

Home Dialysis: Who Cares for the Carer?

Roundtable Summary Paper

Ipsos MORI for NHS Kidney Care

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1. Executive summary

This document records the outcomes of a roundtable discussion event that explored the issues faced by people who care for a loved one with a long-term condition, and looked at how carers can be better supported. The discussion resulted in the following recommendations:

- There is a need for good-quality, fully-comprehensive training and back-up for carers, and for services to gain a good understanding of what the carer needs to be able to manage his or her role. This should be provided via an induction package which includes good and consistent nursing and technical support.
- There needs to be a culture shift from within the support networks, from a strictly medical approach to the care and management of the patient and their carer towards a personalised approach. This should be put in place via a personalised carer's assessment, to be reviewed regularly, as it is important that each and every carer is treated as an individual and changes in their personal circumstances are considered. This assessment would allow services and carers to work in partnership, in order to gain a real understanding of the potential consequences of caring for a loved one and to identify long-term needs. The third sector, the NHS, social services, education (where appropriate) and the Department for Work and Pensions should all network together to provide individualised proactive support. Renal units should be equipped to be able to draw on all of these services, as well as acknowledge the importance of informal networks of support from others in a caring situation. This holistic support should be provided by a one-person point of contact with whom the carer best relates to alleviate the need for carers to deal with an overwhelming number of people.
- It is important to provide proactive support and information to carers, allowing them easy access to information which could aid their role, including expert financial

advice. Established communications channels should be evaluated to see how they could be enhanced in order to deliver comprehensive and sensible information services, particularly in a crisis.

- It should be acknowledged that carers need support, including access to respite care, before, during and after they are caring for someone with a long-term illness. Carers need to be able to connect to their world of support at any stage in their own lives. For instance, if a loved one dies, services should recognise the emotional impact that, for example, giving back equipment can have. In commissioning care pathways, NHS services should be flexible in design, in order to be able to adapt to needs when individual situations change (e.g. emergency dialysis, transplantation, end of life) and acknowledge that support will differ throughout the ‘carer’s journey’, and that this journey could be cyclical .
- There needs to be an agreed acknowledgment that the carer should have a central role in planning and designing services to suit their needs. Carers are taking on a huge burden and should therefore be able to expect a level of service from within their community, as does a patient who expects free healthcare at the point of delivery. This needs to be a proactive partnership between carers and services, which ensures that this burden does not impact on the carer’s aspirations for life.

2. What this document is about

NHS Kidney Care commissioned Ipsos MORI to carry out ethnographic research into the issues people face when caring for a loved one who has a long-term condition. The resulting short films were launched on Carers Rights Day 2012 at a roundtable discussion at the King's Fund in London, which explored how carers can be better supported.

The aim of the discussion was to bring together an invited group of carer and patient representatives, and healthcare professionals, to discuss the research which NHS Kidney Care has been conducting over the past three years on the needs of carers. The group (listed in the appendix) was tasked to discuss this research in order to create content for a mandate which NHS Kidney Care could take to the Department of Health.

Attendance at this launch event highlights the sustained interest in the work NHS Kidney Care has done on recognising carers' needs and understanding how to design services which will allow carers to be able and enabled to care for loved ones at home. This is of particular importance in light of The NHS Outcomes Framework 2013/14¹, which now includes '*and the carer*' within patient experience.

NHS Kidney Care hopes that this summary document can help highlight the important role which carers play in the management of long term conditions, pushing this higher up the Government's agenda.

¹ Department of Health, *The NHS Outcomes Framework 2013/14*, NHS Outcomes Framework Policy, 13 November 2012, <https://www.wp.dh.gov.uk/publications/files/2012/11/121109-NHS-Outcomes-Framework-2013-14.pdf>, Viewed 24 December 2012

3. The main sources of information for discussion

In order to lead the roundtable discussion, Anthea Duquemin and Oliver Sweet presented the recommendations from research that NHS Kidney Care has conducted over the past three years. This section summarises these research sources.

Between April and September 2010 NHS Kidney Care hosted ten *Improving Choice: Home Therapies Roadshow*² events across England. These events described and discussed local approaches towards home dialysis in each region. During these events, a local resident spoke of their personal experience of home dialysis – which proved to be a very moving and powerful part of each event. These personal stories brought to life the realities of home dialysis, and highlighted how moving care into the home can result in huge benefits for the patient. Therefore, with permission, these stories were captured via qualitative depth interviews at a later date and published in a report *Improving Choice: Listening to patient stories*³. During this research process, it became apparent that the patients' experiences could not be described in isolation without including the experiences of their partners and family members, who may not necessarily find the experience as positive as the patient does. This opened a whole undiscovered area, which was explored through further qualitative research looking at the experiences of ten people who, in some way, care for someone who dialyses at home.

