

Guidelines for the supportive care of patients with End Stage Renal Disease on the Conservative Management Pathway

Clinical Director

Sign

Name

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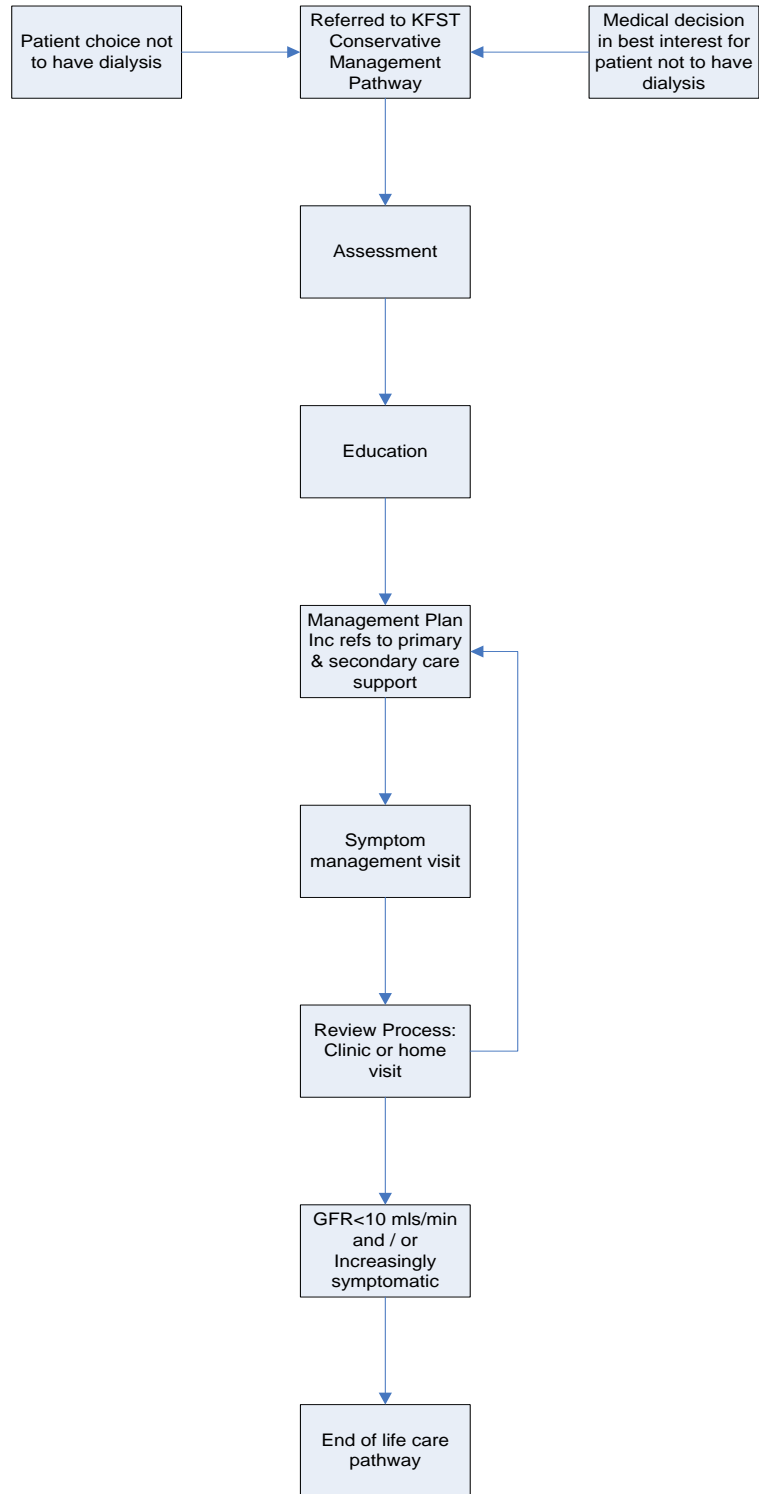
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Conservative Management Pathway



1 Overview/Introduction

The importance of end of life care for those with advanced kidney disease was acknowledged in the National Service Framework for renal Services Part 2 (Feb 2005). This NSF included a quality requirement for end of life care. The aim is to support people with established kidney failure to live life as fully as possible and enable them to die with dignity in a setting of their own choice. These guidelines aim to ensure that patients whom chose not to have renal replacement therapies or whom are deemed unsuitable should receive a high quality service from the Kidney Failure Support Team providing end of life care.

1.1 Reason for Development of the Guideline

These guidelines will ensure that all patients will receive an equitable quality service. Members of the kidney failure support team will have clear guidelines with regard to the conservative management / end of life care of patients whom will not be moving towards renal replacement therapies.

