1. Introduction

1.1 Supportive care for renal patients

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-dialytic or supportive therapy. Other patients, having started dialysis, may opt to stop treatment due to poor quality of life or unacceptable symptoms, often from co-morbid problems. In this leaflet we aim to provide information on established renal failure and the management of symptoms associated with it. The final section provides guidance on end of life care.

1.2 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 10% of normal) dialysis or kidney transplantation is required to relieve symptoms and to preserve life. This level of kidney function is known as established renal failure (ERF)

For people with ERF, 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. 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 other co-morbid conditions and in some cases may not improve 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 discussion over a period of time among the patient, their relatives and carers, the renal team and often other health care professionals in primary or palliative care.

If dialysis is not started, established renal failure will eventually lead to death although the time scale is variable from weeks to months.

Supportive care for renal patients recognises that:-

- Patients with multiple co-morbidities may not benefit from dialysis
- Some patients may choose to stop dialysis and wish to die at home
- Patients may choose not to have dialysis, opting for conservative care
- Patients with a failing transplant may not wish to have a further transplant or dialysis

These patients should be on the GP practice’s supportive care register (Gold Standards Framework or equivalent)
As stated in the Renal NSF a ‘no-dialysis’ option is not a ‘no treatment’ option. The patient and their family should receive continued support from the renal multidisciplinary team working in conjunction with the primary care team and other carers in the community and, where needed, specialist palliative care. The patient will receive symptom management (including treatment of anaemia with erythropoietin) and optimisation of the management of co-morbid conditions to improve quality of life.

1.3 Recognising the pre-terminal phase and end of life care

The symptoms associated with ERF vary. Multiple symptoms such as nausea and vomiting, anorexia, itching, anxiety, depression and lethargy with decreasing performance status may be present for months. Severe symptoms usually only arise in the last few weeks of life.

Introducing palliative care at an early stage for those patients who have chosen not to have dialysis; are failing despite dialysis; or are considering discontinuing dialysis can result in better symptom control and can help with the transition to end of life care. They are also more likely to access palliative care services and to die in the place of their choice.

Early discussion about the patient’s wishes at the end of life will help decision making and should be recorded and communicated to all those involved in the patient’s care so that his/her preferences are known. This may include:-

- Completing an advance care plan
- Registering the patient on the local Supportive Care Register
- Registering the patient on the GSF, or equivalent register
- Discussing preferred place of care and preferred place of death
- Advanced decisions to refuse treatment (ADRT)
- Completing do not attempt resuscitation forms (DNAR)
- Communication with the Out of Hours Services indicating patients’ wishes.

1.4 Symptoms patients may experience

There are a variety of symptoms that patients with ERF may experience in the weeks and days preceding death. Attached is some information regarding the management of these symptoms and suggested treatment options. If you find symptom control difficult please contact the Renal Team (Renal Community Nurse or Renal Consultant/SpR), local palliative care Community Nurse Specialist or LOROS for further advice.

1.5 On-going support from the renal team

Patients whose established renal failure is being managed without dialysis or transplantation will usually remain under the care of a renal physician and continue to attend outpatient clinics. The renal community team will offer support to patients and their families, liaise with the patient’s general practitioner district nursing team and palliative care community nurse specialist and visit at home if required. Joint home visits maybe undertaken where appropriate.

1.6 Useful Telephone Numbers

Renal Community Team 0116 2584120
Renal Dieticians 0116 2588002
Renal Pharmacist 0116 2588177
LGH Palliative Care Team Mon-Fri 09:00-17:00 0116 2584680
UHL Palliative Care Team Sat- Sun and Bank Holidays 09:00-17:00 page 07659 514742
Leicestershire Hospice (LOROS) clinical line 24hrs 0116 2318401
2. Scope
This guidance applies to GPs and community nurses looking after adult patients with ESF.

Clinical guidelines are ‘guidelines’ only. The interpretation and application of clinical guidelines will remain the responsibility of the individual practitioner. If in doubt, consult a senior colleague or expert.

