

# End of Life Care in Advanced Kidney Disease:

A Framework for Implementation





# Acknowledgements

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## Foreword:

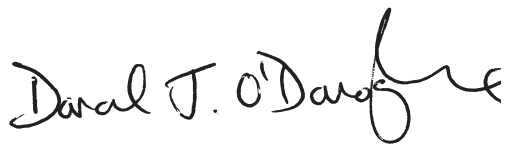
As the National Clinical Directors for End of Life Care and Kidney Care we warmly welcome this document: *End of Life Care in Advanced Kidney Disease: A Framework for Implementation*. It is an important step in ensuring that people with advanced kidney disease receive the very best care in the last years, months and days of their lives. This framework complements and extends work already underway at a national level. It builds on the vision of High Quality for All which requires all strategic health authorities to produce end of life clinical pathways. This informed the End of Life Care Strategy, which aims to ensure that all adults receive high quality care at the end of life, regardless of their age, condition, diagnosis and place of care. The National Service Framework (NSF) for Renal Services was the first national framework to talk about death and dying. *End of Life Care in Advanced Kidney Disease: A Framework for Implementation* now sets out how to achieve high quality end of life care for people with kidney disease in practice.

The Framework is about enabling people to achieve high quality end of life care, rather than 'telling them what to do'. To achieve this, it explores the 'kidney specific' issues of end of life care focusing on patients opting for conservative kidney management and those "deteriorating despite" dialysis. The overarching aim is to help people with advanced kidney disease make informed choices about their needs for supportive and end of life care. Key elements of this are the encouragement of timely recognition that the end of life phase is approaching; **sensitive communication** with patients and carers, **holistic assessment** which includes the needs of carers, **joined-up planning** and effective **multi-professional working across boundaries** linking kidney care, primary care, community care and palliative care services. The Framework aims to support clinical leadership by providing recommendations on measures to optimise end of life care, for advanced kidney disease for all treatment modalities; evidence-based where possible. Where evidence is not yet available, it suggests where further research



is needed, and draws on the collective experience of professionals and people with kidney disease.

Our responsibility is 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” (Renal NSF Part 2). The End of Life Care in Advanced Kidney Disease: A Framework for Implementation now is a further step in helping us to achieve this.



**Donal O'Donoghue**

National Clinical Director for Kidney Care



**Mike Richards**

National Clinical Director for End of Life Care

# 1. Strategic context

1.1. Historically supportive and end of life care has been neglected and undervalued resulting in patchy health and social care provision across the country. However, over recent years a substantial amount of work has been done to raise the profile of end of life care. Significantly, the government's 2005 election manifesto stated that, 'in order to increase choice for patients with cancer we will double the investment going into palliative care services, giving more choice to be treated at home'. This commitment was further developed in *Our Health, Our Care, Our Say* White Paper and followed by an announcement in June 2006 that an End of Life Care Strategy would be developed. At this point it was made clear that the aim of the strategy would be to bring about improved access to high quality care for all adults approaching the end of life irrespective of age, diagnosis, gender, ethnicity, religious belief, disability, sexual orientation or socioeconomic status, or where that care was delivered.

1.2. End of life care was one of the eight clinical pathways developed by each of the Strategic Health Authorities (SHA) in England as part of the Next Stage

Review. The SHA End of Life Clinical Leads were able to draw on the emerging work from the strategy, to further refine this and contribute substantially to the final End of Life Care Strategy which was published in July 2008. The strategy aims to ensure that all adults, regardless of their age, condition, diagnosis or place of care, are able to receive high quality care during this phase of life.

1.3. The importance of end of life care for those with advanced kidney disease was acknowledged in the National Service Framework for Renal Services (NSF) Part 2, published in February 2005 which 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. It's stated aim is that people with established kidney failure should:

*“receive timely evaluation of their prognosis, information about the choices available to them, and for those near the end of life a jointly agreed palliative care plan, built around their individual needs and preferences.”*



With the publication of the National End of Life Care Strategy (2008) and building on the existing Renal NSF and other specific kidney care initiatives the time is now right to set out an End of Life Care Framework for Implementation which specifically meets the needs of those with advanced kidney disease. This is the aim of this document.

There are about 44,000 people on Renal Replacement Therapy in the UK, over half of whom are on dialysis. The median age of those starting dialysis is 65 years. More than half have one or more co-morbidity. Hence, mortality is high. The expected remaining life years of someone receiving dialysis in the age group 65-69 years is only 3.9 years compared with 17.2 years for an age-matched person in the general population. Around 15% of people with advanced kidney failure opt not to undergo dialysis. These tend to be older, more dependent, and have more co-morbidities than those starting dialysis. Their survival is less, though may not differ significantly from that of those receiving dialysis with similar levels of co-morbidity and dependency.

The quality requirement set out in the NSF concerns those who decide:

- i. not to undergo dialysis,
- ii. those who choose to withdraw from dialysis after a period of treatment,

- iii. those who are coming to the end of their lives while already on long-term dialysis,
- iv. those who have a failing transplant and decide not to return to dialysis.

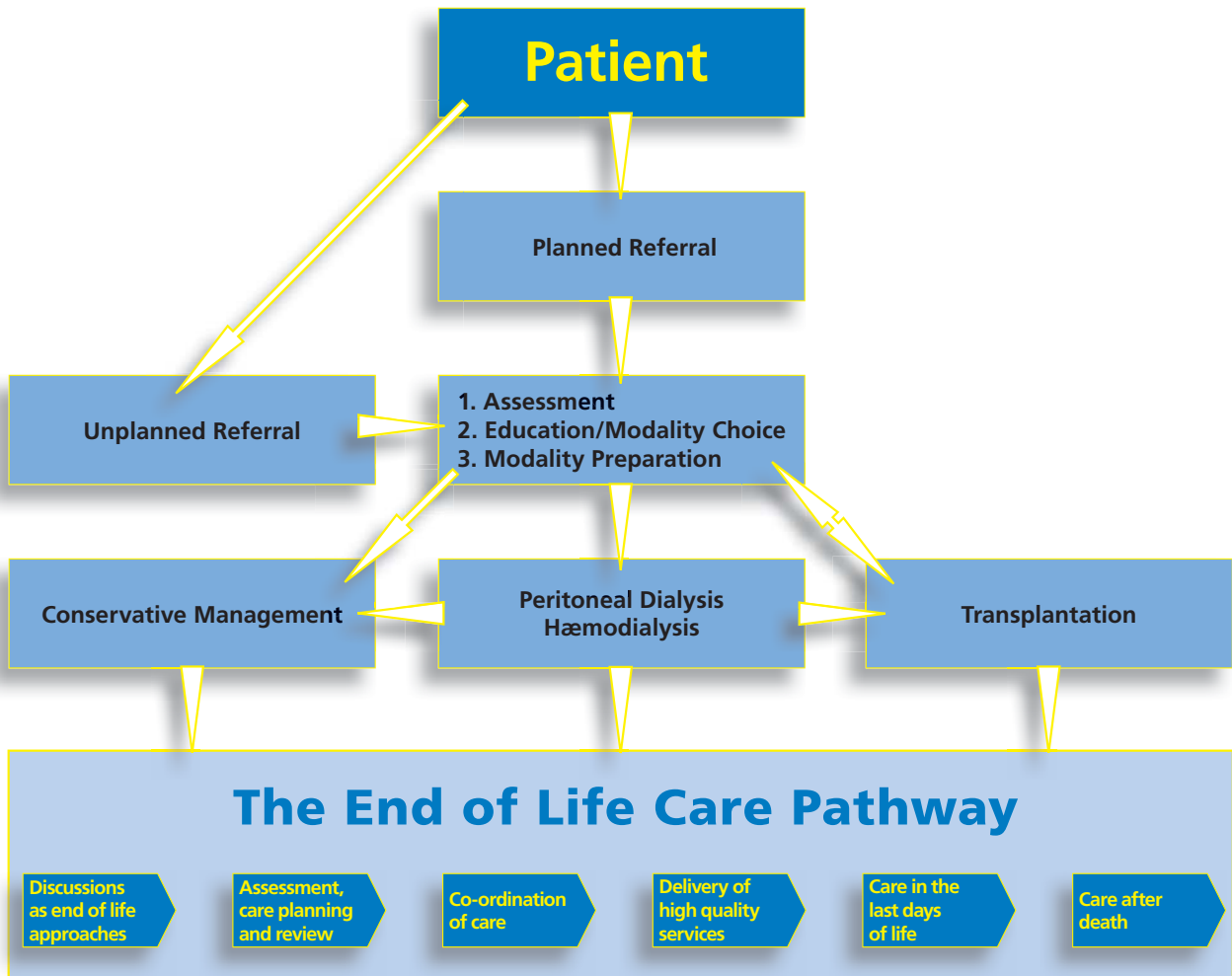
It should be emphasised that a 'no dialysis' option is not a 'no treatment' option: conservative management can relieve many symptoms, and maximise the person's health during the remainder of their life.

- 1.4. In April 2008, to initiate the development of an Implementation Framework for end of life care in advanced kidney disease, a one-day workshop of stakeholders, including patients and carers, was organised by the Department of Health and NHS Kidney Care, the service improvement arm of the Renal Policy Team. The emerging key themes were identified as:
  - i. **Patients and carers** - Develop more effective ways to work in partnership with patients and carers in national and local planning, delivery and evaluation of care
  - ii. **Definitions** - Clarify and standardise the terminologies used in the end of life care setting for patients with advanced kidney disease

- iii. **Commissioning** - Make explicit a national policy on the funding of supportive and end of life care in this setting to inform specialist and local commissioning and contracting arrangements
  - iv. **Coordination** - Ensure effective co-ordination of care throughout the supportive and end of life care stage of the kidney care pathway
  - v. **Concordance** - With national policy – Build on the National End of Life Care Strategy to identify common themes and needs
  - vi. **Education and training** - Develop and implement an education and training strategy to ensure that all Kidney care staff and other health and social care staff who contribute to end of life care possess the confidence and the competence to address issues of supportive and end of life care in the setting of advanced kidney disease.
- 1.5. To take this forward a Kidney Supportive and End of Life Care Steering Group was established by the Department of Health, co-chaired by Dr Stephanie Gomm, Consultant in Palliative Medicine and Dr

Ken Farrington, Consultant Nephrologist. A consensus event was held on 10th September 2008 organised by NHS Kidney Care to agree the elements of implementing the National End of Life Care Strategy in kidney care. The work focused on the identification of the special characteristics which a “Kidney Specific” End of Life Care Pathway would require, over and above those outlined in the National End of Life Care Strategy document. The dominant “Kidney Specific” factor was identified as the potential for renal replacement therapy, ie Dialysis and Transplantation, to provide life-sustaining treatment and, once this has been initiated, the person’s continuing dependence on it. This brings with it specific expectations, and may raise highly challenging and emotive decisions about starting, continuing and ceasing this treatment. The task was to weave together the renal replacement therapy clinical pathway and the key elements of the end of life clinical pathway (as described in the National End of Life Care Strategy) to produce a clinical pathway for the management of advanced kidney disease (figure 1).

