	CONSERVATIVE KIDNEY MA	NAGEMENT GUIDELINES	
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Nephrology, Urology and Transplantation Directorate



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SECTION 1

Rationale – These guidelines are being introduced to provide nursing and medical staff with information and guidelines on the care of patients with End Stage Kidney Disease who opt not to undergo dialysis and for whom dialysis is not an option for clinical reasons. This document is the first of three proposed guidelines to provide guidance on End of Life Care for the patient with Chronic Kidney Disease.

<u>An Bord Altranais (2009)</u> stated that "Nurses can make a difference to older people and their families by creating and facilitating a therapeutic milieu that addresses their physical, psychological, social, cultural and spiritual needs. This includes collaboration with the other healthcare professionals in providing evidence based best practice and establishing mechanisms for consultation regarding practice and referral" "Providing relief from distress will facilitate a comfortable death and on that is remembered with peace and comfort by family and friends".

Irish Medical Council (2009)

"When Death is imminent, it is the responsibility of the doctor to take care that the said person dies with dignity, in comfort and with as little suffering as possible. In these circumstances a doctor is not obliged to initiate or maintain treatment which is futile and disproportionately burdensome."

HSE/Irish Hospice Foundation

In 2006, the Health Service Executive (HSE) stated its commitment to develop a chronic disease management patient support programme.

<u>World Health Organisation (2004)</u> – recommended the provision of appropriate palliative care for all patients regardless of diagnosis.

Palliative Care for all - Integrating Palliative Care into Disease Management Frameworks (2008) recommends – " Collaboration between the relevant speciality / primary care team and SPC(specialist palliative care) has been found to be beneficial in meeting the palliative care needs of people with non – malignant diseases at all stages of their illness. In all cases of collaboration practice the development of local guidelines setting out the parameters for referrals or joint/shared care are recommended. www.hospice-foundation.ie www.hse.ie

Hospice Friendly Hospital (May 2010)

Prepared a development plan for implementation the Quality Standard for End of Life Care in Hospitals resulting from the National Audit of End of Life Care in Hospitals in Ireland 2008/2009 a number of quality standards where recommended for End of Life Care in Hospitals.

SCOPE

The implementation of this guideline will apply at the point on the disease trajectory where the patient would otherwise be preparing for commencing renal replacement therapy. CKD (Stage 3-4)

This guideline is in line with current corporate procedures whereby Beaumont Hospital is currently engaged in the next phase (2) of the HSE/HfH initiative. Practice Development Programme for End of Life Care. (Sept 2010 – April 2012) <u>**Key Staff**</u> – All staff within the Nephrology Urology and Transplantation Directorate have responsibility in implementing and following through on this guideline.

<u>Responsibilities</u> – To use this guideline tool as recommended, and review at each clinic visit. To communicate and document any changes in the medical notes.

PRINCIPLES The basic belief on which this guideline is based is that it is our responsibility to support people with advanced kidney disease to live life as fully as possible and enable them to die with dignity in a setting of their own choice. In addition, Family members are supported throughout the illness of their relative, and are treated with compassion and in a caring manner following the death of their relative.

SECTION 2

THE PPPG – Consisting of:

The statement(s) of the standard that is to be achieved (What)

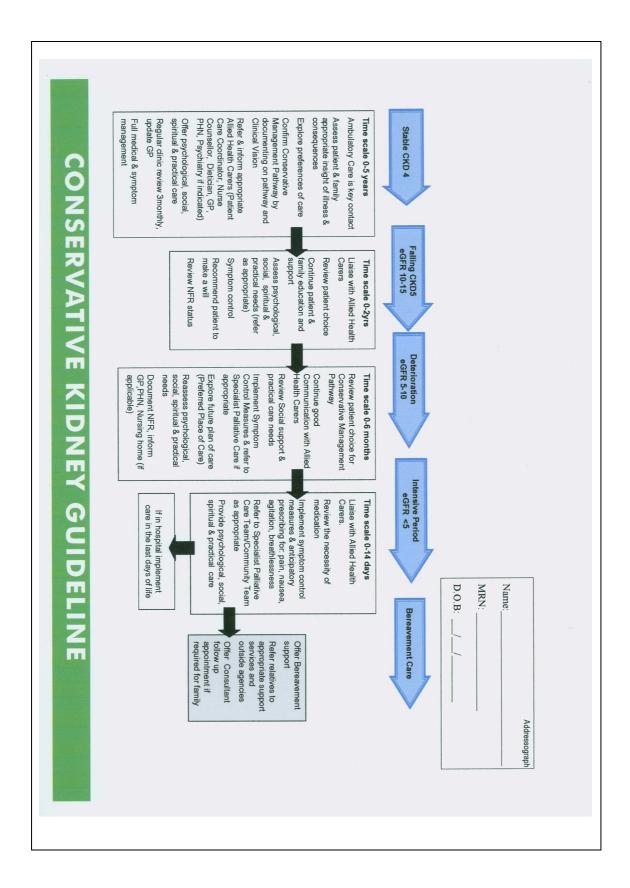
Patients on the Conservative Management Pathway will receive quality treatment and care which includes palliative care that focuses on managing pain and other distressing symptoms, providing psychological, social and spiritual support and support those close to the patient including bereavement care. (GMC 2010)

