

A decorative graphic on the left side of the page, composed of numerous thin, parallel green lines that curve and flow downwards, creating a sense of movement and depth.

# Improving Choice for Kidney Patients: The Carer and Patient Viewpoint

***Better Kidney Care for All***



# Emerging themes and points for consideration

Self-care, care at home and home dialysis offer real benefits for kidney patients. They link closely to the vision of an NHS that is organised around patients, giving them more choice, convenience and control over their care. However, there are differences between renal units across the country and some patients find it much easier than others to receive dialysis at home.

Over the past year, NHS Kidney Care has been engaging with home dialysis patients and local care teams to influence the way services are planned and designed and to promote choice for kidney patients. Some of the most powerful contributions to these events have been the personal stories told by patients and carers about the impact that home dialysis has had on their lives (see links at the end of the document for more information).

In January 2011, an event was held in partnership with the National Kidney Federation for home haemodialysis patients and carers from across England. Its aim was to help identify and understand what support and information they needed and how services could be improved to meet their requirements. The opportunity for patients and carers to meet others from across the country revealed the significant variation in home haemodialysis between different units.

This report summarises the main themes emerging from this event and sets out some key points for patients and carers, service providers, commissioners and national networks to consider. This document is different to traditional clinical guidelines or policy documents. It represents the collected thoughts and ideas of the most important people in healthcare - patients and those who give their time and energy to help care for them.

# Emerging themes

## 1. Quality of life is paramount

For many patients, quality of life is just as important as quality of treatment. Some patients compared dialysis in centre to 'existing', while dialysis at home allowed them to 'live' again.

Patients spoke of increased energy levels and appetite as a result of home dialysis. For one patient, this meant they were able to do a 5k race in Hyde Park, something they had thought impossible before. Independence and freedom are crucial. Another home dialysis patient who runs his own business said he feels able to 'dream again' and has aspirations for the future, rather than being focused solely on his day-to-day treatment.

Some patients at the event felt that quality of life should be the key indicator when services are being commissioned and planned.

However, despite its importance, many patients and carers felt they had rarely or never had conversations with clinicians that directly addressed quality of life.

Health related quality of life (HRQOL) questionnaires were discussed. These are being piloted by the Department of Health and parts of the NHS. Few patients had experience of completing them. Where patients had completed HRQOL questionnaires, they had not always understood their purpose and had not seen how they might result in any changes being made. The kidney disease specific KDQOL was much preferred by patients to the more generic EQ5D.

However, there was a great deal of support for the introduction of HRQOL questionnaires if:

- their purpose was clearly explained to patients;
- they were actively used as a basis and prompt for quality of life discussions between patients, carers and clinicians; and
- they were used consistently across dialysis units, feeding into the information available to help patients make choices.



## 2. The need for continual dialogue

There was discussion at the event around the best time for information to be given and different conversations to be had. What became clear was the need for continual dialogue between patients and carers and their clinicians.

While the options for home dialysis should be introduced at the time of diagnosis, patients shouldn't be expected to make a decision at that time. Conversations about home dialysis may need to evolve over time as the patient finds out more and talks things over with peers and their carer. Some were concerned that if they started dialysing in centre they would be 'put in the dialysis unit and forgotten about'. Regularly reviewed care plans were seen as an important tool for empowering patients and allowing on-going assessment of their satisfaction with their current choice of dialysis.

The need for on-going dialogue applies equally to quality of life issues. It was felt that at every point of contact with the service, patients and carers should be asked how things are going and whether they are happy with their current modality and quality of life. Annual 'MOTs' were seen as valuable, and something all patients should have, but as an addition rather than a substitute for on-going discussions.

Patients and carers at the event frequently said they wanted to be listened to by consultants, dialysis nurses and service managers. As well as through individual patient-clinician discussions, there are various ways this can be achieved at a service level. Patients and carers wanted to be consulted and involved in decisions about service planning, the procurement of dialysis machines, the design of dialysis units and waiting areas, accessibility and parking facilities. Questionnaires, surveys and meetings were all seen as valuable, although it was noted that while all patients should be invited to give their views, not all would want to.

Local kidney patient associations were seen as useful for representing patients and carer views and interests and a good way for commissioners and service managers to engage with patients and carers.

### 3. Comparable information

There was much discussion at the event about the types of information patients and carers need to make informed choices and how that information should be presented.

Patients and carers want to see a range of measures for each dialysis unit and to be able to compare these with other units and with national averages or established benchmarks. The measures they wanted to see for each unit, broken down by modality (including home dialysis) were:

- Total number of patients and number of patients on each modality
- URR, BP, HB, PO4, PTH/bone health and Kt/V rates
- Infection rates
- Survival rates
- HRQOL indicators (if these can be established)
- Number of staff and staff/patient ratios
- Information on cleanliness

One idea was for an annually updated factsheet for each unit, setting out these key measures alongside national averages and established benchmarks and with core details about the unit and the facilities and peer support opportunities available there. Patients and carers were largely happy for this information to be available online, although alternative provision must be made available for those who don't have access to the internet.