**Figure 1: Clinical Pathway for the Management of Advanced Kidney Disease**



## 2. Terminology

### 2.1 General Definitions:

There is no simple way to define the start of the end of life care pathway. The definitions suggested below are based on work by the National Council for Palliative Care and the World Health Organisation.

2.11 *End of Life Care* as defined in the National End of Life Strategy is about the total care of a person with an advanced incurable disease and does not just equate with dying. The phase ends in death and care of the bereaved but the acknowledgement that this phase has been entered may be variable depending on the perspectives of patient, carer and professional. The phase end of life care may last for weeks, months or years. Timely recognition that a person is entering the phase of end of life care is paramount, since it enables the supportive and palliative care needs of the patient and family to be identified and addressed as early as possible during the last phase of life and into bereavement.

A working definition of End of Life Care is:

“*...Care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.*”

**National Council for Palliative Care 2006.**

2.12 Supportive Care is defined as:

“*...Care that helps the patient and their family to cope with their condition and its treatment, from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is accorded equal priority to diagnosis and ‘curative’ treatment.*”

**National Council for Palliative Care 2006.**

2.13 Palliative care embraces many elements of supportive care and has been defined by the World Health Organisation as follows:

*“Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.”*

2.14 *Care of the dying* is the care of the patient and family in the last hours and days of life. It incorporates four key domains of care, physical, psychological, social and spiritual and supports the family at that time and into bereavement.

## **2.2. Terminology: The Kidney Perspective**

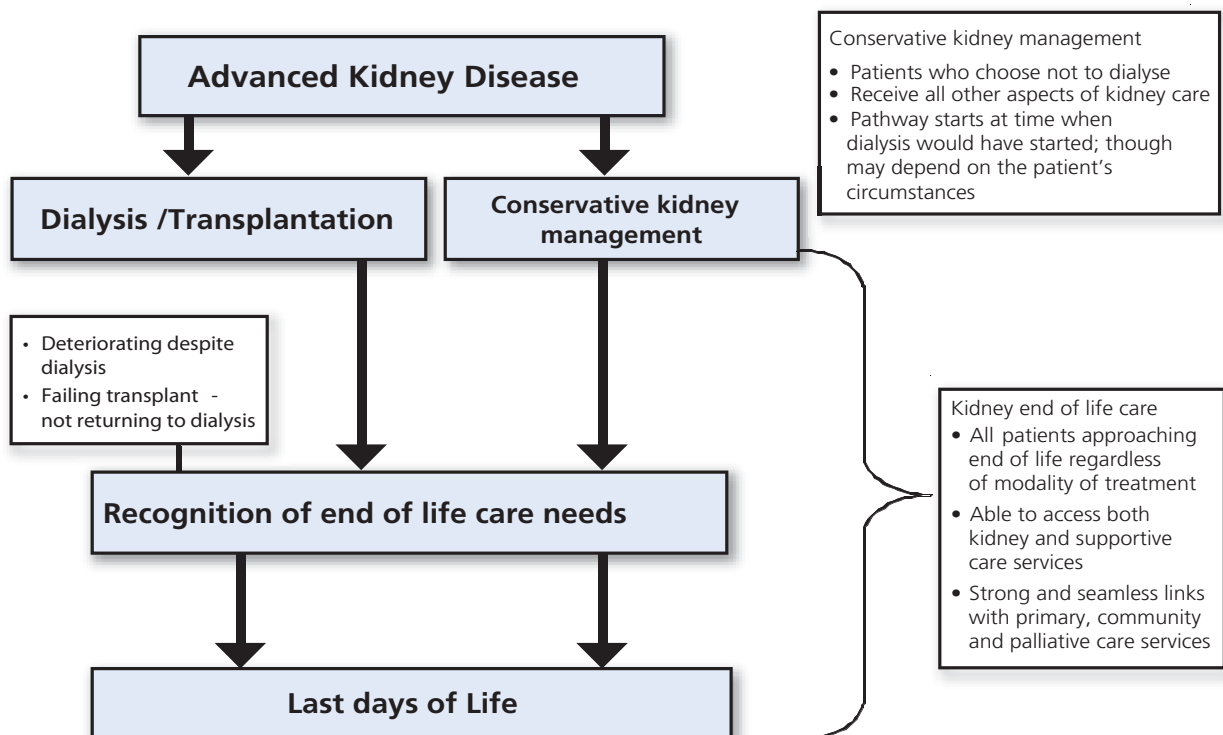
The terms and generic definitions described above may all be applied to people with advanced kidney disease. This term predominantly refers to those with late stage 4 and stage 5 chronic kidney disease (CKD) (see appendix 1), either on renal replacement therapy, being prepared for this treatment or having opted not to undergo it. There are a number of “Kidney Specific” issues with respect to terminology, which need to be

addressed. We have used the term **“end of life care in advanced kidney disease”** to encompass the person’s supportive and palliative care needs over a time period which may vary in lasting for weeks, months or years for those people with advanced kidney disease irrespective of treatment modality. People receiving treatment by any of the modalities may enter a phase when there is concern that continued delivery of conventional care alone will not meet the person’s needs. Such patients require a holistic assessment of their needs in conjunction with their family and carers which may include advance care planning during the phase of end of life care. There are two particular modality settings though, which require more detailed discussion.

The first relates to those people, at or approaching “end-stage”, who choose not to dialyse. These are often elderly and frail, and often have major disease of other organ systems in addition to their kidney problem. Provided referral to the nephrology clinic has been timely, such people can be identified early and supportive treatment planned. Survival is variable, and they may die of uraemia or of associated conditions. There is considerable variation in the current terms used to describe this type of treatment with “supportive”, “conservative” or “maximum conservative” being the most commonly applied.

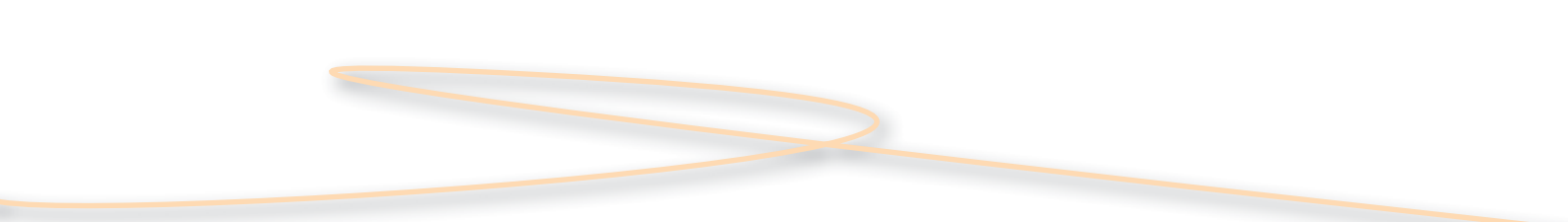
We recommend use of the term “**conservative kidney management**” (Figure 2).

**Figure 2: End of life care in Advanced Kidney Disease**



The second issue affects those already on dialysis and who have often been so for very many years. Many such people also have diseases of other organ systems. As they get older these problems may progress causing the clinical situation to deteriorate to the point at which the person is in need of **end of life care**. Dialysis in this situation can become an additional burden, difficult to endure for the patient and for carers. In such cases “**deteriorating despite dialysis**”,

situations often arise in which the decision to stop dialysis is taken. This is referred to as “**dialysis withdrawal**” and often leads to death usually over days or weeks. We need to be aware though that the requirement for supportive and palliative care during the phase of end of life care often precedes dialysis withdrawal by many months or years, resulting in end of life care needs being under recognised and not addressed in a timely manner. It is also important to



recognise that many people who are “deteriorating despite dialysis” will wish to continue receiving treatment to prevent or treat problems such as fluid overload. Palliative and active approaches are not exclusive – best care is tailored to the individual, and may include elements of management which extend across these broad definitions. In these circumstances it may be appropriate to re-evaluate the goals of treatment, sacrificing aspects only likely to be of benefit in the medium- to long-term in favour of short-term comfort. This may involve prescribing reduced duration and frequency of sessions. This approach is sometimes known as “**palliative dialysis**”.