SECTION 3

THE PROCEDURE – Consisting of:

A step by step account of how the PPPG is to be achieved, including a flowchart in all but the simplest cases.

Beaumont Hospital ncorporating St. Joseph's Hospital		Addressograp
		Name:
Nephrology Urology Tran	spiantation Directorate	MRN:
Steels succumul		D.O.B:/_/
CONSERVATIVE KIDNEY		
GUIDELINE		
Contact List:		
Patient Telephone No:	Mobile No:	
Patient Main Support	Contact no.	Relationship to patient:
Allied Health Carers:		
Consultant:		
Ambulatory Care:		
Patient Care Co-ordinator:		-
lurse Counsellor:		
 SP:		
PHN:		
Psychiatrist (if appropriate):		
Dietician (if appropriate):		
Dther:		
Juliel.		
Commencement date of Conserv	ative Management F	Plan: Stage/ eGFR:
Key issues:		
Agreement by patient on Conservative Ki	idney Management Plan	Date:/_/
To be reviewed at each clinic visit		
NFR status:	Date://_	
Patient preferred place of care:		Date://



SECTION 4

DEVELOPMENT AND CONSULTATION PROCESS – Consisting of:

An outline of who has been involved in developing the PPPG (use template below)

CONSULTANT SUMMARY			
Date PPPG issued for consultation	22 nd April 2010		
Number of versions produced for consultation	4		
End of Life Steering Committee –	End of Life Steering Committee met on the		
Dr Mark Denton – Consultant Nephrologist	following dates -		
Dr Regina Mc Quillan – Consultant Palliative			
Medicine	Dates: 7 th April 2010		
Margie Kennedy – Renal Nurse Counsellor	22 nd April 2010		
Mary T Murphy – Patient Care Co-ordinator	25 th May 2010		
Eileen McBrearty – Patient Care Co-ordinator	31 st August 2010		
Caroline Cregan – CNM11 St Peter's Ward	Sub Committee meeting -21^{st} September		
Teresa Byrne – Specialist Palliative Care	12 th October 2010 2 nd November 2010		
Nurse	2 rd November 2010		
Louise McSkeane – Ambulatory Care			
Olive Byrne – Ambulatory Care			
Eimear O'Sullivan Staff Nurse			

Where Received	Summary of Feedback	Actions/Response
The first discussion on this guideline was at the End of Life Steering meeting on the 22 nd April.	It was agreed that the first draft be designed and circulated to the entire group before the next meeting.	Work began on the design and wording for the guideline.
End of Life Steering Group meeting 25 th May 2010	A general discussion took place to review the first draft of proposed guidelines.	It was decided that it is a work in progress and to follow up again at the next meeting.
End of Life Steering Group meeting 31 st August 2010	It was decided to form a sub-committee to decide on the final wording and to research other areas to see what is in use.	The sub- committee met with the oncology department who have a similar plan in use. This was very productive. It gave the committee insight into how best to

		highlight the guidelines in the patient's chart.
End of Life Steering Group Meeting 12 th October 2010	Work is progressing to the satisfaction of the Committee. One of the ambulatory care nurse's will investigate getting a stamp designed for the patient chart to use for clinic appointments. Checking the best route for documentation.	Decision to make the necessary adjustments to the wording. Proceed to printing a copy of the guideline to bring to the next meeting.
End of Life Steering Group Meeting 2 nd November 2010	Colour and Layout in the final discussion today. Two small areas in the wording need to be changed. Agreed to add the addressograph to both sides.	Agreed to meet again prior to Policy meeting with the final draft and if approved to start the pilot study in January 2011.