This policy aims to meet the Standards set within the National Service Framework for Renal Services: Part Two

1.2 Methodology

This policy has been developed in line with the National Service Framework for Renal Services standards and End of Life Care in Advanced Kidney Disease a Framework for Implementation.

1.3 Implementation

All members of the multi-disciplinary team caring for patients with chronic kidney disease should be made aware of these guidelines through education and training. New and junior staff should be supervised until they are considered competent to practice safely without supervision. All relevant staff members should be given a copy of this guideline and should sign to confirm they have read it.

Multi-disciplinary team to include

- Kidney Failure Clinical Nurse specialist with lead for conservative management/ end of life care.
- Kidney Failure Clinical Nurse Specialists in supportive role
- Lead clinician for conservative management- Consultant Nephrologist.
- Renal Anaemia Nurse Specialist.
- Renal Social Worker
- Renal Outreach Occupational Therapist.
- Renal Dietitian.

1.4 Monitoring

Audit should take place on a quarterly basis to ensure appropriate documentation is maintained. Home Visits should also be audited.

An audit of patient outcomes should also be undertaken to ensure the current guidelines are meeting patient need.

1.5 Application of the Guideline

This guideline applies to all members of the multi skilled renal team caring for patients with chronic kidney disease. It will benefit both patients and staff.

1.6 Objectives of the Guideline

- To outline the process to be followed planning end of life care for a patient with advanced kidney disease.
- To identify the assessments required
- To outline the information that must be relayed to the patient.
- To identify the patient information literature that should be given to the patient.
- To identify the members of the renal multi skilled team who will offer support to the patient.
- To identify agencies within the primary care setting whom may offer support and care to the patient.
- To identify the process for follow-up of the patient in clinic /home.
- To outline appropriate symptom management for patients with advanced kidney disease.

1.7 Guideline Steps

The conservative management service is led by the Kidney Failure Clinical Nurse Specialist (conservative management lead) with the support of the rest of the Kidney Failure Support Team.

1.7.1 Referral Process

There are two routes by which patients will enter the end of life/ conservative management pathway.

1. Patients with deteriorating renal function whom have been referred to the Kidney Failure Support Team for education about renal replacement therapies but have decided upon the non-dialysis /conservative management pathway. These patients will all have had education about renal replacement therapies following the Guidelines for the Assessment and Education of Patients Approaching End Stage Renal Disease by one of the Kidney Failure Clinical nurse specialists or a Kidney Failure Support Nurse.
2. Patients who are deemed medically unsuitable for dialysis referred to the Kidney Failure Support Team by a Nephrologist.
 1. Inform Conservative Lead Kidney failure CNS of the new referral
 2. Record decision on KFST screen and timeline on the Renal database Proton (Timeline should identify if the patient declines dialysis or medical decision not to offer dialysis).
 3. Change status on Proton identity screen to CCM(unless TEB or XDT or XAC)
 4. Record on KFST referral data base and Conservative management database both held in Renal Public server.
 5. Record decision in nursing profile.
 6. Dictate a letter to patient and copy to GP recording decision not to have dialysis. Copy to be kept in Notes and Electronic Patient Record.
 7. If not already done prepare Kidney Failure Support Team Patient Profile, register referral on Proton.
 8. If the patient has not already had a home visit arrange a mutually convenient date and time.
 9. If un-contactable by phone, write to the patient with an appointment.
 10. Plan the route to the patient's home using AA Route planner or A-Z or satellite navigation system.
 11. Ensure all documentation available
 - Patient profile
 - Modified Supportive Care pathway.
 - Most recent clinic letter.

- Blood results.
- Conservative Management Patient Information Leaflet.
- Co-op card

1.7.2 Assessment process

If possible ensure a relative or friend will be present at home visit to provide support to the patient.

On meeting at patient

1. Introduce self
2. Give explanation of team role, nurse led clinics and identify the other members of the team.
3. Complete demographic data.
4. Assessment of patient using the [Modified Supportive Care Pathway](#).
5. Take a past medical history, complete the co-morbidity assessment form.
6. List current medication.
7. Take a social history, lifestyle, work, holidays, family.
8. Assessment of current symptoms. Use Symptom Assessment Tool in Modified Supportive Care Pathway.
9. Assessment of Independence with Activities of Daily Living. Using Barthels score
 - a. Cooking/Meal Preparation
 - b. Washing and Dressing
 - c. Housework
 - d. Toileting
 - e. Mobility /ability to climb stairs.
 - f. Sleeping
10. Assessment of current support mechanisms e.g. Social services, District nurses, carers, family, friends.

1.7.3 Education Re: Conservative Management Pathway.

1. Full explanation about the functions of the kidney.
2. Ensure the patient understands the implications of not choosing dialysis, that the functions of the kidney are required to sustain life.
3. Long term consequence of renal failure is death.
4. Aim of conservative management is symptom management.
5. Aim of conservative management is to support end of life care in the patients preferred place of care.
6. Give the patient an Information leaflet: Treatment of kidney failure without Dialysis/ Conservative Management.
7. Discuss the use of the modified Supportive Care Pathway.
8. Discuss the benefits of Advanced Care Plans
9. Discuss the benefits of Preferred Place of Care Plans.

