End of Life Care in Chronic Kidney Disease

Transplantation, Urology and Nephrology Directorate

GUIDELINES ON END OF LIFE CARE IN CHRONIC KIDNEY DISEASE

Document Number: 31	Reason for Change EXPANSION OF GUIDELINE TO INCLUDE TWO ADDITIONAL SUB-SECTIONS
Original Date of Approval: 30/11/2010	Originally Approved By:
Recent Date of Approval:	Approved By:
Date Effective From 1ST MARCH 2011	Superseded Documents Conservative Kidney Management Guidelines 30/11/2010
Review Date: March 2013	

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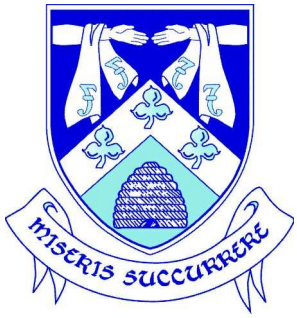
Transplantation, Urology and Nephrology Directorate



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SECTION 1

RATIONALE

This guideline provides a template of care for all staff involved in end of life care of patients with Chronic Kidney Disease within the Transplantation, Urology and Nephrology Directorate.

An Bord Altranais (2009) 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 one 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.

World Health Organisation (2004) – 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)
Produced – "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 were recommended for End of Life Care in Hospitals.

SCOPE
The implementation of this guideline is recommended in the following circumstances –

(a) **Conservative Kidney Management Guidelines**

Apply at the point on the disease trajectory where the patient has made a decision not to opt for dialysis. This is likely to be when Chronic Kidney Disease is stage 3-4, but patients may vary in this regard.

(b) **Non Dialysis Management Guideline**

This Guideline applies to all patients who have made a decision to withdraw from dialysis, or for whom dialysis is no longer a suitable treatment for clinical reasons. The title "Non Dialysis Management" rather than "Withdrawal from Dialysis", highlights to all concerned, especially the patient and his/her family, that the patient will continue to be actively cared for in all but the provision of dialysis. Once the decision has been made under this Guideline, please proceed to Conservative Kidney Management Guideline if applicable, or proceed to "Care in the Last Days of Life", if indicated.

(c) **Care in the last Days of Life**

These guidelines apply where the patient is actively dying and patients from either or both of the previous guidelines will also progress to this guideline.

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)

RESPONSIBILITIES

All staff within the Transplantation Urology and Nephrology Directorate involved in the care of patients with Chronic Kidney Disease have responsibility in implementing and following through on this guideline where appropriate. The appropriateness of the patients care pathway should be reviewed at each out-patient clinic and any changes should be documented 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.

Not all deaths can be anticipated or planned for. Sudden unexpected deaths can be traumatic for the family and staff, and other patients nearby or closely associated through friendship. This guideline does not provide guidance in these circumstances. Local practices continue to apply.

SECTION 2

THE PPPG – Consisting of: **Conservative Kidney Management Guideline**
Non Dialysis Management Guideline
Care in the Last Days of Life Guideline

