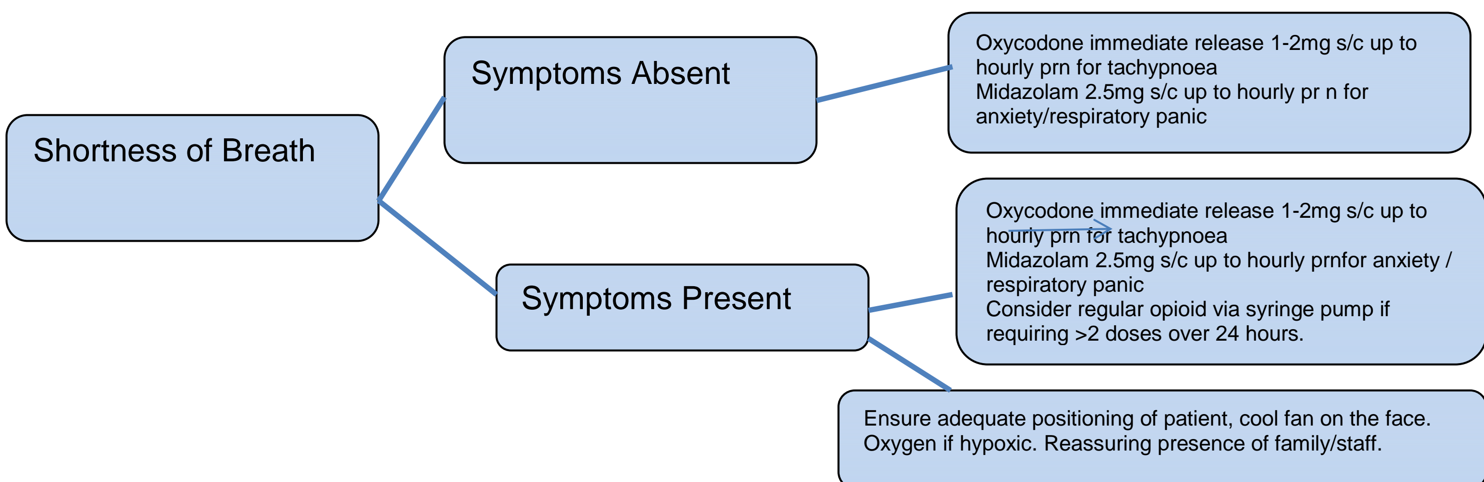
SUPPORTIVE INFORMATION:

- 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**


Retained Respiratory Track Secretions
Symptoms Absent
Glycopyrronium 400mcg hourly prn s/c
Symptoms Present
Glycopyrronium 800-1200 mcg/24 hour s/c via syringe pump + 400mcg hourly prn up to 2400 mcg/24 hours


Nausea and vomiting
Symptoms absent
If not taking an anti emetic prescribe levomepromazine 6.25mg s/c prn 6 hourly
If already taking effective antiemetic eg cyclizine, metoclopramide, haloperidol or levomepromazine, then it can be given in a syringe driver over 24 hrs.
Symptoms present
Start Levomepromazine 6.25mg s/c prn up to 6 hourly


Terminal Restlessness and Agitation
Symptoms absent
Midazolam 2.5 s/c upto hourly prn. NB: may be a cumulative effect
Symptoms present
Midazolam 2.5mg s/c upto hourly prn. If 2 or more doses required. Consider syringe driver with 10-20 mg/24 hrs with prn doses.


Shortness of Breath
Symptoms Absent
Oxycodone immediate release 1-2mg s/c up to hourly prn for tachypnoea
Midazolam 2.5mg s/c up to hourly pr n for anxiety/respiratory panic
Symptoms Present
Oxycodone immediate release 1-2mg s/c up to hourly prn for tachypnoea
Midazolam 2.5mg s/c up to hourly prnfor anxiety / respiratory panic
Consider regular opioid via syringe pump if requiring >2 doses over 24 hours.
Ensure adequate positioning of patient, cool fan on the face. Oxygen if hypoxic. Reassuring presence of family/staff.

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.
4. Clinic review by consultant – regular clinics at GRH, Longfield and Great Oaks

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 document in the medical notes an outline 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/CLINICS

- Dr Paul Perkins: Cheltenham and North Cotswolds Community patients Mobile: 07788 415034
- Dr Emma Husbands: GRH and Forest of Dean Community patients (GRH/Great Oaks) Mobile: 07810126133
- Dr Karen Ricketts: Gloucester and South Cotswolds Community patients. (GRH/Longfield) Mobile 07971066038
- Dr Kate Tredgett: CGH Mobile 07973920731
- Also Hospital Teams GRH – blp 2391/2125, CGH - blp1484/1227

COMMUNITY REFERRALS

- A single point of access co-ordinates referrals.
- Fax referral form to 03004 225125 (form on intranet)
- Referral letters: Community Palliative Care Team, Beacon House, Gloucestershire Royal Hospital, GL1 3NN.
- Telephone advice available on 03004 225370, Mon-Fri 9-5am.