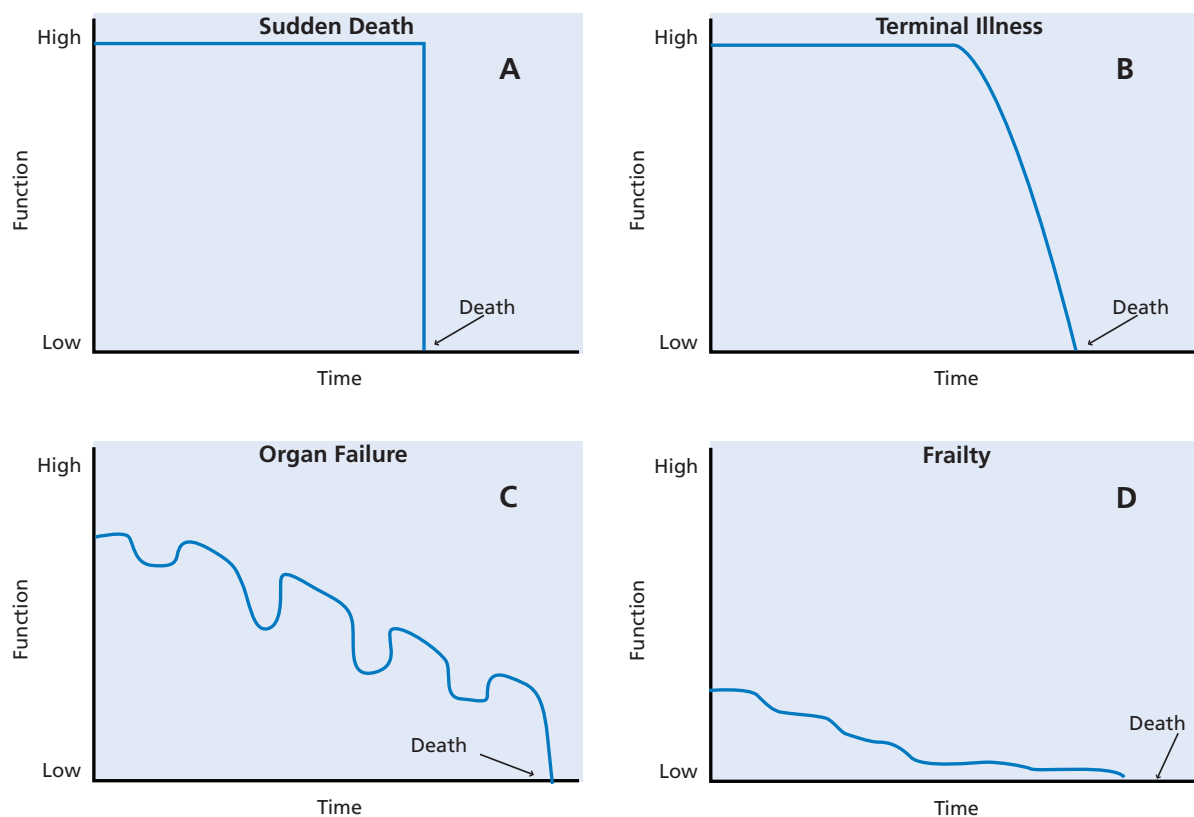
In summary the following terminology is recommended:-

- **End of life care in advanced kidney disease** - end of life care for people with advanced kidney disease irrespective of treatment modality

- **Conservative kidney management** - full supportive treatment for those with advanced kidney failure who, in conjunction with carers and the clinical team, decide against starting dialysis
- **The person “deteriorating despite dialysis”** - the person who is struggling to cope on dialysis, often with increasing frailty, increasing dependency and multiple co-morbidities
- **Dialysis withdrawal** – cessation of dialysis treatment usually in someone “deteriorating despite dialysis” with evident need for end of life care, the decision usually being made by the patient in conjunction with carers and clinical teams
- **Palliative dialysis** – dialysis tailored to align with the supportive needs of a person “deteriorating despite dialysis” and mainly aimed at preventing or treating symptoms such as those related to fluid overload. It may involve reduced duration and frequency of sessions.

### 3. Trajectories of decline at the end of life

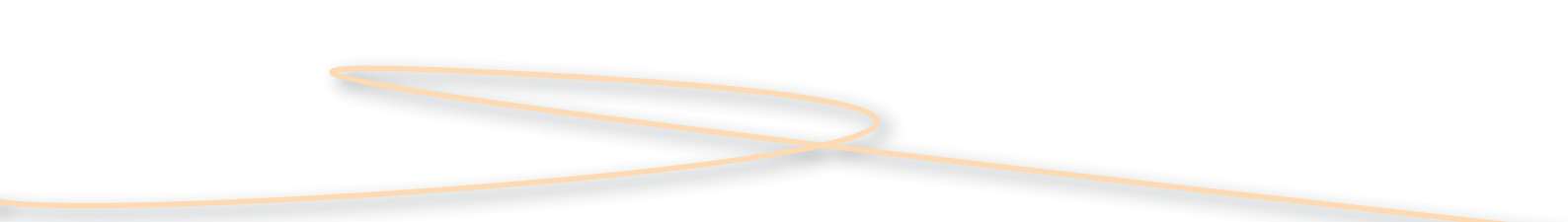
Figure 3: Trajectories at the end of life



Four general patterns of decline at the end of life have been described (Figure 3). Some people experience sudden death usually due to a cardiac dysrhythmia (panel A). Many may remain in reasonably good health until experiencing a steep decline in the last few weeks or months of life related to a terminal malignancy (Panel B). Others may experience a slow deterioration punctuated by abrupt,

partially reversible troughs, such as in severe heart failure (panel C). Others still may undergo a gradual insidious decline such as might occur in the very elderly and generally frail (panel D). In the UK, the prevalence of the trajectories relating to cancer, organ failure, and dementia and/or frailty, are fairly evenly distributed. Sudden death is less common. Understanding the differences





between these trajectories can help in planning services more appropriately to meet patients' and carers' needs. The initial diagnosis of a life-limiting condition, together with critical events and changes in disease progression as indicated in the trajectories, should be recognised in all care settings as triggers for the introduction and subsequent stepping up and stepping down of palliative care input, based on holistic assessment which includes the needs of carers, care coordination, good planning, good communication and regular review.

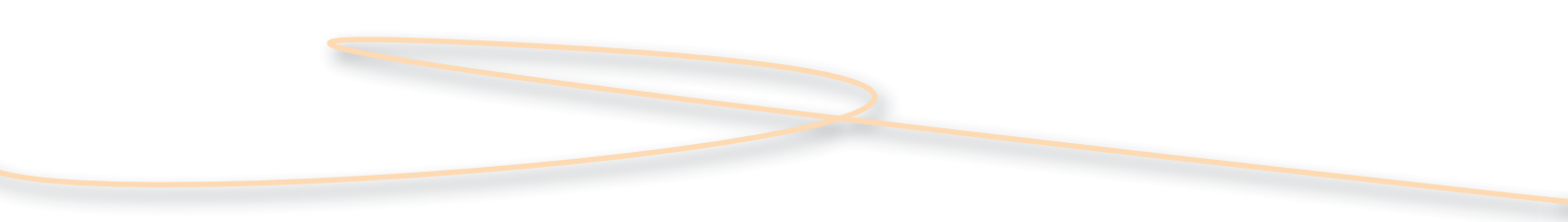
There is little information available on end of life trajectories in those with advanced kidney disease and the position in this setting may well be more complex, due to the contribution of dialysis, and to the high prevalence of extra-renal co-morbidity. Nevertheless the concept of trajectories may well be useful in this setting.

## 4. End of Life Care Tools

Recognised tools are already in place to facilitate the assessment and review of people with supportive and palliative care needs during the phase end of life care. These include the use of palliative care registers which are part of the Quality Outcomes Framework (QOF) in primary care and prognostic indicators in primary care as introduced by use of the Gold Standards Framework, the Preferred Priorities for Care (PPC) advance care plan, and the use of an individual care plan in the last days of life.

- case identification
- holistic assessment
- care planning
- individual case discussions and case management by a multidisciplinary team
- family and carer's assessment and support.

This approach has now been extended to ensure that patients with **any condition**, in **any care setting, and their carers** who have been assessed as having end of life care



needs benefit from the principles and practice exemplified by use of the Gold Standards Framework. A GP practice serving a population of 10,000 would expect to see about two deaths each year of people with advanced kidney disease.

#### **4.1 The Gold Standards Framework**

The Gold Standards Framework provides a valuable mechanism in primary and community care for effective patient-centred planning during the last 12 months of life. Pro-active care planning and timely management of symptoms can enhance quality of life for patients and their family and carers and help to prevent crises and unscheduled hospital admissions. The Framework encourages primary care teams to enhance their knowledge and understanding of palliative care and underlines the need for effective communication, co-ordination and continuity of care. It emphasises the importance of:

#### **4.2 Preferred Priorities for Care**

Preferred Priorities for Care is an example of an Advance Care Plan in which individuals can write down their preferences and priorities for care during the end of life care phase. The document is held by the individuals

themselves so that they can take it with them if they receive care in different places.

The approach aims to help people to prepare for the future by encouraging and assisting them to think and talk about an area of care that is often not discussed. Not all individuals will wish to take part in these discussions but all should have the opportunity to do so. Patients who have a Preferred Priorities for Care or an Advance Care Plan document should have this identified in their primary, secondary and out of hours records.

