decisions for themselves and the kind of care that they would and would not want when they come towards the end of their life including care in the final days of life. This is an important way of increasing the likelihood of people receiving the care they would choose should they become unable to make decisions for themselves (through ill health). If someone’s wishes are known it is more likely medical teams will be able to provide care that reflects the kind of care they would wish for.

The best time to think about these things is when people are well or relatively well and some dialysis units are introducing advance care planning for all dialysis patients, once settled on dialysis and all patients who choose the conservative pathway.

**Care Planning and Co-ordination of Care**

These follow naturally from an assessment of the individual’s needs and agreeing with them their priorities and how symptoms or support needs can be responded to in conjunction with community services. Once services are aware that someone is in the last stages of life systems can be put in place for rapid access to care and appropriate response to emergencies. Plans can be made to try to achieve care at home for individuals who have expressed a wish for home end of life care.

**Conclusion**

While recognising that there is still much to be done to improve the care of people as they approach the end of their lives; it is clear the renal community is working towards this improved care and ways of working that will help teams embed this care into the routine care of their patients are being developed.

***The National Kidney Federation cannot accept responsibility for information provided. The above is for guidance only. Patients are advised to seek further information from their own doctor.***

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End of Life Care for people with advanced kidney disease

There is growing recognition of the importance of the care that is given to people as they approach the end of their lives as well as their care during both acute and chronic illness. Nationally this was promoted through the publication in July 2008 of a National End of Life Strategy which sought to raise the quality of end of life care for adults whatever the disease they suffered from and in what ever setting they lived or were being cared for. Importantly this document emphasised that the need for end of life care is not confined to the last days of life; recognising that an individual may have increased need for support and palliative care in the last months and weeks of their life. This led to the definition below.

A Working Definition of End of Life Care from National End of Life Strategy: 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.

Source: National Council for Palliative Care 2006

The Renal NSF Part 2 which was published prior to this in 2005 stated that: “people with established renal 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.”

It sets out 6 markers of good practice which can be summarised as:

1. Access to communication skills and knowledge of symptom control
2. Offering prognostic assessment
3. Timely information and joint palliative care plan
4. Ongoing medical care for patients opting not to dialyse
5. Dying with dignity
6. Culturally appropriate bereavement support.

So even before the publication of the National Strategy on End of Life Care; the importance of care approaching the end of life was recognised by the renal community. Following this, NHS Kidney Care published a document: End of Life Care in Advanced Kidney Disease: A framework for Implementation in June 2009. This was based on the key elements in the National Strategy but related specifically to patients with advanced kidney disease.

It concerns the care of:

1. People who choose not to receive dialysis (now called “conservative kidney care”) while receiving all other aspects of care for their kidney condition.
2. Those who choose to stop dialysis.
3. Those who continue to dialyse but who are deteriorating on account of other illnesses.

This is illustrated in the diagram below; Fig 1.

Figure 1 End of Life care in Advanced Kidney Disease; modified from the Framework for Implementation

Subsequently, NHS Kidney Care asked three teams across England to test the best way to apply the recommendations made in the End of Life Care in Advance Kidney Disease: A framework for Implementation. These teams undertook detailed work with kidney patients, their families and the professionals involved in providing care, to establish the best ways to improve care.

The key deliverables from this project mirror the elements of the strategy and its implementation and are summarised below:

- Timely identification of kidney patients approaching end of life with supportive care and palliative care needs.
- Detailed assessment of care needs either in primary care or by key members of the renal team, with regular review.
- Key staff trained in assessment of supportive and palliative care needs and advanced care planning.
- Advance care planning initiated and facilitated in accordance with patients’ wishes, using local preferred priorities of care (PPC) documentation when appropriate.
- Improvement in co-ordination of care across kidney and primary care interface.
- Patient and family information and support for end of life care developed.

Identifying people and a register of those in need

It seems obvious to say, but if it is not recognised that someone may be approaching the end of their life, then appropriate discussions cannot take place and any additional supporting services cannot be mobilised. It is suggested that kidney units develop ways of systematically identifying those in need and then recording them on a register. This is so that their needs can be assessed (along with their carers); they can be given the opportunity for advanced care planning and most importantly key decisions regarding their preferences can be communicated, with their consent, with relevant medical and nursing teams particularly their primary care team. How to do this is discussed in detail in “Getting it right: End of Life Care in advanced kidney disease” London, UK; Department of Health 2012

Primary care teams now keep such registers for their patients so it is important that patients with advanced kidney disease are included too where appropriate.

Advance Care Planning and its relevance to advanced kidney disease

Advance Care Planning is a voluntary process of discussion between an individual, those close to them (family and friends) and professionals involved in their care about preferences and priorities for their future care. Such discussions can include decisions about stopping dialysis (or not ever starting it) or what sort of treatment someone would want if the time came when they could not make