The idea of 'league tables' was discussed but it was recognised that this posed numerous difficulties, not least agreeing the single most important factor on which units should be ranked. It was agreed that the main objective is for patients and carers to be able to compare units on the measures that matter most to them.

It was felt that all anonymous information in the Renal Registry should be made available for any patient, carer or member of the public to download and analyse if they wanted to.

## 4. Clear information

In addition to providing access to comparable information, it is important that this information is clear and easily understood. While some patients are comfortable with medical terminology, others are not.

Patients can use the glossaries that are made available by kidney patient groups and on Renal Patient View to help them understand any terms they are not familiar with.

It was recognised that the Renal Registry is primarily a tool for clinicians to share clinical information and if it is used to provide information to support choice, there will need to be some element of translation for a patient and carer audience, although it was not clear who would do this.

Whatever information is made available, it should be provided in a way that is consistent with the NHS good practice guidelines on accessibility which cover issues such as font sizes and avoiding the use of colour combinations that are difficult for some people to see.

## 5. Supporting patients to make informed choices

While information is essential to inform decision making, patients and carers still need considerable support and guidance to make their choices. It was agreed that consultants and home haemodialysis nurses are best placed to introduce the options and help guide people through their choices.

The different modality options should be introduced at the point of diagnosis, but there should be no expectation that patients will make a choice at this point. Diagnosis can be overwhelming and most patients will need time to consider their options, find out more and talk things over with peers and their carer.

Patient information days - giving patients and carers the opportunity to find out more and hear from clinicians and patients about the different options available to them, along with the opportunity to meet and chat with peers - were regarded as very useful. Ideally, prospective home dialysis patients should be able to visit existing patients dialysing in their homes to see what it is really like.

It was felt that carers should be fully involved in these events, visits, and in discussion with clinicians as far as possible, as their active engagement and involvement is crucial.

It was noted that, as most patients spend long periods of time in dialysis units and there are often long periods of waiting, this would be an ideal opportunity to make information available to help inform patients' choices. Information films on video screens in waiting areas were suggested.

It is important that patients know the right questions to ask to help them make their decisions. It was felt that a guide for patients, setting out the pros and cons of different modalities and the kind of questions they should be asking their clinicians to help them make their decisions would be very valuable.

## 6. 'Normalising' home haemodialysis

While no one form of dialysis is better than any other and each individual patient needs to find the modality that is best for them, it was felt that in centre dialysis is still too often seen as the 'norm' and home dialysis, despite its benefits, as the exception.

Many at the event believed that take up of home haemodialysis would 'snowball' as more and more people started. However, it was still felt that home dialysis needed to be mainstreamed in the culture of many units. Introducing it as an option at the time of diagnosis was seen as a good start, but patients said that all staff should continually 'sow the seeds' of the potential for home dialysis.

Some at the event noted that home haemodialysis, because of the very fact that it takes place away from the unit, is not visible to patients who dialyse in centre. There were two suggestions to address this. One was to have dedicated home haemodialysis training facilities in the renal unit so that in centre patients could see people preparing for home dialysis. The other was to encourage patients who are in centre and at home to mix with each other when they are in the unit for appointments.

## 7. Carers are a core part of the team

A recurring theme at the event was the valuable role of carers and their need to be involved and supported. One carer described the transition to becoming a carer as 'like a bereavement'. It was suggested that support services should be commissioned for carers in the same way they are for carers of cancer patients.

As well as patients having regular check-ups, it was felt that carers should be asked 'how are you doing?' at regular intervals too. A helpline for carers to call was suggested as well as access to greater carer peer support. It was noted that meetings, events and appointments at weekends would be easier for many carers to attend.

Carers are a core part of the team and nurses should be encouraged to involve carers on the ward, inviting them to watch and ask questions, building their understanding and confidence.

## 8. The importance of peer support

For patients and carers, peer support was crucial both to help inform decision making and for on-going support. Home dialysis patients sometimes report feeling isolated and there is a greater need for peer support as a result. It was suggested that peer support should be part of a service specification. Many patients and carers would welcome more opportunities to link in with each other, both in the unit and away from it.

It was felt that kidney units, local kidney patient associations and patients and carers themselves could all do more to make this possible. It was noted that there were confidentiality issues that prevented kidney units putting patients in contact with each other. However, most agreed that many patients would be willing to put their names and contact details forward to be shared.



## 9. Facility design

Several points raised at the event touched on the physical design of kidney units. As described above, there was a suggestion that by having designated home haemodialysis training facilities, home dialysis would be given greater visibility in units. Reflecting home dialysis in the design of units would help to 'normalise' it.

Several patients and carers also suggested that the layout and use of space in units could be improved to actively encourage patients and carers to get to know each other and to chat together, developing relationships and extending peer networks. Facilities could also been designed to act as information hubs, making information to support choices available in key waiting areas.