SECTION 5

REFERENCE DOCUMENTS – Consisting of:

A list of works that the author has used as a source of information, evidence or inspiration

An Bord Altranais (2009) Professional Guidance for Nurses working with Older People

Brown, E, Chambers J, Eggeling C, (2007) End of life Care in Nephrology from Advanced Disease to Bereavement (Oxford Specialist Handbooks)

Brown E, Chambers E, Eggeling C. (2008) Palliative Care in Nephrology. Nephrol Dial Transplant 23 789-791

Brown E, (2010) Supportive Care for the Renal Patient (Oxford University Press)

Davision S, Torgunrud C, (2007) The Creation of an Advanced Care Planning Process for patients with ESRD. American Journal of Kidney Disease Vol 49 No.1 pages 27-36

Darrell(2006) Palliative Care and End Stage Renal Disease. Journal of Hospice and Palliative Nursing Vol 8. No 6

Department of Health and Children's Documents. A policy of Framework for the management of Chronic Diseases. Tackling Chronic Disease (2008)

Farrington K, Gomm S (2008) End of life Care in Advanced kidney Disease – a Framework for Complementation NHS (National End of Life Care Programme)

Fliss EM. Murtagh et al (2007) Symptoms in Advanced Renal Disease; A Cross Sectional Survey of Symptom prevalence in Stage 5 Chronic Kidney Disease Managed without Dialysis. Journal of Palliative Medicine Volume 10 No 6

General Medical Council (2010) Treatment and Care towards the end of life: good practice in decision making.

Gold Standards Framework (GSF) NHS End of Life Programme www.goldstandardsframework.uk

Hinton V, Fish M (2006) A Care Pathway for the End of Life in a renal setting. EDTNA/ERCA Journal 2006 xxx113

Murtagh F, et al (2006) Symptoms Management in Patients with established renal failure managed without dialysis. EDTNA/ERCA Journal 2006 xxx112)

Murtagh F, et al (2007) Nephrol Dial Transplant 1955- 1962 Dialysis or not? A comparative survival study of patients over 75years with chronic kidney disease stage 5

Noble H. Kelly, K. (2006) EDTNA/ENCA Journal 2006 xxx112_Caring for people who are dying on Renal wards : A retrospective study.

Noble H Kelly (2006) Supportive and Palliative Care in end stage renal failure: the need for further research: International Journal of Palliative Nursing 2006 (Vol12 no 8)

Mc Kenna, S, (2008) Irish Nephrology Nurses Association. Submission to the Irish Hospice Foundation on the Draft Report 'Palliative Care for all'

The Renal Association (2009) RA Guidelines – Planning, Initiating and Withdrawal of Renal Replacement Therapy.

Starzomski R (2006) Ethical Challenges in Nephrology Nursing. American Nephrology Nurses Association 2006 (797-815) Contemporary Nephrology Nursing:

Principles and Practice, 2nd Edition

White Y. Fitzpatrick G. (2006) EDTNA/ENCA Journal 2006 xxx112 Dialysis: prolonging life or prolonging dying? Ethical, Regal and Professional consideration for End of Life decision making.

Palliative Care for all (2008)_Integrating Palliative Care into Disease management Frameworks HSE/HfH Report on the Extending access study.

Appendix 1.

GP Name and address

Patient Name Address

DOB

Date

Dear Doctor

The above named patient has advanced chronic kidney disease/end stage renal disease. He/she has been attending the Department of Nephrology in Beaumont Hospital with this condition. It has been agreed between the patient, family, nursing staff and medical staff to pursue a conservative management strategy. This means that after being fully informed by the health care team, the patient is <u>opting not</u> to have dialysis of any kind should the renal failure worsen.

We will continue to manage the patient's chronic kidney disease in the nephrology clinic (e.g. blood pressure, extracellular fluid volume, metabolic acidosis, calcium / phosphate balance and anaemia) and review medications, but we <u>will not</u> be making any plans for future dialysis (such as vascular access). We will continue to review the patient's wishes, should the patient have a change of mind at a later date.

The rate of progression of kidney disease is highly variable and it may be that the patient's level of renal function remains steady for some years. During this time the patient will be continued to be reviewed in the outpatient clinic or may even need to be admitted to hospital for an intercurrent illness. However as the renal function declines to very low levels, and the patient becomes symptomatic of uraemia we will communicate further with you because it may be better for the patient to be managed at home for end of life care. Symptoms of uraemia include loss of appetite, nausea, vomiting, itch, insomnia and restless legs. Symptoms can usually be controlled by anti-emetics, antihistamines and other medications. We will communicate closely with you during the later stages. Ultimately patients may develop loss of consciousness from uraemic encephalopathy.

Death from end stage renal failure is usually painless. However, if the patient has other co-morbid conditions, pain may be a feature and need to be managed. It may be necessary to refer to palliative care if available in your area. Otherwise please refer back to us for advice. Should you have any questions or concerns at any stage, for example regarding safe prescribing in chronic kidney disease, please do not hesitate to contact the Nephrology Registrar on 01 8093000, or Ambulatory Care nursing staff on 01 8528395.

Thank you

Registrar : Dr Medical Council Number..... Attending Consultant..... cc. PHN (if appropriate) enc. Conservative Management Guideline