

Valuing Carers

Recognising and Valuing Carers: The Creation of a Leaflet

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Problem:

Having someone in the family with kidney failure can affect everyone within that family, as well as anyone else involved with caring for that person. As part of an analysis of our pre-dialysis care programme, carers and relatives told us that they had different information needs from the person with kidney failure. The Department of Health are aware of the considerable public support for carers following their consultation in preparation for the White Paper. 'Our Health, Our Care, Our Say'⁽¹⁾ and have responded with 'The New Deal for Carers'⁽²⁾.

Design:

A renal social worker met with two carers of renal patients and discussed developing information specifically for carers. Our renal service does have 'A Guide to Living with Kidney Failure' for patients and their families but the carers felt that was really directed at the patients. Topics to be covered were identified and a leaflet written to provide appropriate information. This was circulated to the members of a pre-dialysis Action Learning set and to other carers looking after patients with advanced kidney failure for their thoughts and comments.

Findings:

We have produced a six-page leaflet entitled 'A Carers Guide to Living with Kidney Failure: Information for families and carers'. The leaflet includes the topics; carers' rights, diet, medication, exercise, benefits, employment, who's who in the renal team and important telephone numbers including the regional Carer's centres.

This leaflet was sent out to all dialysis patients with a letter asking them to pass this onto their relative/care plus a feedback form. 100% of the returned questionnaires thought that the leaflet had the right amount of information. The themes which emerged most strongly in the answers to the question "what was the most helpful thing about the leaflet?" were knowing that the renal team are here to help and who is in the team and the phone numbers on the back of the leaflet. In answer to "what would you like more information on?" carers most frequently identified information on diet and the names of good renal cookery books plus holiday arrangements.

Additional comments included; "very useful, just what I would have expected from such a good team", "it covers how you can find out further help and information without confusing the carer", "useful given to a relative of a recently diagnosed kidney patient"

Relevance:

The Health Service and Social Care depend on the six million carers who look after family members because they are sick, frail or disabled. The economic value of the contribution of carers is estimated at equivalent to the cost of the NHS every year⁽³⁾. Carers of people with kidney failure should have appropriate information and access to support to sustain them in their caring role. Provision of 'A Carer's Guide to Living with Kidney Failure' enables carers involved with our services to have that information and know where they can receive the support and help they need.

1. Department of Health 'Our Health, Our Care, Our Say' (2006)
2. Department of Health 'New Deal for Carers' (2007)
3. Carers UK 'Without Us...? Calculating the Value of Carers Support'