1.7.4 Management Plan

1. Agree management plan with patient and relatives.
2. Referral to Renal Social Worker if required.
3. Referral to Renal Outreach Occupational therapist if required.
4. Referral to renal dietitian.
5. If required refer to District Nurses for support and palliative care assessment.

6. Consider referral to palliative nursing teams/ Hospice, Marie Curie or Macmillan Nurses.
7. Arrange to review patient in the multi disciplinary, nurse led conservative management clinic which is held once monthly at Birmingham Heartlands Hospital. Second Friday of each month.(clinic code)
8. Patient may prefer to continue to be seen in one of the satellite nurse led low clearance clinics if closer to home.
9. If patient unable to attend clinic due to poor health or mobility, home visits may be made by the KFST to review patient.
10. Complete nursing documentation.
11. Record Home Visit (Palliative care Visit) on Proton timeline.
12. Record co-morbidity on renal registry co-morbidity screen.
13. Arrange follow up clinic appointment if not already made.
14. Refer to anaemia team as per Renal Anaemia Guidelines.
15. Discuss cultural and spiritual needs with patient.
16. Complete Care Plan and ensure a copy is sent to the patient.

1.7.5 Symptom Management

All patients from the conservative management clinic should have a symptom assessment questionnaire filled on referral to the conservative management clinic and at regular intervals thereafter.

Symptoms may include:

- Pruritus
- Restless Legs
- Nausea
- Shortness of Breath
- Cramp
- Depression
- Pain
- Poor appetite/ Anorexia/ Weight Loss*
- Deteriorating Mobility*
- Inability to carry out ADL*

1.7.5.1 Pruritus

Itch can affect between 50 and 90% of patients with end stage renal disease. At best it may be only annoying but can be frequently very distressing. It may be localised or generalized, of variable intensity, paroxysmal and is usually worse in warmer weather. It is often characterised by xerosis (dry skin) and excoriation and occasionally complicated with secondary infection.

The pathogenesis remains obscure. There are hints that derangements of either the opioidergic and/or the immune system are involved.

1.7.5.1.1 Management

Non Pharmacological

Ensure advice given on adequate skin hydration including liberal use of emollients such as emulsifying ointment or 50/50.

Advise use of non soap based cleaning agents

Adequate Phosphate control $PO_4 < 1.6$
Correct Secondary Hyperparathyroidism
Correct Iron Deficiency
Exclude Liver dysfunction
Exclude co-existent skin conditions such as Eczema, Scabies etc
UVB treatment if available and symptoms very distressing (referral to Dermatology)

Pharmacological

Topical

Eurax Cream- for localised itch

Capsaicin Cream 0.025%- warn regarding side effects; for use in moderate to severe symptoms

Oral

Antihistamines

Patients report benefit but there is no evidence to support their use; the sedative side effect may be of benefit at night

First line- Atarax (hydroxyzine hydrochloride) 10 mg od

Second Line -Chlorpheniramine 4 mg every 4–6 hours, max. 24 mg daily
(warn re- sedative side effect)

Thalidomide 100mgs daily

(Not for use in women of child bearing age, may cause peripheral neuropathy)

Ondansetron 2-8 mgs tds

(Side effect Constipation)

Mirtazapine 7.5 to 15 mgs od

Paroxetine 20 mgs od

1.7.5.2 Restless legs

Restless legs syndrome (RLS) is a neurological disorder characterized by unpleasant sensations in the legs and an uncontrollable urge to move when at rest in an effort to relieve these feelings. RLS sensations are often described by people as burning, creeping, tugging, or like insects crawling inside the legs. The most distinctive or unusual aspect of the condition is that lying down and trying to relax activates the symptoms. As a result, most people with RLS have difficulty falling asleep and staying asleep. Left untreated, the condition causes exhaustion and daytime fatigue.

1.7.5.2.1 Management

1. Stop or reduce any exacerbating medications; SSRI antidepressants, Lithium
2. Optimise anaemia management
3. Clonazepam 500 micrograms nocte upto a maximum of 2 mgs /day
4. L-Dopa/Carbidopa 50/12.5- 100/25 nocte

(Most patients eventually will develop augmentation, meaning that symptoms are reduced at night but begin to develop earlier in the day than usual; therefore consider small doses for limited periods of time)

1.7.5.3 Nausea and Vomiting

1. General advice on eating small quantities of food more often.
2. Ensure on Proton pump inhibitor
3. Exclude Hypercalcaemia
4. Treat Constipation
5. If diabetic gastropathy, consider pro-kinetic agent such as Erythromycin 125-250 mgs bd