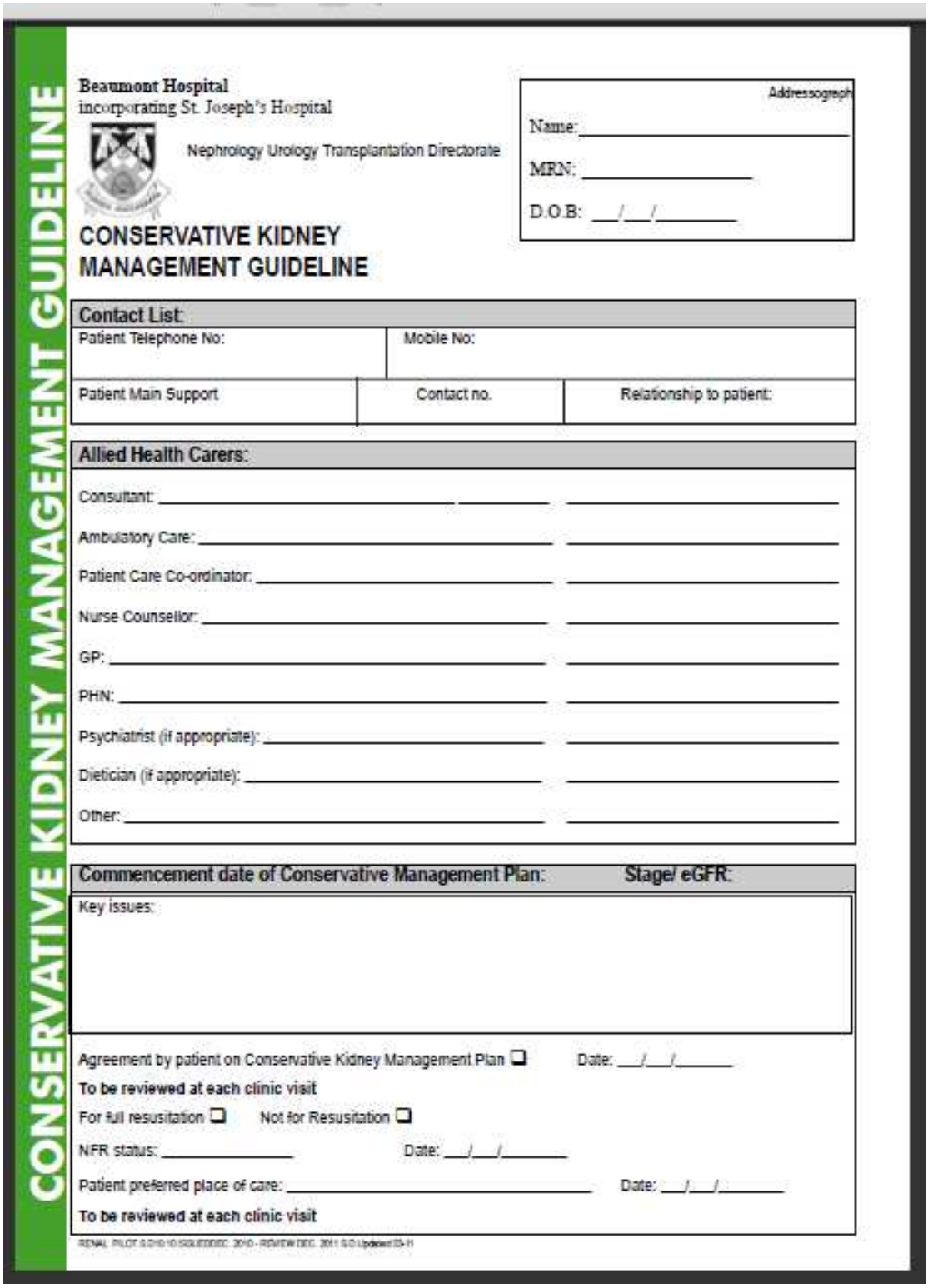
STANDARD

Patients whose care is guided by Guidelines on End of Life Care in Chronic Kidney Disease 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 for those close to the patient including bereavement care. (GMC 2010)

SECTION 3

THE PROCEDURE – Consisting of: Conservative Kidney Management Guideline, Non Dialysis Management Guideline and Care in the last days of Life Guideline.

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



CONSERVATIVE KIDNEY MANAGEMENT GUIDELINE

Beaumont Hospital
incorporating St. Joseph's Hospital

Nephrology Urology Transplantation Directorate

Addressograph
Name: _____
MRN: _____
D.O.B: ___/___/_____

CONSERVATIVE KIDNEY MANAGEMENT GUIDELINE

Contact List:

Patient Telephone No:	Mobile No:	
Patient Main Support	Contact no.	Relationship to patient:

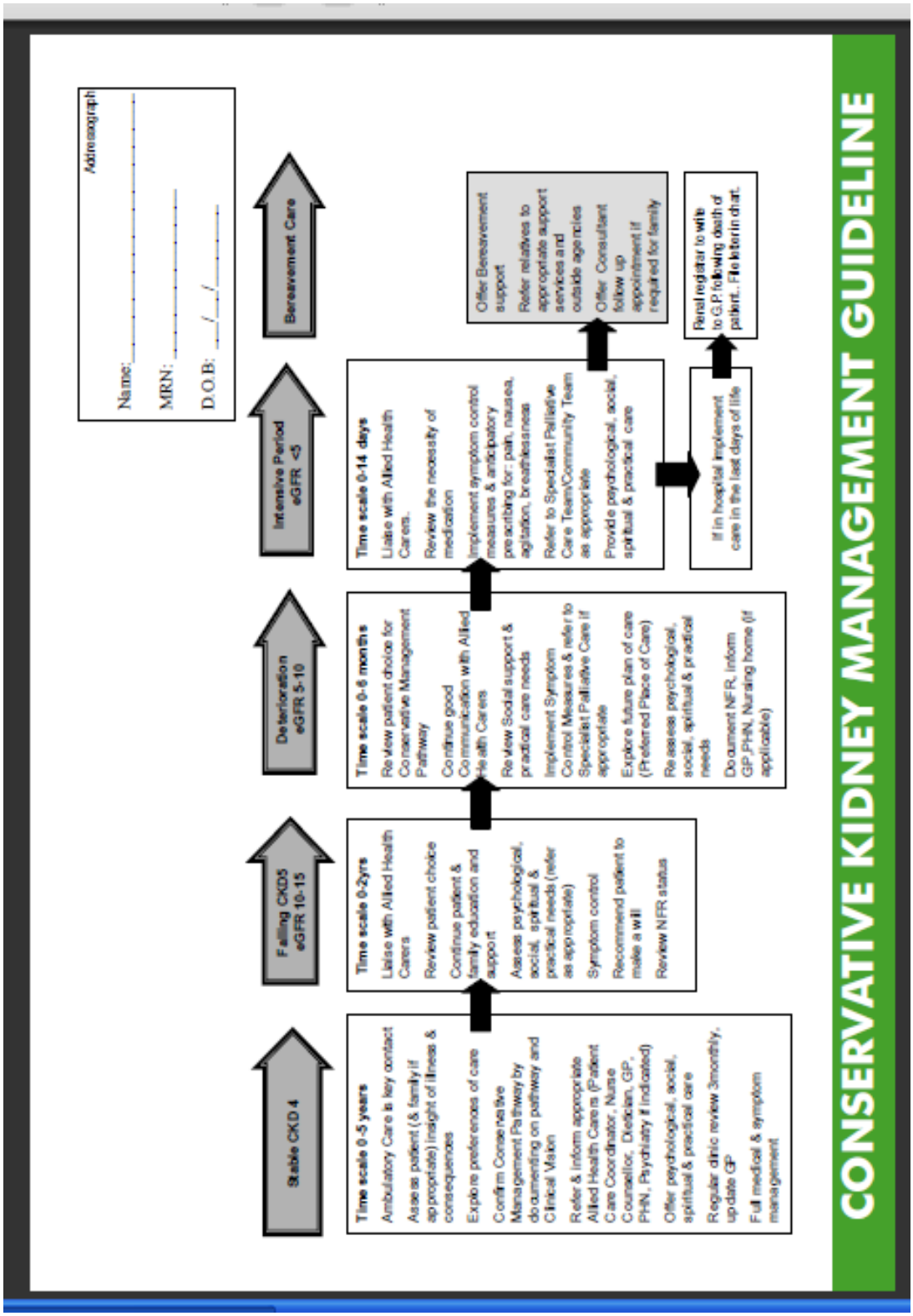
Allied Health Carers:

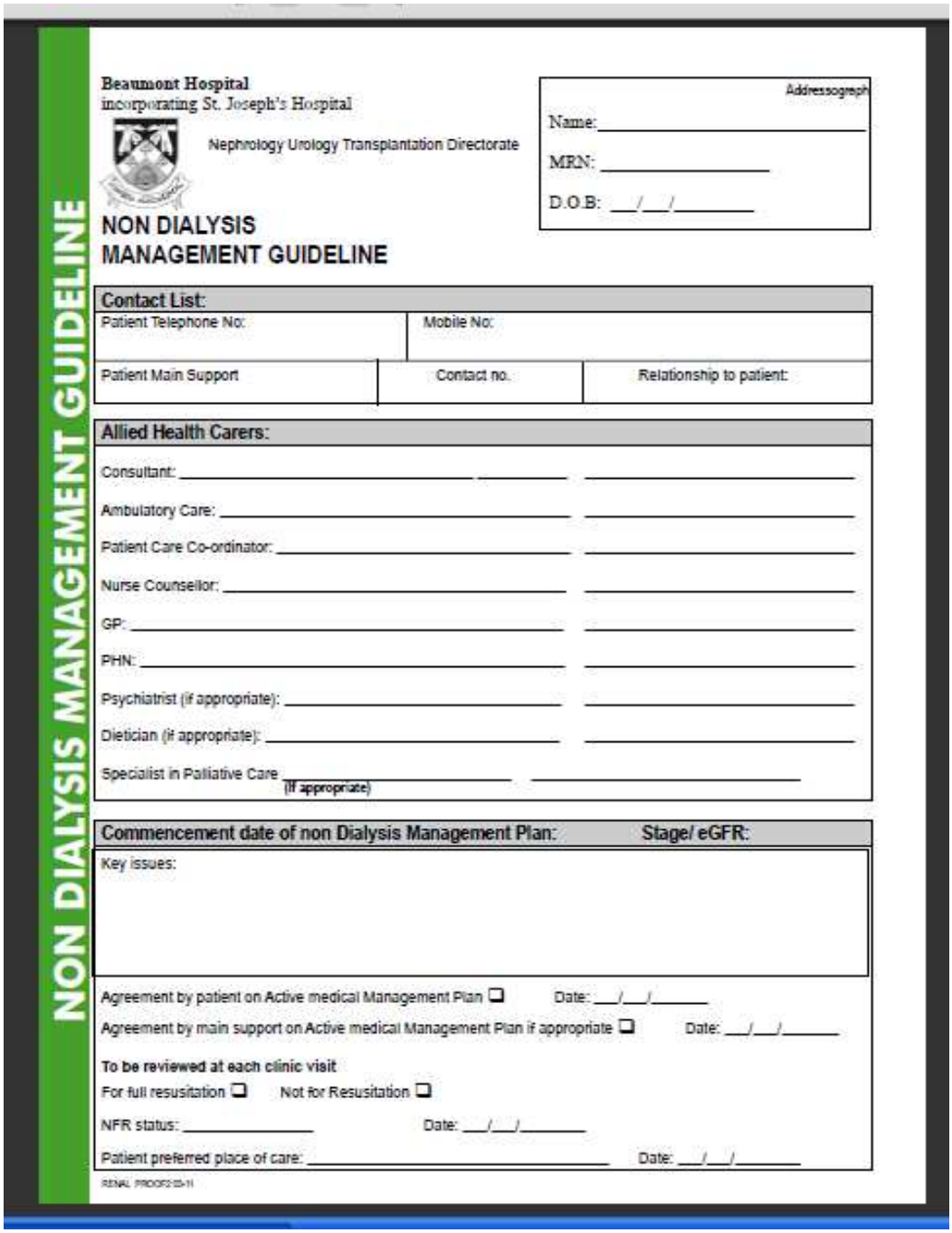
Consultant: _____ _____ _____
Ambulatory Care: _____ _____
Patient Care Co-ordinator: _____ _____
Nurse Counsellor: _____ _____
GP: _____ _____
PHN: _____ _____
Psychiatrist (if appropriate): _____ _____
Dietician (if appropriate): _____ _____
Other: _____ _____

Commencement date of Conservative Management Plan: **Stage/ eGFR:**

Key issues:

Agreement by patient on Conservative Kidney Management Plan ❑ Date: ___/___/_____
To be reviewed at each clinic visit
For full resuscitation ❑ Not for Resuscitation ❑
NFR status: _____ Date: ___/___/_____
Patient preferred place of care: _____ Date: ___/___/_____
To be reviewed at each clinic visit