3. Recommendations, Standards and Procedural Statements

**SYMPTOMS PATIENTS MAY EXPERIENCE**

<table>
<thead>
<tr>
<th>Problem/Symptom</th>
<th>Possible causes</th>
<th>Treatment/Management</th>
</tr>
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<tbody>
<tr>
<td>Nausea and vomiting</td>
<td>Identify cause and treat appropriately. Commonly caused by uraemic toxins but ensure other causes such as gastroparesis, common in diabetes, are considered</td>
<td>Haloperidol – first line for uraemia. Use reduced doses starting with 0.5mg od, po/sc increasing to 1.5mg od, po/sc. Maximum dose 5mg od. If ineffective, levomepromazine 6.25mg od, po/sc up to 12.5mg in 24 hours. For gastroparesis: domperidone 10mg tds</td>
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<tr>
<td>Anaemia</td>
<td>Decreased production by the kidneys of the hormone erythropoietin (EPO) which stimulates the bone marrow to produce red blood cells.</td>
<td>Weekly/fortnightly injections of erythropoietic stimulating agent (ESA or EPO (sc) (Aranesp or Eprex are brands used in Leicester) usually prescribed by the nephrology medical staff. Iron supplementation may also be necessary (usually iv). Aim for haemoglobin 10.0-12.0g/dl</td>
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<tr>
<td>Shortness of breath</td>
<td>Anaemia Pulmonary oedema Acidosis Pulmonary embolus Any cause</td>
<td>Correct anaemia with ESA (Eprex or Aranesp) High dose diuretic i.e. furosemide 80-500mg po per day, higher doses divided morning and lunchtime. Correct acidosis with sodium bicarbonate 1.0-1.2g tds po Low dose oramorph with increased time interval 1.25 -2.5mg po 6-8hrly or 0.5 -1.25mg sc 6-8hrly Lorazepam 0.5-1mg S/L prn</td>
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<tr>
<td>Pruritis/Itchy skin</td>
<td>Uraemia</td>
<td>Correct electrolytes, in particular ca, phosphate and PTH levels where possible. Emollients can be used generously Eurax cream tds – Crotamiton content eases localised itch Oral antihistamines e.g. hydroxyzine (little evidence but sedative properties may help at night) Ondansetron 4mg bd Capsacin cream 0.25% if localised Gabapentin, pregabalin, mirtazapine can help (see below - under pain: adjuvant drugs for doses).</td>
</tr>
<tr>
<td>Symptom</td>
<td>Cause</td>
<td>Treatment</td>
</tr>
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<td>---------------------------------</td>
<td>-----------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
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<tr>
<td>Iron deficiency</td>
<td>Treat iron deficiency; usually by iv iron</td>
<td></td>
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<tr>
<td>Lack of appetite Uraemia</td>
<td>Small regular meals of whatever patient likes. Advice from renal dieticians Corticosteroids and megestrol acetate (Megace) may be used but evidence for effectiveness is limited</td>
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<tr>
<td>Depression Reaction to physical illness</td>
<td>Anti-depressant e.g mirtazapine, fluoxetine</td>
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<tr>
<td>Restless legs Specific cause unknown, common in renal failure</td>
<td>Clonazepam 0.5mg-1mg po nocte Levodopa (Madopar) 62.5mg po nocte Rotigotine patch 1mg/24hr patch increasing in steps of 1mg/24hrs at weekly intervals as required; max 3mg/24hr</td>
<td>Treat anaemia/iron deficiency</td>
</tr>
<tr>
<td>Anaemia</td>
<td></td>
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<tr>
<td>Cramps Specific cause unknown</td>
<td>Quinine sulphate 300mg nocte (little evidence of benefit)</td>
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<td>Dry mouth Uraemia, medication, exclude oral thrush</td>
<td>Good mouth care Artificial saliva, oral balance gel Corsodyl mouth wash bd Treat oral thrush</td>
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<tr>
<td>Insomnia Multiple causes</td>
<td>Review medication Treat as any other patient</td>
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<tr>
<td>Lethargy Depression</td>
<td>Correct anaemia as above Where appropriate provide spiritual support Psychological support/interventions if needed Consider antidepressants e.g mirtazapine Manage poor sleep if present</td>
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</tr>
<tr>
<td>Constipation Reduced dietary and fluid intake/immobility/analgnesia and other medications</td>
<td>Review diet Senna and lactulose can be used in normal dose Sodium picosulphate 10mls od initially and titrate to bowel action Avoid Laxido due to increases in sodium and potassium levels</td>
<td></td>
</tr>
<tr>
<td>Loss of sexual function Anaemia Depression Lethargy Peripheral neuropathy Hormonal abnormalities</td>
<td>Review medication Correct anaemia Psychological support/ intervention Psycho sexual counselling Consider Viagra</td>
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</tbody>
</table>
Pain
Not usually a symptom in ESRF but often related to co-morbidities e.g. Arthritis Peripheral vascular disease Diabetic Neuropathy Angina Decubitus ulcers Calciphylaxis

Refer to WHO analgesic ladder modified for ERF as below:
Step 1
Paracetamol 1g qds
Step 2
Tramadol 50mg bd up to a maximum of 50mg qds. Avoid if GFR<15
Caution tramadol should not be used with SSRIs or tricyclics

Many opioids and/or their metabolites are renally excreted therefore use with caution and avoid slow release oral preparations particularly in opioid naïve patients.

Step 3
Oral Route – Intermittent Pain
Oramorph 1.25 2.5mg po 6-8 hourly then titrate up. All opioids require significant dose reduction and increase in dosing interval in renal failure

Topical Route – Continuous Pain or frequent intermittent pain
Evidence shows Alfentanil and fentanyl are the safest opioids in renal failure. The lowest fentanyl patch (12mcg/hr) is too high a dose for opioid-naïve patients therefore commence with Buprenorphine (Butrans) patch up to 20mcg/hr. If still in pain, switch to fentanyl 12mcg/hr and continue with prn oramorph and titrate upwards.

