

# RENAL ASSOCIATION WORKING PARTY ON PERITONEAL DIALYSIS

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### MEMBERS OF WORKING PARTY

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### Background

Home dialysis, peritoneal or haemodialysis, has many advantages for patients requiring dialysis therapy as patients are enabled to take control of their own medical treatment and thereby improve their sense of well-being. Home therapies also use less resource in terms of space required, numbers of nurses and reliance on hospital transport. Historically, the majority of patients in the UK dialysed at home – using haemodialysis in the 1970s and early 80s and then peritoneal dialysis from the late 80s. Since around 2000, the number of patients on home dialysis has declined, so that currently, only 1-2% dialysis patients are on home haemodialysis and numbers starting on peritoneal dialysis have declined from 40% in 2000 to 20% in 2006 (1). Furthermore, there is huge variation with many units in the UK having no or hardly any patients on home haemodialysis and less than 10% patients on peritoneal dialysis. A wide spectrum of utilisation of home dialysis modalities is also seen within other countries and the national and international differences in the prevalence of home dialysis cannot be ascribed primarily to patient case-mix.

Peritoneal dialysis has many advantages for patients starting on dialysis. As a home therapy, it is less intrusive than haemodialysis and therefore enables patients to continue working, travel, socialise, care for other family members, etc. Peritoneal dialysis is also easier for carers and family members to help older and/or frail patients to have their treatment at home rather than have the disruption of 3 times a week travel to and from a haemodialysis unit.

The median age of patients starting on dialysis in the UK in 2006 was 65 years. Transplantation rates are rising with increasing numbers of living donor transplants, but many older patients have comorbidities making them unsuitable for transplantation and/or do not have suitable donors. This means that with an ageing population, the number of older patients requiring dialysis will continue to rise. Proportionately fewer older patients, however, start on peritoneal dialysis; in 2006 in the UK 30% patients <65 years old started on peritoneal dialysis compared to only 17% of patients >65 years old. With the predicted increasing number of older patients, this trend will result in expanding haemodialysis numbers requiring more haemodialysis units and specialist dialysis nurses.

The decline in utilisation of peritoneal dialysis is occurring in most Western countries. Several reasons have been suggested for this: lack of patient education, physician bias, inadequate education and/or exposure of trainee nephrologists to peritoneal dialysis, a belief that older patients cannot cope with a home treatment, and increasing numbers of more frail elderly patients who would require assistance from family or community-based healthcare workers. The situation is also confounded by the economic need to fill haemodialysis spaces once a unit exists – this is particularly important in private healthcare systems.

### **Objectives of Renal Association Peritoneal Dialysis working party**

The members of the working party met on 31<sup>st</sup> October and discussed the following issues:

- Is the percentage of patients starting on peritoneal dialysis a measure of quality of patient choice – and if so, what should be the target?
- What are the advantages of home dialysis and peritoneal dialysis in particular?
- How are patients educated to choose dialysis?
- What is the impact of the increase in pre-emptive transplantation in the number of patients starting on peritoneal dialysis?
- How relevant are economic considerations?
- What are the reasons for physician bias?
- How could numbers of patients starting on peritoneal dialysis be optimised?

A literature review had been performed by the working party prior to the meeting. The conclusions reached at the meeting are summarised below.

### **Patient survival on Peritoneal Dialysis and Haemodialysis**

There are numerous registry based studies from US, Europe and Australia comparing survival on haemodialysis and peritoneal dialysis. All are confounded by the different case mix of patients choosing the 2 modalities. Attempts can be made to correct for these confounding factors by statistical adjustments for comorbidities, age, sex and cause of primary renal disease but there are other differences which are more difficult to make statistical adjustments for, e.g., social support, ability to work. Most studies suggest that survival on peritoneal dialysis may be better during the first 2 years but thereafter any survival benefit is lost and survival on HD may become better with longer duration of dialysis. Any survival rate differences however are very small and are hard to relate to the management of an individual patient. The most recent review on this topic is by Vonesh in 2006 (2). He concluded from his review of recent publications and additional analyses of US Medicare data that overall patient survival is similar for HD and HD, but that there are differences within select subgroups of patients related to age and diabetes. These

differences, though, were confounded by small numbers in some groups, and differences in survival being small with limited clinical significance.

**CONCLUSION:** It was agreed by the group that clinically, there is no significant difference in survival of patients starting the two modalities.