## 5. National End of Life Care Strategy for England (2008)

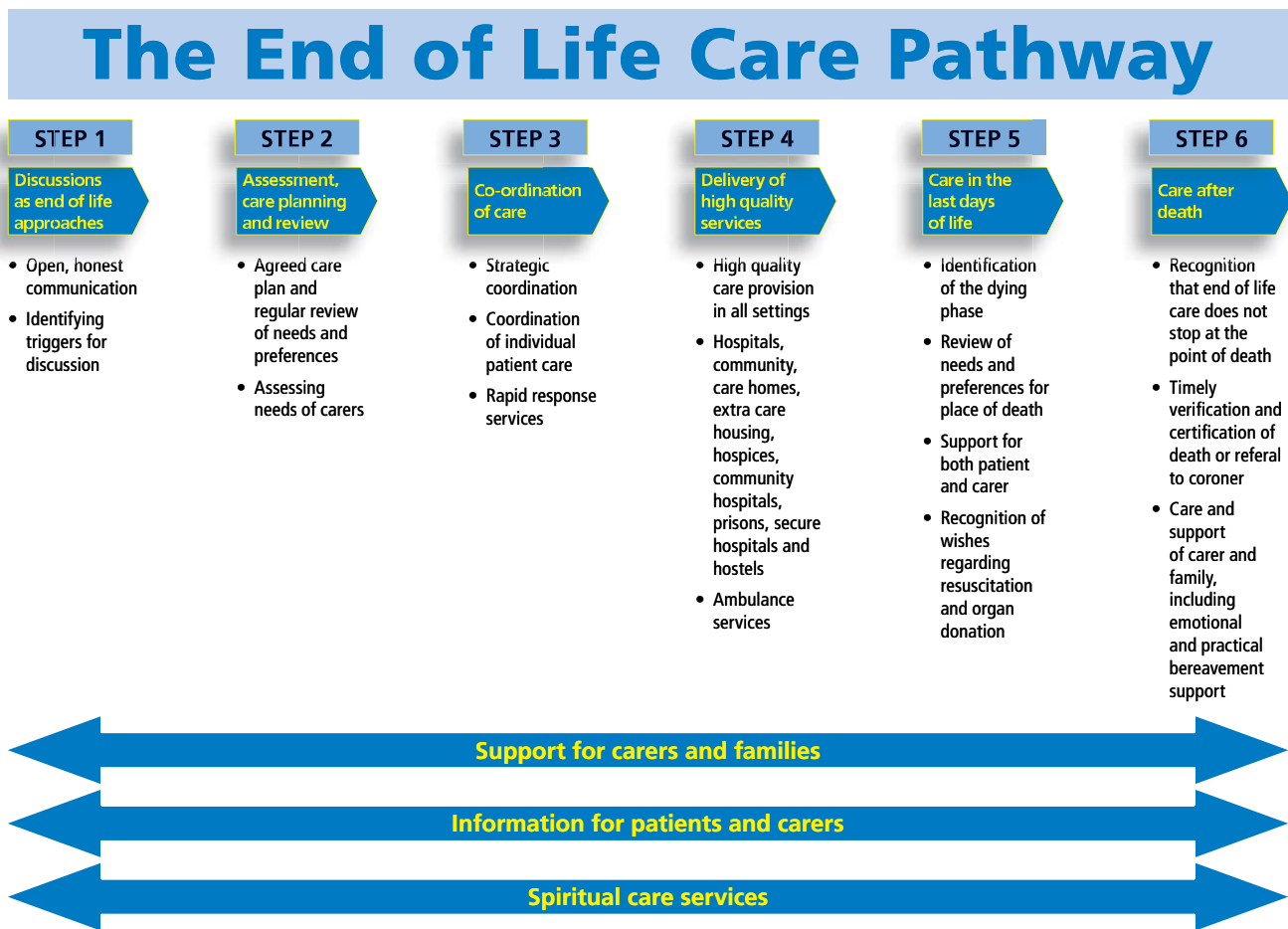
The twelve key areas addressed in the National End of Life Care Strategy are outlined in Table 2. The following sections discuss these, and other relevant issues in relation to end of life care in advanced kidney disease.

**Table 2: Key areas addressed in National End of Life Strategy**

1. Raising the profile
2. Strategic commissioning
3. Identifying people approaching the end of life
4. Care planning
5. Coordination of care
6. Rapid access to care
7. Delivery of high quality services in all locations
8. Last days of life and care after death
9. Involving and supporting carers
10. Education and training and continuing professional development
11. Measurement and research
12. Funding

**Figure 4: The National End of Life Care Clinical Pathway**

The six steps of the end of life care clinical pathway are described in figure 4.



## 6. Identifying people approaching end of life

Identifying when someone with advanced kidney disease is approaching the end of life care phase of their illness is important because it enables a change of emphasis from cure and active prolongation of life to symptom relief, maintenance of comfort and attention to psychological, social and spiritual concerns. An assessment of the need for supportive and palliative care may need to be undertaken at **any point** in the clinical pathway for the management of advanced kidney disease (Figure 1) but specifically:

- At the onset of the choice of “conservative kidney management”
- When the person is “deteriorating despite dialysis” due to severe symptoms from co-morbid conditions or increasing dependency
- At times of crisis e.g. a recent stroke, new diagnosis of malignancy
- For those who develop kidney failure as a consequence of other life-threatening conditions or its treatment e.g. cancer
- Following kidney transplant failure when after appropriate discussion by the person with their family and the kidney team a decision is made not to commence or recommence dialysis
- Around the decision to withdraw from dialysis.

Front-line clinical staff, particularly those involved in looking after people receiving dialysis, need training to enable them to recognize the signs of the approaching phase of end of life care, and in communication skills to allow them to broach issues with patients, carers, and with the other professionals involved. The Gold Standards Framework (GSF) prognostic indicator guidance describes general triggers which may give clues as to whether a palliative approach is now the most appropriate. These include:

- significant weight loss (> 10% over 6 months)
- severe hypoalbuminaemia (serum albumin < 25 g/l).

The GSF also refers to other kidney specific prognostic indicators including patients with stage 4 or 5 CKD whose condition is deteriorating with at least 2 of the indicators below:

- Patients for whom the ‘surprise question’ is applicable i.e. “would you be surprised if this patient were to die in the next 6 to 12 months?” This approach may be effective in identifying those in the dialysis population with end of life care needs

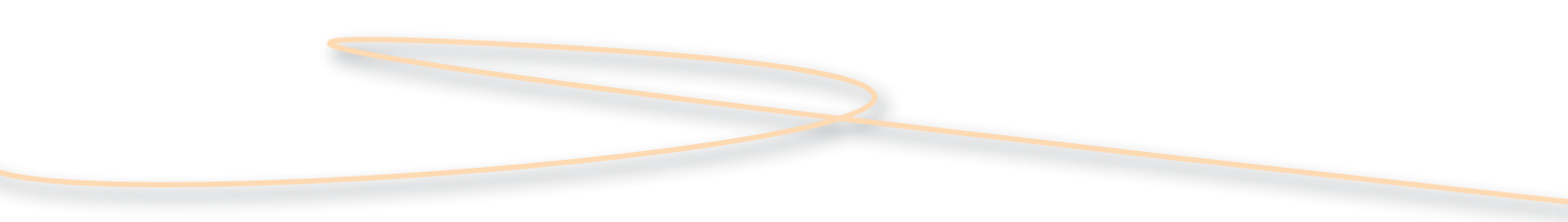
- Patients choosing the no dialysis option, discontinuing dialysis or opting not to start dialysis if their transplant is failing
- Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy.

To facilitate care planning and communication consideration should be given to creation within the local kidney unit of a “Cause for Concern” register to facilitate the identification of those within the unit who are approaching the end of life phase. The aim is to facilitate care planning, communication and use of end of life care tools and link with the palliative care registers held by GP practices, which are part of the QOF.

#### **“Cause for concern” register**

- A ‘Cause for Concern’ support register - identifies patients ‘deteriorating despite dialysis’ and those patients deteriorating during conservative management, as potentially approaching the end of life phase. It promotes a consistent and proactive approach in supporting patients and staff to facilitate communication and care planning
- The register facilitates regular review by the multidisciplinary team of those on the register and of new referrals
- The register links to a care pathway which incorporates the Gold Standard Framework, Preferred Priorities for Care and Advance Care Plans.

Locality-wide end of life care registers are being tested and piloted as recommended in the National End of Life Care Strategy and may eventually link with GP-held palliative care registers (part of the QOF) and ultimately with those created in acute settings.



Starting the conversation with patients and carers about end of life issues requires judgement, sensitivity and well-developed communication skills. Most people wish to discuss these issues. Some do not. The clinician needs to be sensitive to cues and not burden the person with issues they do not want to discuss. It is important to consider this aspect of care as an on-going process not an event. Establishing a shared view of the person's current situation and likely prognosis between the patient, the family and carers and among all members of the multidisciplinary team, is necessary before moving on to develop care plans relating to future wishes and preferences for care. Achieving this mutually shared view can take time.

These issues bring with them a major training need touching all healthcare professionals concerned in the care of people with advanced kidney disease. These needs should be addressed in the formulation of the local end of life care action plans for patients with advanced kidney disease and linked to PCT and Local Authority end of life care strategic action plans.

## 7. Care planning

*“All people approaching the end of life, need to have their needs assessed, their wishes and preferences discussed and an agreed set of actions, reflecting the choices they make about their care, recorded in a care plan. In some cases people may want to make an advance decision to refuse treatment, should they lack capacity to make such a decision in the future. Others may want to set out more general wishes and preferences about how they are cared for and where they would wish to die. These should all be incorporated into the care plan.”* **National End of Life Care Strategy**

As part of the on-going assessment of the needs of patients with advanced kidney disease, for all those identified as approaching the phase of end of life care; individual care plans should be developed and agreed with the patient and their carer(s). Planning care in the end of life phase is vital to ultimately achieving a “good death”, though what is meant by this is highly personal. Planning should be based on shared decision-making and clear communication, acknowledging the values and preferences of individual patients and their families and carers. People vary in their need for information and in their desire for involvement in clinical decision-making. The planning process and the content of the care plan needs to be tailored accordingly.

The plan should:

- Be drawn up with a team-member competent in assessment processes with knowledge of local service providers, referral criteria and support services and with access
- to multidisciplinary input which includes social workers, counsellors and palliative care specialists
- Include details of a nominated kidney key-worker
- Record the person’s preferences and the choices they wish to make including, when appropriate, their views on resuscitation
- Be patient-held, provided the patient wishes this
- Assess and record the individual needs of carers
- Be reviewed regularly
- Provide a record of on-going assessments, outcome of multidisciplinary team meetings, and communication with primary care and palliative care services.
- Be available to all who have a legitimate reason for access, including out of hours and emergency/urgent care services. Holding a care plan electronically will facilitate this.