If nausea is frequent and disabling;

1. Cyclizine 50 mgs tds OR Metoclopramide 10 mgs tds
2. Haloperidol 1 mg nocte

If patient remains nauseated on maximum dose of regular oral drug therapy or is vomiting;

1. Consider s/c syringe driver with Metoclopramide 20-30 mgs over 24 hours OR Haloperidol 2.5-5 mgs if no improvement with metoclopramide
2. s/c syringe driver with cyclizine 100-150 mgs over 24 hours

1.7.5.4 Shortness of Breath/Dyspnoea/Peripheral Oedema

1. Correct anaemia
2. Stop/ reduce/ change any contributing medications such as NSAIDS, Calcium channel blockers, Alpha Blockers, Steroids
3. Consider underlying chest disease; treat infections; exclude pleural effusion
4. If secondary to fluid overload- tailor diuretics and consider use of metolazone
5. Trial of oxygen therapy at home

If patient moribund or has decreased conscious level and troublesome breathlessness and respiratory tract secretions

- Hyoscine Hydrobromide 0.4 mgs s/c bolus injection OR 1.2 mgs over 24 hours via s/c syringe driver(increase total dose to 2.4 mgs after 24 hours if symptoms persist)

1.7.5.5 Cramp

- Quinine Sulphate 200-300 mgs nocte
- Check CK if on statin therapy

1.7.5.6 Depression

It is estimated that between 20-30% of patients with ESRF will have symptoms of depression. This may adversely affect a patient's quality of life and morbidity and hence should be addressed.

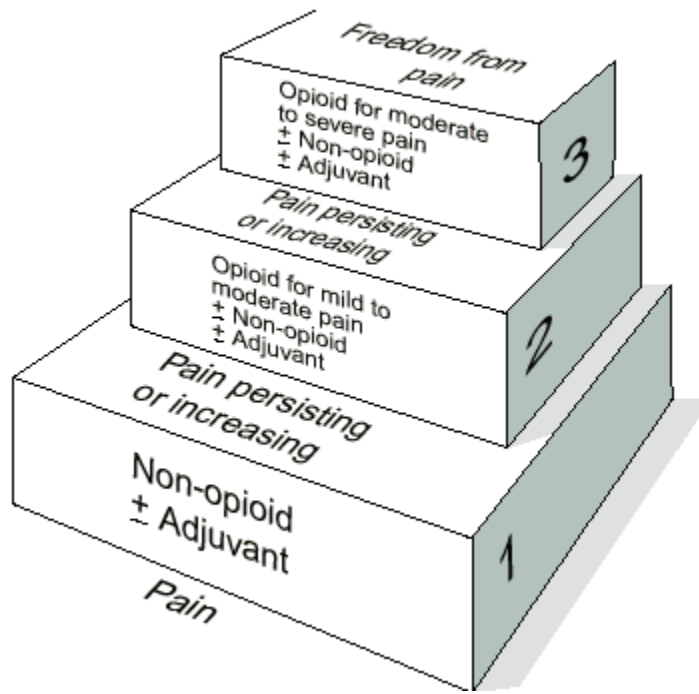
1. Treat underlying secondary hyperparathyroidism
2. Ensure referral made for social services support
3. Trial of antidepressant treatment- Paroxetine 10-20 mgs od

1.7.5.7 Pain

Most patients with ESRF will complain of a degree of pain. Important aspects of treating pain in ESRF patients should include;

1. Assessment of pain
2. Explanation
3. Monitoring of symptoms
4. Addressing psycho-social issues
5. Screening and treatment of depression

Pain should be treated using the WHO Analgesic Ladder



Step 1 Paracetamol regularly

Step 2 Paracetamol + opioid such as Codeine (monitor renal function which may deteriorate) OR Tramadol 50-100 mgs bd

Step 3 Paracetamol + change to opioid patch Fentanyl 25 patch or Buprenorphine 35 patch (change patch every 72 hours)

1.7.6 GFR <10mls/min and/or increasingly symptomatic

1. Request that GP places patient on Register for Gold Standard Framework for palliative care
2. Discuss with patient, relatives and carers' Preferred Place of Care to meet end of life.
3. Discuss use of Advanced Care Plan / Directive.

4. If not already done consider referral to Renal Social Worker and Renal Outreach Occupational Therapist.
5. If not already done refer to District nurses for palliative care assessment.
6. Refer to palliative care nurses/Hospice.
7. Consider referral for continuing health care support.

2 References

Department of Health. National Service Framework for Renal services-Part Two: Chronic Kidney disease, acute renal failure and end of life care.2005

End of Life care in Advanced Kidney Disease. A Framework for Implementation.2009

Department of Health. End of Life Strategy. 2008

Advance Care Planning: A Guide for Health and Social Care Staff