CONSERVATIVE KIDNEY MANAGEMENT GUIDELINE
Admission graph
Name:
MRN:
D.O.B: __/__/____
Stable CKD 4
Falling CKD5 eGFR 10-15
Deterioration eGFR 5-10
Intensive Period eGFR <5
Bereavement Care
Time scale 0-5 years
Ambulatory Care is key contact
Assess patient (& family if appropriate) insight of illness & consequences
Explore preferences of care
Confirm Conservative Management Pathway by documenting on pathway and Clinical Vision
Refer & inform appropriate Allied Health Carers (Patient Care Coordinator, Nurse Counsellor, Dietician, GP, PHN, Psychiatry if indicated)
Offer psychological, social, spiritual & practical care
Regular clinic review 3monthly, update GP
Full medical & symptom management
Time scale 0-2yrs
Liaise with Allied Health Carers
Review patient choice
Continue patient & family education and support
Assess psychological, social, spiritual & practical needs (refer as appropriate)
Symptom control
Recommend patient to make a will
Review NFR status
Time scale 0-6 months
Review patient choice for Conservative Management Pathway
Continue good Communication with Allied Health Carers
Review Social support & practical care needs
Implement Symptom Control Measures & refer to Specialist Palliative Care if appropriate
Explore future plan of care (Preferred Place of Care)
Re assess psychological, social, spiritual & practical needs
Document NFR, inform GP,PHN, Nursing home (if applicable)
Time scale 0-14 days
Liaise with Allied Health Carers.
Review the necessity of medication
Implement symptom control measures & anticipatory prescribing for: pain, nausea, agitation, breathlessness
Refer to Specialist Palliative Care Team/Community Team as appropriate
Provide psychological, social, spiritual & practical care
If in hospital implement care in the last days of life
Offer Bereavement support
Refer relatives to appropriate support services and outside agencies
Offer Consultant follow up appointment if required for family
Renal registar to write to G.P following death of patient.. File letter in chart.



NON DIALYSIS MANAGEMENT GUIDELINE

Beaumont Hospital
incorporating St. Joseph's Hospital

Nephrology Urology Transplantation Directorate

Addressograph
Name: _____
MRN: _____
D.O.B: __/__/_____

NON DIALYSIS MANAGEMENT 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: _____ _____
Nurse Counsellor: _____ _____
GP: _____ _____
PHN: _____ _____
Psychiatrist (if appropriate): _____ _____
Dietician (if appropriate): _____ _____
Specialist in Palliative Care _____ _____
(If appropriate)

Commencement date of non Dialysis Management Plan: **Stage/ eGFR:**

Key issues:

Agreement by patient on Active medical Management Plan ❑ Date: __/__/_____
Agreement by main support on Active medical Management Plan if appropriate ❑ Date: __/__/_____

To be reviewed at each clinic visit
For full resuscitation ❑ Not for Resuscitation ❑
NFR status: _____ Date: __/__/_____
Patient preferred place of care: _____ Date: __/__/_____

RENAL PROG2:03-11

NON DIALYSIS MANAGEMENT GUIDELINE
Decision Making Process / Communication
Withdrawal from dialysis may be raised by patient, family or a member of the MDT.
MDT inclusion in all discussions regarding withdrawal of dialysis especially core staff already involved in the care. Update communication to all as necessary.
Assess patients decision making capacity by
Nephrologist ,
Medical Team,
Psychiatrist (Optional)
Psychogeriatridian (Optional)
Palliative Care (Optional)
Ensure request for withdrawal is not due to any possible reversible factors such as –
Painful needle insertion
Frequent hypotensive episodes
Depression
Symptoms / Issues eg:
Dyspnoea
Pruritis
Restless Legs
Intradialytic muscle cramps
Pain
Fatigue
Nausea
Patient's perception that they have poor quality of life and that they are a burden.
Identify the person that the patient gives permission to discuss about their condition.
Withdrawal Process
Ensure that the patient's main support is aware of the decision to undergo Non Dialysis Management
Consider a trial period of dialysis in patient's with depression, other psychological conditions or displaying any doubt re decision and review.
Patient continues under Nephrologist care.
Discuss patients preference of place of care.
Refer to the Conservative Kidney Management Guidelines.
Name:
MRN:
D.O.B: __/__/____
Admission graph

