

## **1. Introduction**

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 guideline we aim to provide guidance on when and where to refer patients for specialist input and management.

## **2. Scope**

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.

This guideline is for the use of all staff involved in the care of patients with renal failure who wished to be managed in a conservative way (e.g. not with renal replacement therapy), are failing to thrive on their treatment or coming to the end of their life and who are being considered for referral to the palliative care team.

## **3. Recommendations, Standards and Procedural Statements**

### *3.1 Trigger factors to identify patients for inclusion in the Supportive Care Register*

The following is adapted from National Gold Standards Framework Prognostic Indicator Guidance (2008). Any one of these triggers should prompt a multidisciplinary discussion regarding consideration of inclusion in the Supportive Care Register and offer of Advance Care Planning:

- 3.1.1. The 'surprise question': patients with stage 5 CKD (including those with a failing transplant who do not wish to return to RRT) whose condition is deteriorating and for whom the 'surprise question' is applicable i.e. overall you would not be surprised if they were to die in the next 6 months
- 3.1.2. Choice or need
  - a. Patient has expressed a desire to stop dialysis or is receiving palliative dialysis
  - b. Symptomatic renal failure (anorexia, reduced functional status, intractable fluid overload) where a decision has been made not to have dialysis
- 3.1.3. Clinical indicators
  - a. Greater than 10% unintentional weight loss (non fluid) over 6 months
  - b. Symptomatic renal failure (anorexia, reduced functional status, intractable fluid overload) despite optimal dialysis
  - c. Serum albumin <25 g/l
  - d. Reducing performance status e.g Karnofsky score < 50% (Appendix 1)
  - e. Dependence in most activities of daily living (ADL's)
  - f. In bed more than 50% of the time

g. Identification by GP (already on the GP practice end of life register)

h. Dementia, where health and social care needs are increasing

### 3.2 *Using the Supportive Care Register and referring patients for specialist support*

If a patient has one or more of the trigger factors listed above, any member of staff should:

- 3.2.1. Discuss the concern with the multidisciplinary team (or patient's renal consultant if no meeting imminent). Ideally, this should be during one of the regular PD / HD / Pre dialysis review meetings.
- 3.2.2. If appropriate, offer patient leaflet 'Planning for your future - Advance Care Planning'. Ask advice from a senior colleague if you are unsure about whether the timing is right.
- 3.2.3. If the patient and/or family is in agreement, add patient details to Supportive Care Register on PROTON. To find follow - Update, Demographic, More, 'Sup Care Rg'
- 3.2.4. Refer the patient to the Renal Community Team for advice about advanced care planning and onward management if needed.

### 3.3 *Direct referral to the Specialist Palliative Care Team*

3.3.1 There may be times when it is appropriate for staff to refer patients directly to specialist palliative care services, both for in-patient and out-patient settings.

3.3.2 Referrals will be considered for:-

- Patients with difficult and uncontrolled symptoms
- Complex psychological issues for patients and carers
- Concerns about future care and/or treatment
- Last days of life
- Support and guidance in the management of the patient.

Criteria for direct referral are included below and a pathway is included for reference in appendix 2. Direct referrals from the patient and/or their family will be accepted but only with agreement of the patient and medical and nursing team caring for the patient on the ward. If there is any doubt, patients should always be discussed with the specialist palliative care team. Please note that patients may be discharged if their condition stabilises or if input from the Specialist Palliative Care Team is no longer required.

3.3.3. Information required for all referrals:-

- Diagnosis, medical history and reason for referral
- Patient's name, date of birth, hospital number and first language.
- If patient is not in hospital the following information is required - address, home telephone number, first language and GP details
- Medical team in agreement with referral
- If patient is at home, GP in agreement with referral
- Whether the patient is aware of their diagnosis and referral.

3.3.4 Criteria for routine referrals:

- The patient should have advanced chronic kidney disease (CKD stage 4 or 5) including patients on dialysis

- The patient should understand, appropriate to their capacity and preferences for information, that the focus of treatment has shifted from active management towards optimising comfort and quality of life (although steps will continue to be taken to preserve renal function for as long as this is not excessively burdensome to them)
- They may be either:-
  - Managed conservatively (without dialysis) and have significant symptom control, psychological or family/social issues
  - Managed conservatively and approaching last few weeks or days of life
  - Considering withdrawal of dialysis or conservative management in the face of a failing transplant
  - Having dialysis and experiencing significant symptoms such as pain, nausea, fatigue, pruritus, intractable fluid overload, restlessness or breathlessness.
  - Expected to deteriorate rapidly for any reason
  - Require further support in the terminal phase
- The following should have already taken place:-
  - Open discussion with patient and family/carers. If this is challenging, please discuss with palliative care team.
  - First line management of identified symptoms

#### 3.3.5 Criteria for urgent referrals:

- needing assessment within 1-2 days
- difficult symptoms or psychological issues causing distress and not responding to current management
- rapidly deteriorating condition

## **4. Education and Training**

This guideline is intended to raise awareness of systems and processes already in place and therefore no additional training is required.