## 8. Coordination of care

Coordination of service delivery across boundaries is vital to ensure high-quality end of life care. Measures to facilitate this include:

- A register within kidney units of patients with end of life care needs (e.g. Cause for Concern Register). This should link with GP palliative care registers and eventually with locality-wide registers, to facilitate identification, regular clinical review and holistic assessment in kidney units, palliative and primary care. Care may be further improved by the introduction of joint multidisciplinary meetings
- The use of key-worker roles within renal, palliative and community services with each taking mutually agreed lead responsibility for coordination of the phase of end of life care of individual patients across care sector boundaries
- Use of Advance Care Plans e.g. Preferred Priorities for Care, to document preferred treatment decisions and choice of place of care. This document is held by the patient, and is recognised by and linked to end of life care plans
- IT links between different sectors of care (kidney centre, district general hospital, and primary care/community facility). This is alluded to in the national End of Life Care Strategy. End of life care service providers (including hospices) may soon have access to the N3 NHS link. This may facilitate the development of a shared Summary Care Record
- Identification of Clinical Leads (medical and nursing), for end of life care at local kidney unit level, with responsibilities which include care coordination
- Identification of a member of the local specialist palliative care team as a lead for end of life care in advanced kidney disease, with responsibilities which include care coordination
- Generic end of life care leads in commissioning, in primary and community care, whose roles will include, responsibilities for end of life care in advanced kidney disease, including care coordination
- The formation of a local group to oversee the development and implementation of a local action plan for end of life care in advanced kidney disease.



## 9. Rapid access to care

Rapid access to end of life care is important to prevent inappropriate default “cure-centred” care being administered in the event of sudden, irreversible deterioration in a person with advanced kidney disease, who is not known to have an existing advance care plan. In these instances the importance of careful, timely assessment cannot be overemphasized. Eventualities such as these highlight the importance of adequate anticipatory (advance) care planning.

In such circumstances, if the patient and/or family, express a wish to be cared for at home, then use may be made of the rapid discharge pathway for care of the dying. There will be a need for timely access to medication and equipment including out-of-hours provision. The role of the clinical lead and key-worker is important in ensuring effective operational links have been established with all services involved in end of life care including primary care, community, palliative care and the ambulance services.

# 10. Delivery of high quality services in all locations

*“High Quality Care for All”* (2008) identifies quality as the organising principle of the NHS. End of life care of people with advanced kidney disease needs to be delivered in a range of locations at different stages of the care pathway and in response to changing circumstances. A range of agencies need to work together if patient and carer experience is to be optimised. The needs of individuals are often intensified during this phase of advanced kidney disease, and often added to by the presence of other co-morbid conditions. Health and social care professionals addressing these needs must work as a team so that support is co-ordinated and consistent. This can often entail sharing responsibilities and transferring skills but maintaining clarity of leadership for the patient and family is essential. In addition to the role of the key-worker, senior clinical leadership (medical and nursing) is needed to ensure joint working across organisational, cultural and professional boundaries to deliver high quality, seamless care whatever the setting. In most instances this will be the patient’s home or another community setting. Services should be delivered as locally as possible.

At an organisational level, hospital-based kidney care team members with responsibilities for end of life care, need to work with patients and carers representatives,

SHA end of life care pathway groups, primary care trusts, commissioners, health care and social care providers, and third sector organisations, to put in place clear pathways, robust governance arrangements and a quality improvement culture.

## Kidney Centres

Actions may will facilitate the delivery of high quality end of life care services for patients with advanced kidney disease include:

- Appointment of clinical leads (medical and nursing) for end of life care
- Developing the role of kidney key-worker
- Developing links with all sub-specialist areas e.g. dialysis units, transplant units, and nephrology clinics. This may be through a system of link workers who normally work in these areas but have regular training in end of life care and liaise with clinical leads and key-workers
- Using the expertise of local hospital specialist palliative care teams
- Establishing a local end of life care group to oversee development and implementation of a local end of life care action plan for patients with advanced kidney disease

- Developing the local action plan incorporating
  - Staff awareness and training
  - Links with community, palliative care services and out-of-hours services
  - Joint working - development of regular kidney care and palliative care multidisciplinary team meetings to discuss those approaching the need for end of life care
  - Enablement of mechanisms to 'fast track' assessments for NHS Continuing Health Care
  - A framework to ensure the delivery of appropriate care for people in the dying phase of their illness and after death
- Developing improved facilities for patients and their families. Areas highlighted by the King's Fund report include: a room where family members can talk privately; informal 'gathering' spaces where family and friends can meet to confer and talk with staff; and guest rooms where close family and friends can stay overnight.

### **The community (mainly in a person's home)**

The establishment of clinical lead roles for end of life care in advanced kidney disease, a Palliative Care lead role for end of life care in this setting, the Kidney key-worker role and the local kidney end of life care steering group will facilitate:

- Shared care planning for all those with end of life care needs in patients with advanced kidney disease
- Establishment of links with Primary Care systems to identify, assess and plan for the care of people approaching the end of life e.g. GSF and PPC
- Prevention of unnecessary hospital admissions
- Out-of-hours providers with access to up-to-date information on patient's preferences as expressed in their care plan
- Effective planning for the need for prompt access to additional medicines, e.g. the use of anticipatory prescribing and palliative care 'Just in Case' boxes in the patient's home.

## Hospices

The establishment of clinical lead and key worker roles for end of life care in advanced kidney disease, and of a local kidney end of life care steering group will also facilitate:

- Full integration of hospices in the strategic planning for end of life care services for patients with advanced kidney disease
- The expert resource of hospices as specialists being available to those with advanced kidney disease enabling:
  - admissions for those with complex pain & symptom control and care for the dying
  - provision of day therapy and community outreach teams
- Education and training in communication and palliative care for renal professionals by hospice and specialist palliative care professionals
- Staff exchanges between kidney units and hospices to improve knowledge and skills of their respective services.

## Ambulance services

Actions which will facilitate the continuity and coordination of the delivery of high quality kidney end of life care services include:

- Development of clinical lead for kidney end of life care and kidney key-workers roles with responsibilities to include development of appropriate links with ambulance services, and to facilitate coordinated care
- Education and training of staff in the ambulance service on end of life care issues
- The availability of rapid, timely, transport of patients to their preferred place of care at end of life
- Development and improvement of information systems, to facilitate the sharing of patient information to facilitate:
  - staff awareness of the needs and wishes of patients
  - out-of-hours communication e.g. GSF handover forms
  - appropriate use of rapid discharge pathway for care of the dying.

# 11. Last days of life and care after death

High quality care at the end of life is achieved through shared decision-making and clear communication which acknowledges the values and preferences of individual patients and their families. The characteristics of care during the last days of life, which have consistently been found to be important from the patient's perspective are, receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden on loved ones, and strengthening relationships with loved ones. The means to achieve high quality care in the last days of life should be addressed in the local action plan which should incorporate:

- An agreed care plan, which should be in place for all patients with advanced kidney disease approaching last few days of life. The plan should address patient preferences for care in the last days recognising the specific physical, psychological, spiritual needs and addressing the cultural needs of the dying individual and their family.
- Recording of resuscitation status. If not previously addressed, there is no need to initiate discussion at this stage, as for any other futile treatment. Patients consistently report that they do not wish to be

subjected to interventions with minimal, if any, potential for benefit. In this context communications indicating the intention to allow a "natural death" may be more appropriate than "Do Not Resuscitate" orders.

- The need for effective symptom control. Pain, agitation, myoclonus, dyspnoea, nausea and respiratory tract secretions, are major symptoms in patients with advanced kidney failure in the last days. It is good practice to prescribe in anticipation of common symptoms deploying the easiest and least invasive route of administration.
- An integrated approach to care after death. This should include the provision of culturally appropriate bereavement support.

## 12. Involving and supporting carers

The family, including children, close friends and informal carers of people approaching end of life, have a vital role in the provision of care, especially for patients with advanced kidney disease who have often required an intense level of support for many years or even decades. Their enormous contribution often goes unrecognised and needs to be formally acknowledged. Over what is often many years of caring they will frequently have developed very close relationships with members of the renal team. In spite of this, it will often be the first time they have cared for someone who is dying.

Carers have the right to have their own needs assessed and reviewed and to have a carer's care plan including plans for their support after the death of the person. This is amplified in the DoH Carers Strategy (2008). They also need access to culturally appropriate bereavement services.

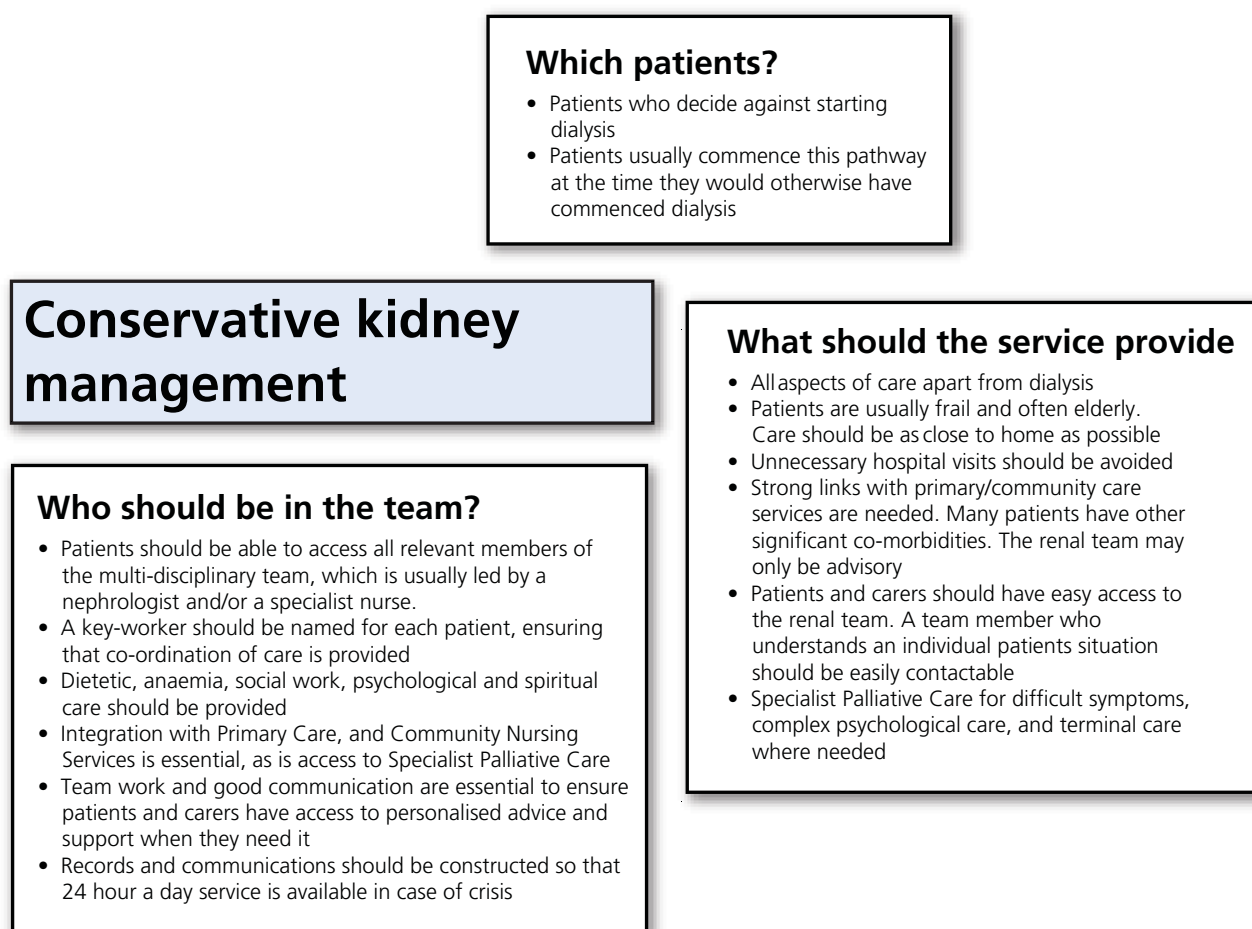
They need:

- Information about the likely progress of the person's condition. Time scales may be difficult to predict, but it is important for the carer to be able to gauge how long they will be able to sustain a certain level of commitment, which is often in the context of work and other family commitments
- Information about services which are available
- Practical and emotional support both during the person's life and after bereavement.

# 13. Models of care

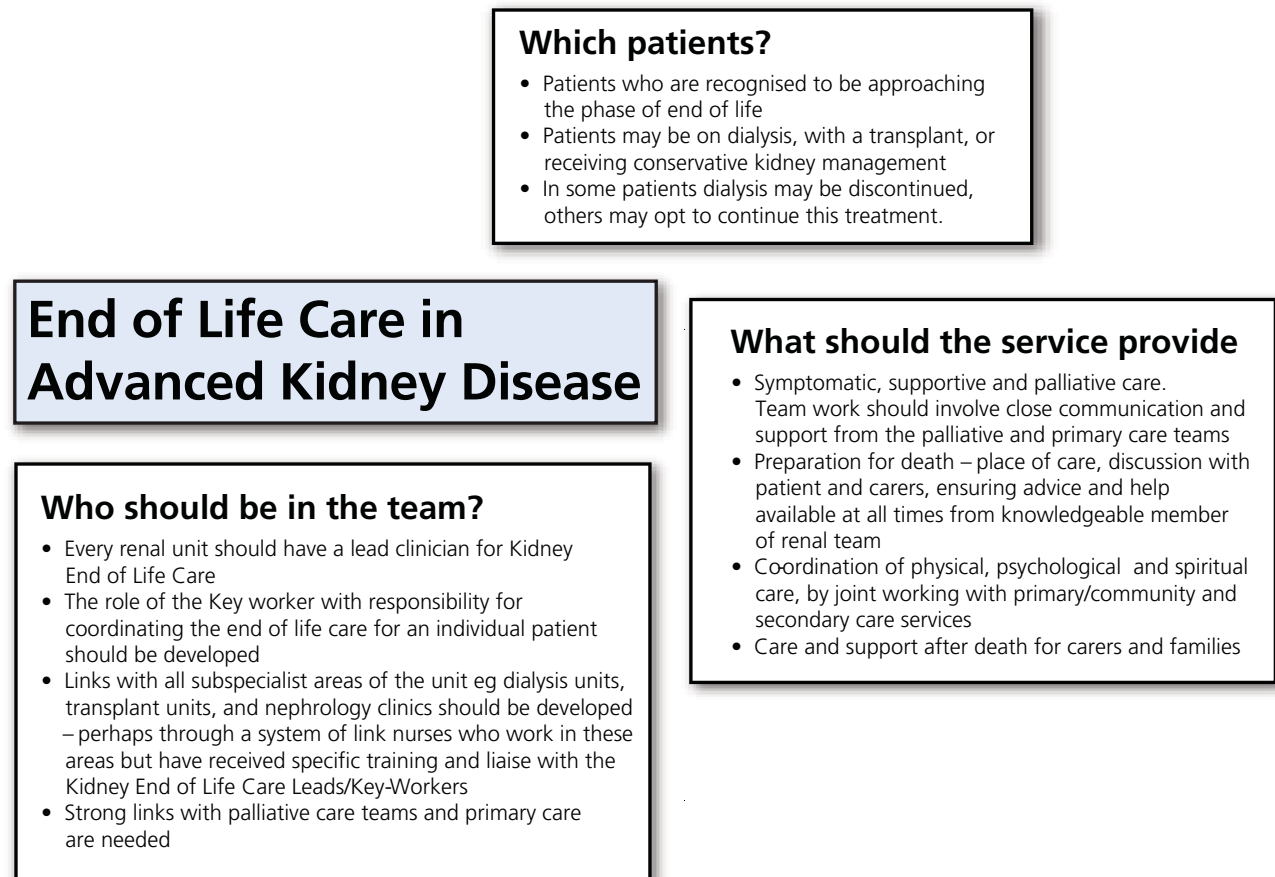
Building on what has already been discussed above, suggested models of care for conservative kidney management in particular and end of life care in advanced kidney failure in general, are presented schematically in figures 5 and 6.

**Figure 5: Schematic Model of Conservative Kidney Management**





**Figure 6. Schematic Model of End of Life Care in Advanced Kidney Disease**



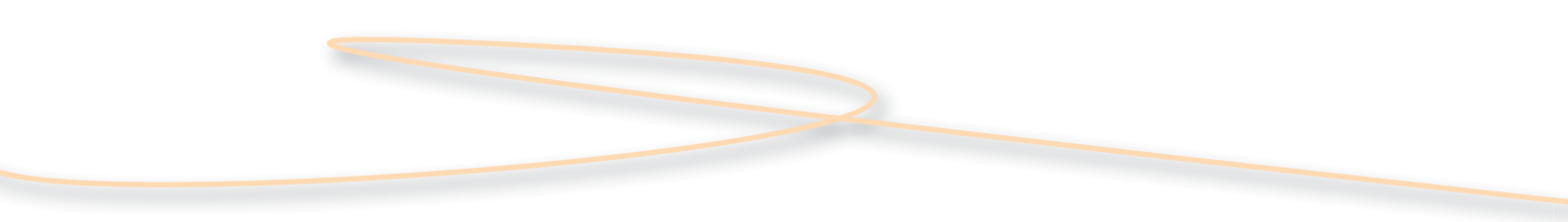
# 14. Education and training and continuing professional development

A workforce, education and training strategy is central to achieving high standards of end of life care in advanced kidney disease. The Department of Health has commissioned Skills for Care and Skills for Health working in collaboration with the Academy of the Royal Medical Colleges to lead a joint project to identify a set of common core principles and competencies for end of life care. This work will be published in June 2009. The following are seen as important core elements relating to kidney end of life care:

- The core common requirements for workforce development are:
  - Training in communication skills – basic, intermediate and advanced level as appropriate
  - Assessment of the person's needs and preferences
  - Advance care planning
  - Symptom management
- The National End of Life Strategy document classified the Clinical Workforce into 3 tiers according to their working exposure to End of Life issues (see Appendix 2)
  - *Group A* – Staff working in Palliative Care Services who essentially spend the whole of their working lives dealing with end of life care
  - *Group B* – Staff in other specialties who frequently deal with end of life care as part of their role
  - *Group C* – Staff working as specialists or generalists within other services who infrequently deal with end of life care.

In the kidney setting many of clinical staff would fall into Group B though some such as the clinical leads and key workers would belong to Group A.

- Training in End of Life Care issues should form part of the curriculum for core medical training and specialist training in Nephrology and for specialist renal nursing training
- Each SHA, as part of the NHS Next Stage Review End of Life Care workstream, is focussing on end of life care workforce development. It is important that staff caring for people with advanced kidney disease, are included in this. As part of this overall framework each kidney unit should have a multidisciplinary group overseeing education and training about end of life care issues. The lead clinicians, medical and nursing for end of life care should play a key role
- Regional training days should be developed for renal, palliative care and primary care multidisciplinary teams

- 
- There is a need to enhance general communication skills training for all staff involved in end of life care. Advanced communication skills training should be rolled out to all senior clinical and middle grade clinical staff - similar to the national roll out for advanced communication skills training for cancer
  - Training in kidney end of life care should form part of appraisal discussions for all kidney unit clinical staff
  - Learning resources should be developed, building on e learning for healthcare end of life care modules, with examples of good practice from different kidney units, electronic resources of patient voices and stories from families. Booklets on aspects of end of life care to be accessible to patients at clinics, on wards, and in dialysis units
  - There are also training requirements for palliative care clinicians relating to the understanding of advanced CKD and its management – multi-professional study days will provide mutual benefit for renal and for palliative care clinicians
  - An education programme in end of life care in advanced kidney disease will be developed, piloted in a small number of units, and evaluated, prior to being offered more widely. This will be linked to the current development of the national end of life care principles and competences for the health and social care workforce in end of life care.