REFERENCES

1) Mehta D (eds). 2015. *British National Formulary No. 70.* London: Pharmaceutical Press
2) Devaney A, Ashley C, Tomson C. How the reclassification of kidney disease impacts on dosing adjustments. *Pharmaceutical Journal* 277: 403-405, 2006
3) Dean M. Opioids in renal failure and dialysis patients. *J Pain Symptom Manage*. 2004;28:497-504.
4) Twycross R, Wilcock A, Thorp S (eds). 2007. Palliative Care Formulary Third Edition. Abingdon: Radcliffe Medical Press.
5) Aronson J K. Drugs and Renal Insufficiency. *Medicine 2003; 103-9.*
6) Launay-Vacher V et al. Treatment of Pain in Patients With Renal Insufficiency: The World Health Organization Three-Step Ladder Adapted. *Journal of Pain, Vol 6, No 3 (March), 2005: 137-148*
7) Chambers EJ, Germain M, and Brown E, eds. Supportive Care for the Renal Patient. *Publisher: Oxford University Press; 2004.*
8) Ashley C, Currie A (Eds). *The Renal Drug Handbook Second Edition*. *Oxford Radcliffe Medical Press; 2004.*
9) Kurella M et al. Analgesia in patients with ESRD: A review of available evidence. *Am J Kidney Dis. 2003;42:217-228.*
10) *Davism, Glare P, Hardy J (Eds) Opioids in Cancer Pain. Oxford University Press.*
11) Mercadante S and Arcuri E. Opioids and Renal Function *Journal of Pain, Vol 5, No 1 (February), 2004: 2-19*
12) Department of Health. NSF for renal services – Part two, 2005: chronic kidney disease, acute renal failure and end of life care. 2005
13) Douglas C, Murtagh FEM, Chambers EJ et al. Symptom Management for the adult patient dying with advanced chronic kidney disease: A review of the literature and development of evidence-based guidelines by a United Kingdom Expert Consensus Group. *Palliat Med 2009;23: 103-10.*
14) Chambers J. Bowel Management in Dialysis Patients. *The American Journal of Nursing, Vol. 83, No. 7. (Jul., 1983); 1051-1052.*
15) http://www.renal.org/eGFR/index.html
16) The Marie Curie Palliative Care Institute Liverpool. Liverpool Care Pathway for the Dying Patient (LCP). National LCP Renal Steering Group. Guidelines for LCP Drug Prescribing in Advanced Chronic Kidney Disease. June 2008.
17) End of Life Care in Advanced Kidney Disease. A Framework for Implementation (2009)
18) CKS. *Restless legs syndrome.* October 2015 Available at: http://cks.nice.org.uk/restless legs syndrome

DOCUMENT TITLE – DOCUMENT PROFILE

DOCUMENT PROFILE	
REFERENCE NUMBER	
CATEGORY	Clinical
VERSION	3
SPONSOR	Jon Burford
AUTHOR	Preetham Boddana/Emma Husbands/Israr Baig
ISSUE DATE	March 2016
REVIEW DETAILS	March 2018
ASSURING GROUP	
APPROVING GROUP	Trust Clinical Policy Group
APPROVAL DETAILS	Minutes details including date and reference number where possible
COMPLIANCE INFORMATION	**End of Life Care in Advanced Kidney Disease: Kidney Care National End of Life Care Progamme** A Framework for Implementation **2009** Renal Liverpool Care Pathway 2008 **National Service Framework for Renal Services - Part Two: Chronic kidney disease, acute renal failure and end of life care 2005**
CONSULTEES	Diana Moore Ward Sister 7b Sally Pugh, Renal Dietician
DISSEMINATION DETAILS	Upload to Policy Site; Global email; Cascaded via divisions; Article in Outline
KEYWORDS	Renal failure, conservative management, symptom control, end of life
RELATED TRUST DOCUMENTS	Care of the Dying Patient, Their Relatives and carers
OTHER RELEVANT DOCUMENTS	**Supportive Care for the Renal Patient** E. Joanna Chambers, Edwina Brown, and Michael Germain. OUP 2011
ASSOCIATED LEGISLATION AND CODES OF PRACTICE	Hyperlink where possible