## **5. Monitoring and Audit Criteria**

All guidelines should include key performance indicators or audit criteria for auditing compliance.

Key Performance Indicator	Method of Assessment	Frequency	Lead
Appropriate referral	Audit of referral letters	annual	Caroline Cooke
Quality referral	Audit of referral letters	aAnnual	Caroline Cooke
Number of patients registered on supportive care register	Count from PROTON	annual	James Burton/ Bev Pearce
Number of patients with advance care plan	Count from PROTON	annual	James Burton/ Bev Pearce

## **6. Legal Liability Guideline Statement**

See section 6.4 of the UHL Policy for Policies for details of the Trust Legal Liability statement for Guidance documents.

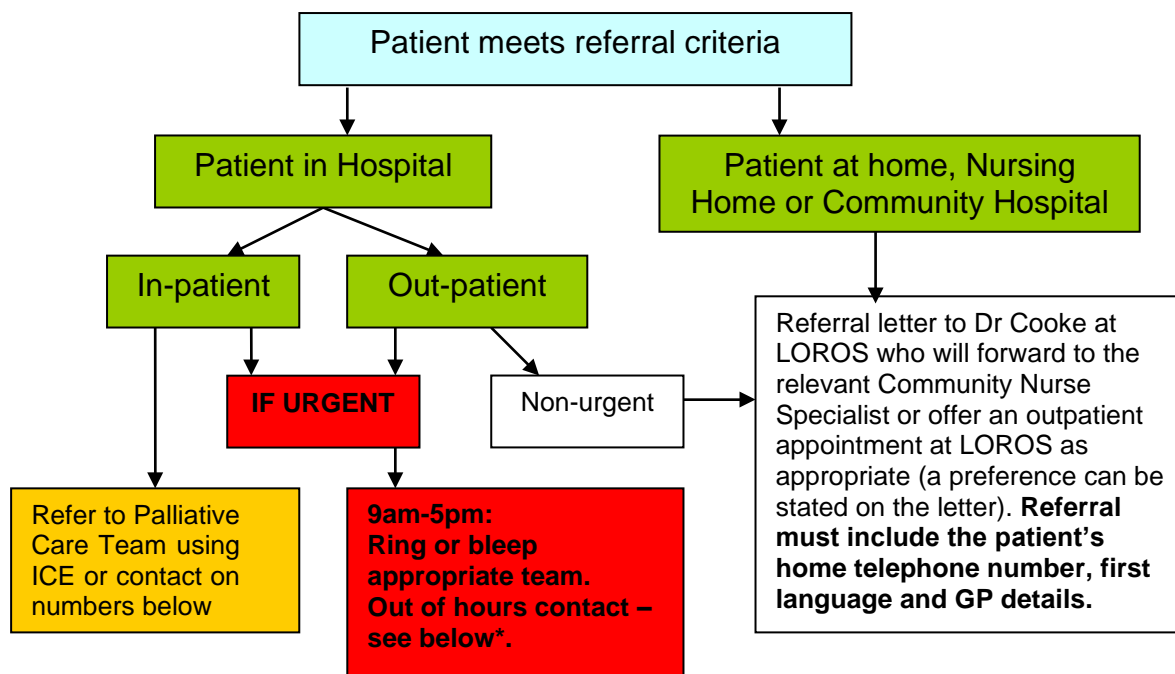
## **7. Key Words**

Palliative care, end of life, referral, end stage renal disease, dialysis, supportive care.

**KARNOFSKY PERFORMANCE STATUS SCALE DEFINITIONS RATING (%)  
CRITERIA**

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

Referral Pathway to Specialist Palliative Care Services from Nephrology



Contact Numbers:

Hospital Palliative Care Teams

Leicester General Hospital ext 4680

Leicester Royal Infirmary ext 5414

Glenfield General Hospital ext 3540

LOROS

Consultants 0116 231 3771

(ask for secretary)

Out of hours 0116 231 3771 / 8415

\* Out of hours during 9am-5pm at weekend and Bank Holidays, call the in Hospital Palliative Care Team on 07984 545070. At all other times, call LOROS.

Community Clinical Nurse Specialist in Palliative Care / Macmillan Nurses

Based at LOROS 0116 231 8402

(Note that parts of the County are covered by Macmillan nurses based elsewhere. For contact numbers, phone the Hospital Palliative Care Team)

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DEVELOPMENT AND APPROVAL RECORD FOR THIS DOCUMENT			
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<b>Approved by:</b>	RRCV CMG Category C		<b>Date Approved:</b> October 2018
REVIEW RECORD			
Date	Issue Number	Reviewed By	Description Of Changes (If Any)
26Mar2016	2	James Burton	Updated to new UHL template and minor changes
25Oct2018	2	James Burton	None
DISTRIBUTION RECORD:			
Date	Name	Dept	Received