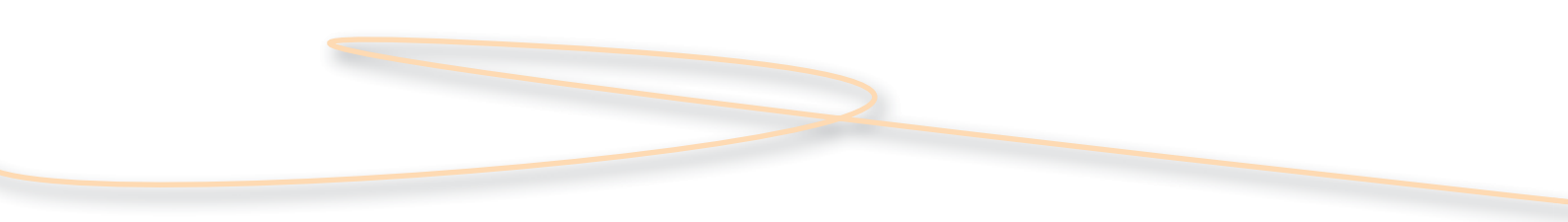
# 15. Measurement and research

Recommended measures are:

- Kidney units should participate in National audits e.g. the Gold Standards Framework After Death Analysis, which is currently being piloted in primary care
- Future audits of end of life care in advanced kidney disease to incorporate elements included in the draft Quality Markers for End of Life Care published by the Department of Health in November 2008 and currently awaiting outcome of consultation. A series of quality markers are proposed, based on the structures and processes of care most likely to yield good outcomes for people approaching the end of life, their families and carers. The markers are associated with suggested measures for assessment of compliance, which commissioners and providers should use to audit and evaluate services. Such a measure would be the availability of locality-wide registers. These markers could be adapted for local and kidney care network use, and are due for publication in Spring 2009
- Utilisation of national public awareness assessment tool to assess trends and attitudes within specific communities.

A tool to assess change in awareness/attitudes is under development. Local end of life care plans to include actions on awareness/attitudes. (The National Council for Palliative Care are establishing a Coalition to lead this work supported by the Department of Health)

- Use of VOICES questionnaires to bereaved relatives & carers with consideration of modification of VOICES to address the kidney-specific issues such as the decision - making processes surrounding the continuance and withdrawal of dialysis
- The National Renal Dataset specifies the information to be collected by renal services in England, in order to assess progress against the National Service Framework for Renal Services. Further development of the dataset should include details of patients receiving end of life care with advanced kidney disease including those undergoing conservative kidney management, and those withdrawing from dialysis
- Development of the Renal Registry could include data on conservative kidney management, patients withdrawing from dialysis, and other aspects of end of life care in advanced kidney disease

- 
- Support for the UK Kidney Research Consortium in fostering the development of portfolio studies in end of life care
  - Support for NIHR Comprehensive Clinical Research Network's Local and National Renal Speciality Groups in enhancing opportunities for recruitment into such studies
  - Establishment of collaborative cross boundary audit and R&D in end of life care between kidney units, primary care and specialist palliative care with collection of patient and carer reported outcome measures including quality of life, control of symptoms and quality of death.



## 16. Strategic commissioning

Dialysis and Transplantation are currently subject to Specialised Commissioning arrangements. Payment by Results for dialysis services is planned to be introduced in 2010/11 with a Best Practice Tariff. The current plans for the introduction of tariffs for Palliative Care and End of Life Care services, in the general context only includes hospital specialist palliative care services for April 1st 2009 and are not developed in the clinical services for advanced kidney failure. Hence, local commissioning agreements along the clinical pathway for Conservative Kidney Management programmes and further developments in end of life care services for patients with advanced kidney disease is required. The commissioning aim should be to provide a service for patients with advanced CKD (Stages 4 or 5) which meets their end of life care needs irrespective of sector(s) of care delivery, as defined in the end of life care strategy.

# 17. Funding: Operating Framework

Delivery of a national tariff is a complicated process. It must be built over a number of years and all the building blocks must be in place. The Department of Health will be considering how work on a national tariff for palliative/end of life care may be taken forward after reviewing the latest cost data. This work will not be limited to kidney conditions; it will consider palliative/end of life care more broadly.

Currencies, that is, Healthcare Resource Groups, for specialist palliative care services have already been developed and there are two Payment by Results (PbR) End of Life Care "development sites" - organisations which are developing new funding models for services at the local level. These will be evaluated in 2009 to extract useful learning to inform central PbR development.

The Department has also begun work on developing currencies for community services, although this is even more complex. It is aiming to conclude this work by 2010.

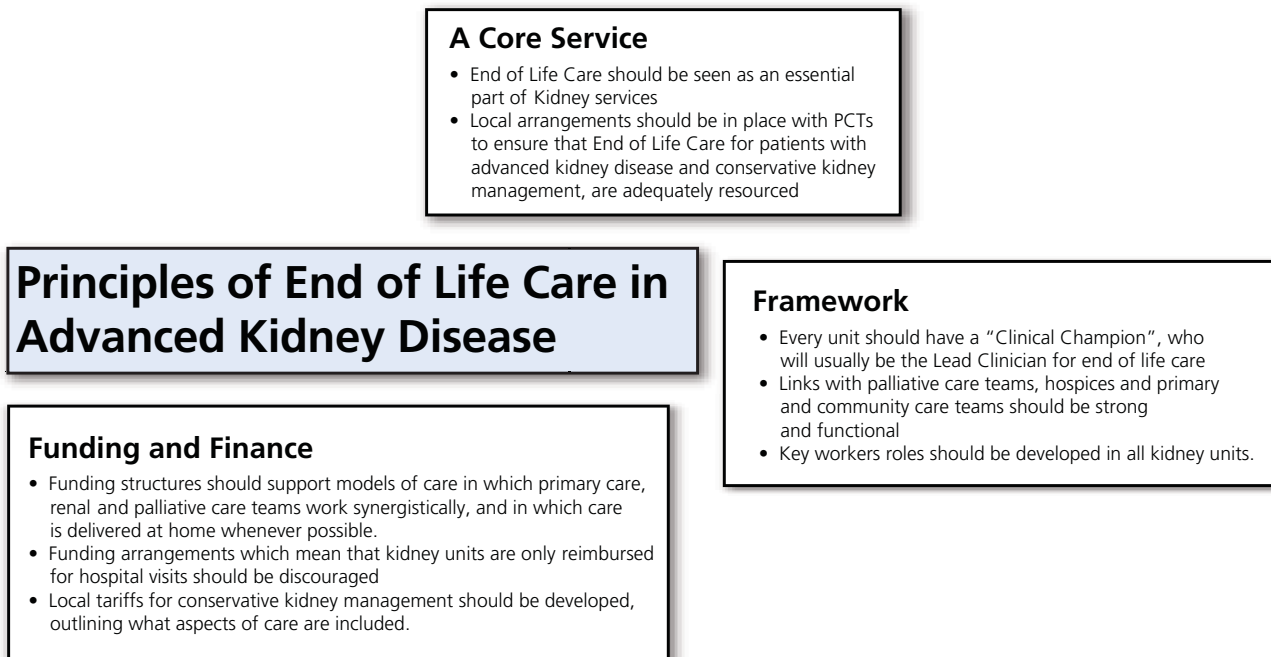
Local agreements with commissioners will therefore be required (Figure 7).

- Every PCT should have clarity on their local commissioning arrangements to ensure that end of life care in advanced kidney disease and conservative kidney management is adequately resourced.

This should be an integral part of world class commissioning.

- The Lead Commissioner for Specialised Renal Services may wish to review and revise the commissioning arrangements relating to conservative kidney management and end of life care in advanced kidney disease in general in partnership with their constituent PCTs
- Funding structures should support models of care in which primary care, palliative and renal teams work synergistically, and for care to be at home whenever possible. Arrangements which mean that kidney units are reimbursed only for hospital visits should be discouraged since it is important that care takes place as near to the patient's home as possible
- Local tariffs for conservative kidney management should be developed, outlining what aspects of care are to be included
- NHS Kidney Care to support development sites for system-wide implementation of this framework (See section 14).

**Figure 7: Principles of End of Life Care in Advanced Kidney Disease: A Model for Funding**





## 18. Raising the profile

Improving end of life care will involve Primary Care Trusts (PCTs) and Local Authorities (LAs) working in partnership to consider how best to engage with their local communities to raise the profile of end of life care. This may involve engagement with schools, faith groups, funeral directors, care homes, hospices, independent and voluntary sector providers and statutory employers amongst others. Kidney care, primary care, social care and palliative care services and kidney patient associations are integral to ensure that end of life care in advanced kidney disease is included and prominent in this change in public awareness.

The kidney community is tight-knit both nationally and locally. This provides major opportunities for raising the profile of kidney end of life care.

18.1 At a national level opportunities exist in a number of areas:

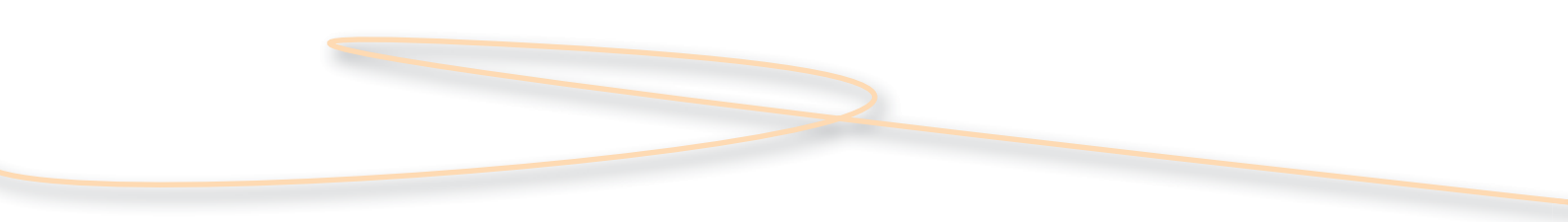
- **Patient information:** Kidney patients organisations such as the National Kidney Federation (NKF) and other organisations involved in the commissioning, production and dissemination of high-quality patient-centred information, to ensure appropriate prominence of material related to kidney end of life care
- **Inclusion of end of life care for patients with advanced kidney disease as part of the death, dying and bereavement coalition during implementation of the national end of life care strategy**
- **Production of clinical guidelines:** Specialist societies such as the Renal Association concerned in formulation of guidelines, to ensure appropriate emphasis on kidney end of life care
- **Workforce planning:** Specialist societies such as the British Renal Society concerned in planning of the renal workforce to take account of the needs for end of life care in advanced kidney disease. There is also a need for the specialist palliative care workforce to plan for an expansion in the referral of this group of patients, and for an education role in supporting end of life care for patients with advanced kidney disease
- **Education and training:** Royal Colleges to ensure end of life care is appropriately represented in curricula for renal specialists in training, and in the requirements for ongoing continuing professional development. Specialist societies such as the Renal Association, and the British Renal Society, concerned in the provision of Education and Training for health care professionals, to ensure appropriate emphasis on end of life care

- **Research:** Organisations concerned in the strategic development and/or funding of research, such as Kidney Research UK, the British Renal Society and the Association of Palliative Medicine to ensure appropriate prominence for proposals related to end of life care in advanced kidney disease. There is a need to establish large multi-centre studies, which would be facilitated by the development of national and regional collaborations between service and academic departments of nephrology, primary care and palliative care
- **Measurement** UK Renal Registry data to explore the benefit of a dataset on conservative management, dialysis withdrawal, to ensure appropriate emphasis on end of life care
- **Steering Group:** The formation by NHS Kidney Care of a National Steering Group to oversee and advise on the implementation of the End of Life Care in Advanced Kidney Disease Framework, to facilitate relevant initiatives including those listed above, and to influence policy decisions relating to service commissioning, education and training programmes and research and development opportunities concerning kidney end of life care

The Steering Group will need to link with SHA leads for other long-term conditions as an integral part of other end of life clinical pathways such as advanced heart failure.