In September 2011 *Home Dialysis: Who cares for the carer?*⁴ was published. The report discusses the carer's role and highlights the realities of life for the family members and

² NHS Kidney Care, *Improving Choice for Kidney Patients and Carers - Increasing access to home dialysis*, National Institute of Health and Clinical Excellence, 14 February 2011, <http://www.nice.org.uk/usingguidance/sharedlearningimplementingniceguidance/examplesofimplementation/eximpresults.jsp?o=479>, Viewed 24 December 2012

³ NHS Kidney Care *Improving Choice: Listening to patient stories*, October 2010, <http://www.kidneycare.nhs.uk/document.php?o=474>, viewed 24 December 2012

⁴ NHS Kidney Care, *Home Dialysis: Who Cares for the Carer?*, September 2011, <http://www.kidneycare.nhs.uk/document.php?o=464>, viewed 24 December 2012

partners of those on home dialysis, beginning to address the gap in understanding carers of home dialysis patients. To complement this report, in spring 2012, NHS Kidney Care commissioned Ipsos MORI Ethnography to undertake a further study⁵ using a filmed ethnographic technique to bring to life the importance of the role of carers.

⁵ Ipsos MORI Ethnography, *Who cares for the carer? Ethnographic films*, NHS Kidney Care, November 2012, http://www.kidneycare.nhs.uk/our_work_programmes/improving_choice_for_kidney_patients/support_for_carers/, viewed 24 December 2012

4. Summary of the roundtable discussion

4.1. Accepting the role of carer

There is often a great deal going on in the lives of carers, who usually have to adapt their own lives and change situations in order to carry out their roles. Carers may therefore lack long-term peace of mind; they are often stressed and anxious and in the long-term may feel drained.

Caring for a loved one brings a huge responsibility, and carers need strength and resolve; however, they can also feel a lot of guilt when worrying about their own health, feeling concerned that things could go wrong or not spending all of their time with the loved one they are looking after. They can struggle to ask for a break even if they need one, as they feel so integral to the situation that they don't feel they can 'let the patient down'.

There is need for a system designed to allow carers to take a break and not feel guilty in doing so, but it should be acknowledged that it is sometimes hard for carers to accept support, and they may deny needing it. This calls for both practical and emotional support from services before emotions reach boiling point.

4.2. The implication of becoming a carer

With the drive to place services within the home, and the emotional ties between carer and patient, sometimes carers agree to do what they think is best for their loved ones without fully understanding the implications that this choice will have on themselves and their own long-term health and wellbeing.

It has to be acknowledged by services and carers that caring for someone with a long-term condition – especially where medical machines are used – carries a heavy burden. For instance, when a home haemodialysis machine is in use, to ‘Joe public’ it looks complicated and awkward to use. They not only have to use the machine, but understand their patient’s needs and emotions. What does this do to the emotions of a carer?

There is a clear need for an awareness campaign which would help disseminate better information to carers, resulting in a full consideration of the options and how the carers would be affected.

Services need to provide this support, in order to help carers fully understand and make informed decisions about what could be coming and the implication this will have on their current life.

4.3. Recognising the carer's role

Within society and politics, there will be people who like the term 'carer' and some who don't (as with the term 'patient'); it is a very personal term and can sometimes denote negative connotations. With respect to the individuals, there has to be a term to define what carers are doing in addition to being a mum, wife, husband, etc. As seen in the research NHS Kidney Care has commissioned, it could become difficult to even open this discussion, as not everyone wants to be known by their social status.

Therefore, the recognition of the carer's role and how this is described is imperative. The system needs to work in a way which will benefit the carer as an individual, not just when they are looking after a loved one.

But it is often not the terminology which causes issues; it is how services and support networks treat that individual. It will be important going forward that, during the initial carer's assessment, services understand how the carer would like to be recognised, thus creating a personalised carer's plan.

4.4. The carer's assessment

Within the draft Care and Support Bill⁶, the local authority has a duty to carry out a needs assessment for the carer, yet experience of this assessment varies dramatically in terms of content and quality. There should be a review of this assessment, standardising it across England to include a full evaluation of the individual's situation and consideration of the impact of caring for someone with a long-term condition.

Services should look across other areas and to other long-term conditions, in order to establish best practice. For instance, there is already a structure in place to support young carers, which draws on the network surrounding them in order to look after their wellbeing. A new carer's assessment should look to this structure – and others which are already in place - for guidance.

The most critical part of the assessment will be to evaluate the need for practical everyday support; to understand when carers may need a break, what sort of equipment they need, the extent to which they can access information, and through which channels, i.e. online access. However, with any long-term condition, situations change, and so do emotional and practical needs. It is therefore imperative that the carer's assessment does not remain static and is reviewed dependent on triggers.

This tailored package should be put into place disseminating practical and real information in a timely manner, with monitoring from a distance, and become standardised practice. This is important because carers may not ask for help even when it is needed.