Patients and carers would welcome the opportunity to be consulted and involved in any proposals for changing the design or layout of their local units.

# Points for consideration

## For patients and carers

Don't be afraid to talk about quality of life as well as quality of treatment with the team caring for you.

If you aren't being offered the choice of home dialysis, find out why. It isn't appropriate for everyone, but you should at least have the chance to discuss whether you are medically suitable and whether it is something you want to consider. You may also find it useful to contact your local kidney patients association, kidney care network or specialised commissioning group.

If you choose to dialyse in centre, don't feel that you are stuck with that decision forever. Many people start dialysing in centre and then move to home dialysis as their understanding of their illness and confidence in self-care increase. You should review these issues regularly with the team caring for you.

Get involved in your local kidney patients association and make the most of any opportunities to provide feedback to your kidney unit through questionnaires, surveys and meetings. It is only through your feedback that services can learn how to better meet your needs.

Take responsibility for understanding what is happening to you and for making choices about your treatment. If you don't understand any words or terms, use the glossaries produced by kidney patient associations or on Renal Patient View.

Peer support is very valuable, so consider making contact with other patients and carers in your unit. Put your name and contact details forward so that your unit has your consent to make them available to other patients and carers. You can also get involved in national support groups like the National Kidney Federation.

## For service providers

Consider how to encourage your patients and health professionals to discuss quality of life issues. Consider introducing HRQOL questionnaires and using these as a starting point for discussions with patients, but make sure that the purpose of the questionnaires is made clear and that their results are followed up.

Introduce modality options at the time of diagnosis, but don't expect patients to make any decisions at that stage.

Consider introducing patient-held care plans (you can use the NHS Kidney Care) if you don't already. These enable patients to record their current preferences and questions they might have about alternatives and can be reviewed at regular intervals.

Consider how to ensure that discussions about modality choices and quality of life are not one-off tick-box exercises, but part of continual dialogue with your patients.

Consider how to ensure patients and their carers have sufficient information to make their decisions. As well as written information, consider holding patient information days, and displaying information videos in the renal unit. If you are holding events, consider holding them at weekends to make it easier for carers to attend.

Consider how to involve patients and carers in the design of services and facilities and work closely with your local kidney patient association.

Consider how to encourage patients and carers to provide comments and feedback on the services and care they receive. For example, comment boxes in outpatients clinics and satisfaction surveys or feedback facilities on websites.

Consider how to 'normalise' home haemodialysis within the culture and design of your unit.

Consider how to better involve, engage and support carers, helping to build their understanding and confidence enabling them to better support you in providing care to your patients.

Consider how you can put patients in touch with each other for peer support in ways that are consistent with patient confidentiality rules, especially for putting patients considering home dialysis in touch with those who are already doing it.

Consider the importance of psychological and social wellbeing in addition to clinical outcomes.

### **For commissioners**

Consider quality of life measures when commissioning services and consider requiring providers to measure and act on HRQOL data.

Consider involving your local kidney patient association to find out more about how patients want to see their services develop.

Consider including information provision to patients to help them make their choices as part of the commissioned service.

Consider commissioning specific support for carers.

Consider making patient and carer support facilities a key component of any home therapies service. These could include peer support groups, buddying schemes and online resources such as Renal Patient View.

### **For local and national networks**

Consider establishing one single consistently applied and validated HRQOL questionnaire for kidney patients.

Consider collating and producing online information on each renal unit that enables patients and carers to compare units against the range of measures set out above, and with national averages and established benchmarks.

Consider making all the anonymous information in the Renal Registry available for download.

When producing information for patients, make sure it is visually accessible, following NHS guidelines around font size and colour combinations.

Consider producing a patient information video that renal units could display in waiting areas to give patients more information about their modality options.

Consider producing a patient leaflet that could be provided in all renal units, setting out patients' modality options and the kinds of questions patients should ask in order to help make their decision.

# Further information and resources

## **Improving choice resources**

A selection of resources from NHS Kidney Care to improve patient choice, including a report on patients' stories and several short films:

[http://www.kidneycare.nhs.uk/\\_Ourworkprogrammes-Preparation-Improvingchoice.aspx](http://www.kidneycare.nhs.uk/_Ourworkprogrammes-Preparation-Improvingchoice.aspx)

## **National Kidney Federation**

The NKF website provides a wealth of information and resources for kidney patients and links to local kidney patient associations:

<http://www.kidney.org.uk/>

## **Acknowledgements**

Thanks are due to Marion Higgins of the National Kidney Federation, who chaired this event, and to all the patients and carers who gave their time to attend. We hope this report helps to improve access to home therapies, allowing more people in future to have genuine choice over their treatment.



## Kidney Care

[www.kidneycare.nhs.uk](http://www.kidneycare.nhs.uk)

For further copies contact:

Prolog

Prolog House

Sudbury

Suffolk

CO10 2XG

[bdm@prolog.uk.com](mailto:bdm@prolog.uk.com)