#### 18.2 At the **local level** opportunities exist for:

- Local Kidney Patient Associations to be involved in the dissemination of information relating to end of life care within the local renal community and beyond.
- The appointment of clinical leads, medical and nursing, for end of life care, at local kidney unit level, who link with end of life care leads in commissioning, in primary care, community services, and in palliative care services
- The establishment of the role of the end of life care key-worker for patients with advanced kidney disease to co-ordinate patients' care, promote continuity, and ensure good access to information and advice. The key worker role may change during the persons illness trajectory as needs change, since it is essential that the person is guided by the health professional most appropriate for current needs e.g. CKD nurse, dialysis nurse, district nurse, community matron or palliative care nurse specialist

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- The nomination of a member of the local palliative care team as palliative care lead for end of life care in advanced kidney disease
  - The involvement of clinicians, patients and carers in training in end of life care in advanced kidney disease, both as trainers and trainees
  - The formation of Local Steering Groups to oversee development and implementation of a local end of life care action plan for patients with advanced kidney disease. This development should be led by the kidney centre working with primary care, palliative care and the voluntary sector services. The groups could also influence the commissioning processes through
- dialogue with Primary Care Trusts, Strategic Health Authorities, Specialist Commissioning Groups and Kidney Care Networks. The membership of the groups should include clinical leads for end of life care, patients, carers, and end of life care leads in commissioning, in primary and community care, and in palliative care services
- There are opportunities to link initiatives in end of life care for patients with advanced kidney disease, with those of other associated clinical conditions e.g. advanced heart failure. This will enable aligned support.

# 19. Making it happen

Leadership is needed at all levels to provide direction, motivation, support and to demonstrate a commitment to staff working in this area. Steps which will facilitate this include:

- Implementation of this End of Life Care in Advanced Kidney Disease Framework
- Implementation of the national initiatives to raise the profile of End of Life Care in Advanced Kidney Disease (see section 18.1)
- Renal workforce and palliative care workforce planning initiatives to take account of the needs of end of life care in advanced kidney disease
- Strategic commissioning of cross-organisational models of service for end of life care in advanced kidney disease, including developments to enhance coordination of care and education and training of the workforce
- Partnership working between SHA End of Life Care Pathway leads, PCT End of Life Care Leads and Kidney End of Life Care Leads
- The setting up of a National Kidney End of Life Care Steering Group to oversee the development and implementation of the End of Life Care in Advanced Kidney Disease Framework and to facilitate other initiatives including those relating to service commissioning, education and training programmes and research and development opportunities concerning end of life care in this setting
- The establishment of local agreements with commissioners to ensure end of life care in advanced kidney disease and conservative kidney management is adequately resourced (see section 17)
- The nomination of Lead Clinicians (medical and nursing) for end of life care in each kidney unit
- The nomination of a member of the local palliative care team in each locality as palliative care lead for end of life care for patients with advanced kidney disease
- The development of the role of Key Workers in end of life care in each kidney unit linking to key workers in community settings
- Recognition of key role of patients and carers representatives on local and national end of life care steering groups for patients with advanced kidney disease
- The formation of local groups to oversee development and implementation of a local action plans for end of life care in advanced kidney disease, and to encourage and facilitate other local initiatives.

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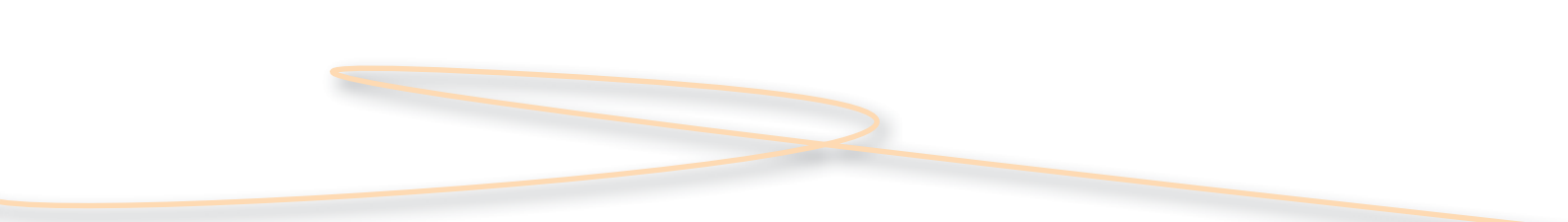
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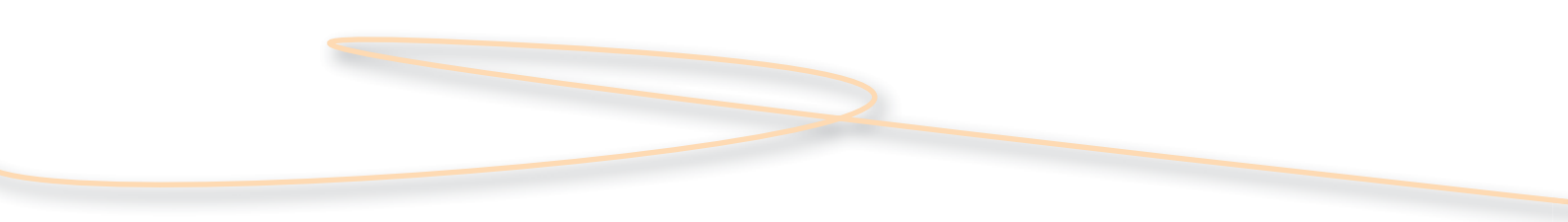
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National VOICES  
<http://www.nationalvoices.org.uk/>

# Appendix 1

## Stages of Kidney Disease

Stage <sup>a</sup>	GFR (ml/min/1.73 m <sup>2</sup> )	Description
1	≥ 90	Normal or increased GFR, with other evidence of kidney damage
2	60–89	Slight decrease in GFR, with other evidence of kidney damage
3A	45–59	Moderate decrease in GFR, with or without other evidence of kidney damage
3B	30–44	
4	15–29	Severe decrease in GFR, with or without other evidence of kidney damage
5	< 15	Established kidney failure

<sup>a</sup> Use the suffix (p) to denote the presence of proteinuria when staging CKD (recommendation 1.2.1).



# Appendix 2

## Workforce groups levels of skills and knowledge (adapted from End of Life Care Strategy)

Group definition	Minimum levels of skills and knowledge
<p><b>Group A</b> – Staff working in specialist palliative care and palliative care and hospices who essentially spend the whole of their working lives dealing with end of life care. This includes:</p> <ul style="list-style-type: none"> <li>Physicians in palliative medicine, palliative care nurse specialists and allied health professionals, hospice pharmacists, senior palliative care pharmacists, chaplains and all health and social care staff working in or with hospices. <a href="#">End of life care leads and key workers for patients with advanced kidney disease</a>.</li> </ul> <p><b>Group B</b> – Staff who frequently deal with end of life care as part of their role. This includes:</p> <ul style="list-style-type: none"> <li>Secondary care staff working in A&amp;E, acute medicine, respiratory medicine, care of the elderly, cardiology, oncology, <a href="#">renal medicine</a>, long term neurological conditions, intensive care, hospital chaplains and some surgical specialties</li> <li>Primary care staff including GPs, district nurses, community matrons, some care home staff, ambulance staff and community based carers</li> <li><a href="#">Specialist nurses</a>, such as in heart failure, <a href="#">chronic kidney disease and dialysis</a>, based in primary or secondary care</li> <li>Community pharmacists.</li> </ul> <p><b>Group C</b> – Staff working as specialists or generalists within other services who infrequently deal with end of life care. This includes:</p> <ul style="list-style-type: none"> <li>Other professionals working in secondary care or in the community, e.g. staff in care homes and extra care housing, day centre and social care staff not involved in hospices, domiciliary care and prison services staff.</li> </ul>	<ul style="list-style-type: none"> <li>All staff should have the highest levels of knowledge, skills and professional development (CPD).</li> <li>These should include communication skills, assessment, advance care planning and symptom management as they relate to end of life care.</li> <li>Staff will need to be supported to develop existing skills and knowledge to enable them to develop or apply of life care through CPD, or further specialist training and overcome any personal or team barriers</li> <li>This group has the greatest potential training need, in particular secondary care doctors (and their immediate teams), GPs (and teams) and district nurses, who may be key in the ‘trigger’ discussion at the start of the pathway and with ongoing continuity of care</li> <li>These should include communication skills, assessment, advanced care planning and symptom management as they relate to end of life care.</li> <li>This group must have a good basic grounding in the principles and practice of end of life care and be enabled to know when to refer or seek expert advice or information</li> <li>Many of the staff within care home settings and providing domiciliary care in this group have significant unmet training needs, including access to induction programmes.</li> </ul>



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