⁶ Department of Health, *Draft Care and Support Bill*, 11 July 2012, <https://www.wp.dh.gov.uk/careandsupportbill/files/2012/07/CARE-AND-SUPPORT-BILL-FINAL.pdf>, viewed 24 December 2012 p7

4.5. Support needs

A lack of support, coupled with the lack of recognition for the carer, manifests itself in a huge emotional burden, which in turn can have health implications for carers themselves. More often than not, after extensive training in hospital, once a carer gets home they are alone with massive pressure to keep their loved one well (and alive, in some instances) and see no option but to muddle through. Therefore, after-care needs to come in the guise of both practical and emotional support, with the emotional support on a fundamental and deeper level - for the carer's wellbeing, and consequently, the wellbeing of the patient.

As a guide, practical and emotional support should include a number of key components:

- Good nursing support
- Good practical support
- Continuing emotional support
- Awareness and access to third sector support
- Buddying system
- Renal counsellors
- GP support

These components should take into consideration the following:

- Flexibility: given the complexity of the lives of carers, with the ups and downs that come with the role, support needs to be flexible and allow carers to duck in and out at certain points; carers need to be able to use the parts that they want to use but then get on with their lives.
- Carers' experience: the knowledge of the carers should not go to waste. They will come to services with ad-hoc solutions, which should be acknowledged and evaluated.

- Out-of-hours support: there is a need for some support to be available out-of-hours; in some instances medical and technical knowledge is lacking during out-of-hours times, and some things cannot wait until the morning. However, fundamentally, knowing a number is available and someone is on hand to talk things through, if necessary, takes away some of the burden.
- Informal networks: in some instances, carers have great informal support networks around them, including empathetic employers, which allow carers to approach their care in a flexible manner. This support should be evaluated within their individual care plans.

It is acknowledged that there are numerous different contact points, places and people for support who all know snippets of information about an individual case. It is important to look within the structures already around the carer to pinpoint the best single point of contact for the carer, as research demonstrates that consistency in contact is key in helping carers to get the most from the support package.

Turning back to the carer's assessment, this package needs to include access to the above support with caveats, in order to understand what carers need to cope on all levels.

4.6. Developing services to respond

Services should turn to areas where practical and emotional support is offered proactively to understand how best practice can be rolled out to all carers, for instance, young carers are able to get emotional support but not always in a way where they know it is happening.

As a starting point, our research has demonstrated an example of how Matthew⁷ (who is caring for his mother on home dialysis) is getting both emotional and practical support under the care of University Hospitals Birmingham NHS Foundation Trust.

In saying all of this, western healthcare systems tend to focus on a traditional view of support; a culture which is really tough to change. However, as seen in Matthew's case study, taking a holistic view of support will undoubtedly benefit the carer and their patient.

Moreover, within the health service, the landscape of income is changing, which means that the third sector should step up and become an integral part of the care package; indeed there are third sector parties already in place to fulfil this need, e.g. British Kidney Patient Association. Part of the care plan should include access to support services, connecting all of the different solutions.

For kidney patients, renal units will have a really important job in understanding the right package of support for an individual case. However, like other specialised services renal units often work in silos, producing their own support materials, so to begin, an evaluation of the third sector and an asset map of Government services need to take place, to understand the depth and breadth of support services and materials. The role of this will be key to bringing some consistency across the board, allowing open access to all support services. This information should be distributed via the carer's assessment.

⁷ Ipsos MORI Ethnography, *Matthew's case study*, NHS Kidney Care, November 2012, <http://www.kidneycare.nhs.uk/vid.php?o=254>, viewed 24 December 2012

5. Next steps

The recommendations in this report need to be considered by a wide range of stakeholders including the following groups and individuals:

- Kidney health community
- National Kidney Federation
- NHS Improving Quality
- Domain leads for patient experience and long term conditions
- The Carers National Association
- British Kidney Patient Association
- Local government

If the relevant groups take notice of the findings from this report, they can work together to coordinate and develop services to improve the carer experience, ensuring carers access practical, emotional and social support at all stages.

6. Appendices

Appendix A: The people who shared their ideas

Chair:

Ann Lloyd, Trustee, Patients Association

Participants:

Beverley Matthews, Director NHS Kidney Care

Grace Sweeney, Head of Research & Evaluation, NHS Kidney Care

Oliver Sweet, Head of Ethnography, Ipsos MORI

Anthea Duquemin, Research and Evaluation Officer, NHS Kidney Care

Angela Hancock, carer representative

Kate Cresswell, National Kidney Federation

Rosemary Macri, British Kidney Patient Association

Rebecca Campbell, Yorkshire & the Humber renal network

Michaela Firth, NHS Institute

Fiona Loud, Kidney Alliance

Billie Ing, Ipsos MORI

Jen Hartley-Bond, NHS Kidney Care

7. References

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7. Ipsos MORI Ethnography, *Matthew's case study*, NHS Kidney Care, November 2012, <http://www.kidneycare.nhs.uk/vid.php?o=254>, viewed 24 December 2012