Beaumont Hospital
incorporating St. Joseph's Hospital

Addressograph

Name: _____

MRN: _____

D.O.B: __/__/_____

Care plan – Care in the last days of life

Date initiated and signature	*Patients problem/ potential problem or need*	*Date resolved and signature*
	Patient is actively dying.	
	Nursing goals	
	1. _____ is comfortable and remains peaceful.	
	2. _____ has a dignified death	
Date initiated and signature	*Nursing Intervention*	*Date resolved and signature*
	❑ Acknowledgement that the patient is actively dying between ❑ MDT, ❑ patient and ❑ family. ❑ Ensure resuscitation status is charted in the Healthcare Record by medical team. ❑ Ensure good communication with Patient, Family/Carers in relation to medical updates, plan of care, rationale and what to expect in the dying phase. ❑ Offer support of the ❑ pastoral care team, ❑ medical social worker Other_____. ❑ Discontinue all inappropriate nursing interventions, eg routine observations. ❑ Assess, document and treat symptoms of ❑ Pain ❑ Nausea and Vomiting ❑ Dyspnoea ❑ Agitation ❑ Give appropriate medications as prescribed, monitor their effectiveness ❑ Assess pressure areas, reposition for comfort and document same. ❑ Assess comfort status of patients bowel and bladder function and document same. ❑ Regular mouth care and gentle oral suctioning for comfort only. ❑ Advise family of facilities available and offer open visiting. ❑ Liaise with Palliative care team if needing further advice and support.	

Care Plan Dying, Care in the last days of Life NAIVE 33

STAGE 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	22nd April 2010
Number of versions produced for consultation	4
End of Life Steering Committee – Dr Mark Denton – Consultant Nephrologist Dr Regina Mc Quillan – Consultant Palliative Medicine Dr Tahmina Rahman – Renal Registrar Margie Kennedy – Renal Nurse Counsellor Mary T Murphy – Patient Care Co-ordinator Eileen McBrearty – Patient Care Co-ordinator Caroline Cregan – CNM1 St Peter's Ward Teresa Byrne – Specialist Palliative Care Nurse Louise McSkeane – Ambulatory Care Olive Byrne – Ambulatory Care Eimear O'Sullivan Staff Nurse Ruth O'Malley – Ambulatory Care	End of Life Steering Committee met on the following dates - Dates: 7th April 2010 22nd April 2010 25th May 2010 31st August 2010 Sub Committee meeting – 21st September 10 12th October 2010 2nd November 2010 14th December 2010 25th January 2011 8th February 2011

Where Received	Summary of Feedback	Actions/Response
The first discussion on this guideline was at the End of Life Steering meeting on the 22nd 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 25th 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 31st 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 12th 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 2nd 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.

End of Life Steering Group Meeting 14th December 2010	The first part of the guideline Conservative Kidney Management was piloted in the outpatient clinic and this will be audited in 6 months time.	It was agreed to start on the second part of the guideline – withdrawal of dialysis. It was decided to name it Non Dialysis Management Guideline. A date was arranged for January to discuss it further.
End of Life Steering Group Meeting 25th January 2011	Final Adjustments to the wording of the document – Non.D. M.	Discussed the "Care in the Last Days of Life" Document.
End of Life Steering Group Meeting 8th February 2011	The last part of the Guideline - Care in the Last Days of life was discussed and this is already used around the hospital.	The three parts of the guideline were looked over again and it was decided to send them to the printer room to get final draft on each. Then to bring the updated policy to the policy meeting for review.

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

Guidelines on Development, Maintenance and Review of Hospital Policies, Procedures, Protocols and Guidelines. Beaumont Hospital September 2010.

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

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

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)

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

Pre Dialysis Team Committee, Conservative Management Pathway (2008) Plymouth Hospitals NHS Trust, UK

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, Legal and Professional consideration for End of Life decision making.