Subcutaneous Route- Intermittent Pain
Small doses of morphine 0.5-1.25 mg s/c prn 6-8 hourly. After 24 hours, review medication, if two or more PRN doses or patient still in pain consider a syringe driver to run over 24 hours (as below)

Subcutaneous Route – Continuous Pain
Start subcutaneous infusion in syringe driver with Alfentanil. Starting dose is 500mcg over 24hrs if patient is not on regular opioids. If patient is on regular opioids contact Specialist Palliative Care Team for advice on conversion to alfentanil. Continue morphine s/c as prn.

Fentanyl and alfentanil are not ideal for use as a breakthrough medication due to their short half-life and doses may only last 10-30mins. An alternative opioid such as low dose morphine may therefore need to be considered, but care is needed to avoid over sedation as metabolites may accumulate
When converting patients from fentanyl patches to a syringe driver it is better to leave the patch in place and top up with the syringe driver starting with a dose equivalent to the sum of the breakthrough doses in the previous 24 hours. For further advice please contact your local Palliative Care Team.

### Adjuvant Drugs

- **Clonazepam** - useful for neuropathic pain. No dose adjustment required. 0.5mg po or s/c 12 hourly. Maximum dose 1mg in 24 hours.
- **Amitriptyline** - start low 10mg nocte and titrate up slowly.
- **Gabapentin** - start with the lowest possible dose and titrate upwards on alternate days to a maximum of 300mg on alternate days.
- **Pregabalin** – initially 25mg od titrated to maximum of 75mg od.
- **NSAIDs** should not be used in patients who are not being dialysed as may actively worsen renal failure except where this is the only means of symptom control and it has been discussed with patient, family and renal team.

### Respiratory Tract Secretions

<table>
<thead>
<tr>
<th>Fluid overload</th>
<th>Dying</th>
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| **Diuretic** Patient positioning | Stop IV s/c fluids or NG/PEG feed
Glycopyrronium 200mcg s/c prn up to every 4 hours. If 2 or more doses given consider starting a syringe driver with 600-1200mcg glycopyrronium/24h
Alternatives to glycopyrronium include: hyoscine butylbromide 20mg s/c up to tds, or 40-60mg in a syringe driver /24hr |

### Restlessness and Agitation

<table>
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<tr>
<th>Uncontrolled pain</th>
<th>Drug related Full bladder Full rectum Dyspnoea Anxiety and fear Terminal event</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Review pain</strong> Review medication including laxatives Where anguish and anxiety are predominant give midazolam 2.5-5mg s/c. If two or more doses have been given in 24 hours consider starting a subcutaneous infusion of 5-10mg midazolam via a syringe driver over 24 hours. This can be titrated up to maximum of 30mg/24hrs. Where delirium and psychotic features are predominant (e.g. hallucinations, confusion) give</td>
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</tbody>
</table>
The Dying Patient

The principles of end of life prescribing in patients with renal failure are similar to those in patients with normal renal function and guidance for the care of patients in the last days of life should be followed. The patient’s comfort is paramount and it is important that drugs should not be withheld because of renal impairment e.g. NSAIDs. All drugs should be prescribed at an appropriate dose for comfort. For further guidance and advice, contact the Renal Unit or Specialist Palliative Care Team at Leicester General Hospital or LOROS advice line.

4. Education and Training

LOROS and the Palliative Care Team will continue to deliver education and training about symptom control in renal failure and end of life care. This guidance is to raise awareness and help structure normal clinical activity rather than develop new skills.

5. Monitoring and Audit Criteria

<table>
<thead>
<tr>
<th>Key Performance Indicator</th>
<th>Method of Assessment</th>
<th>Frequency</th>
<th>Lead</th>
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</thead>
<tbody>
<tr>
<td>Documentation and appropriate supportive care including prescribing for symptom control for patients with established renal failure.</td>
<td>Audit</td>
<td>Annually</td>
<td>Dr. James Burton (Consultant Nephrologist) with support from Dr. Caroline Cooke</td>
</tr>
</tbody>
</table>

6. Legal Liability Guideline Statement

Guidelines or Procedures issued and approved by the Trust are considered to represent best practice. Staff may only exceptionally depart from any relevant Trust guidelines or Procedures and always only providing that such departure is confined to the specific needs of individual circumstances. In healthcare delivery such departure shall only be undertaken where, in the judgement of the responsible healthcare professional’ it is fully appropriate and justifiable - such decision to be fully recorded in the patient’s notes.
7. Supporting Documents and Key References

Supportive care for the renal Patient 2004 Edited by Chambers, Germain and Brown


British National Formulary (BNF) 68. bnf.org

Palliative Care Formulary (PCF) 5th edition 2014 www.palliativedrugs.com Ltd


8. Key Words

Established Renal Failure, symptom control, supportive care, end of life care, palliative care

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