### **Technique Survival**

Technique survival is lower for patients on peritoneal dialysis and is accepted as being 50-60% at 2 years (data from UK Renal Registry and NECOSAD study); i.e., 40-50% patients who remain alive and who are not transplanted will transfer to haemodialysis by 2 years. In a recent study of 3269 incident PD patients in UK during 1999-2004 with a mean age of 59.9 years technique survival was <50% at 2 years (4). More dramatically this study observed a 45% technique failure rate over a mean observation of 430 days

In contrast in the NECOSAD study only 9% of HD patients transferred to peritoneal dialysis after 2 years. Few haemodialysis patients are transferred to peritoneal dialysis despite frequent problems with lack of reliable vascular access or inability to dialyse effectively because of symptomatic hypotension. Some patients appear to continue on haemodialysis rather than be transferred to peritoneal dialysis despite multiple attempts at creating vascular access, often with limited longer term success.

**CONCLUSION:** Lower technique survival should not prevent patients being offered peritoneal dialysis, though this information should be given as part of patient education. Longer technique survival is not necessarily the principal objective for many patients starting dialysis as many patients in clinical practice will be transplanted (younger patients) or will die (older patients) within 2 years of starting peritoneal dialysis. Furthermore, the integrated care concept (5) demonstrates how PD as first line therapy can be utilised to provide good clinical outcomes.

### **Quality of life, rehabilitation and satisfaction with treatment**

Studies on quality of life have looked at the dialysis population as a whole and have not been restricted to specific age groups. In all studies, peritoneal dialysis patients are more likely to be younger, Caucasian, better educated, employed and have less co-morbidity. This creates great difficulty in comparing quality of life outcomes on different dialysis modalities. Data from the CHOICE study shows that patients on peritoneal dialysis are more satisfied with their treatment at 1 year (6), but overall most studies show that some items on questionnaires score better for peritoneal dialysis and some other items score higher for haemodialysis (7, 8). No studies have specifically focused on how older patients cope with dialysis; this is being examined by BOLDE (Broadening Options for Long-term Dialysis in the Elderly) which is comparing several measures in matched patients on haemodialysis and peritoneal dialysis (lead investigator, E Brown; funded by Kidney Research UK, results expected in 2009).

**CONCLUSION:** It is hard to capture “living with dialysis” with quality of life studies. Patients and families should be given realistic guidance how each modality will impact on their individual lifestyles

## **Cost-effectiveness of haemodialysis and peritoneal dialysis**

Only one study (9) has formally measured costs of dialysis in the UK, but this was based on stated supplier price lists and not contracted prices. It was generally agreed that costs of peritoneal dialysis treatment are less than standard haemodialysis for several reasons:

- fewer nurses needed
- no capital costs apart from APD or home HD machines and training area
- no costs for patient transport
- less erythropoietin used in peritoneal dialysis

**CONCLUSION:** PbR tariffs for dialysis are still being worked out and will not be introduced until 2010/11. It is therefore not possible to be specific about costs at present, but it was recognised that a higher proportion of patients placed appropriately on peritoneal dialysis would reduce the expenditure incurred by hospital haemodialysis and may ultimately release funding for other healthcare initiatives or requirements.

## **Patient choice and education**

Patient choice is enshrined in the National Service Frameworks for renal disease. Education is key to enable patients to make choice, but there are no UK guidelines how this should be delivered and what information should be given to patients. Education is mostly given by predialysis nurses, but it was recognised that comments from doctors can make patients feel that they have no choice. The role of the predialysis nurse has emerged over the last decade; there is no formal training for the role and there is no professional group overseeing objectives and standards of education.

Manns et al (10) showed in a randomised control trial that one-to-one education enables patients to make a choice; indeed, in this study, 80% patients in the intervention group chose a home therapy. How dialysis education is delivered varies considerably across the UK; some units offer group sessions only, while others offer individual sessions in the hospital or in the patient's home. Predialysis nurses also take on other roles, such as anaemia management, management of conservative care patients, and so with increasing numbers of predialysis patients, many have little time for education outside the clinic setting. Furthermore, many patients approaching dialysis are elderly, often with a degree of cognitive impairment, and many will have hearing or visual problems making it difficult to follow information. These patients, and the many patients from ethnic minorities with a poor understanding of English, will often not attend group sessions and will need their education tailored to their special needs – this tends not to happen.

Two studies have looked at outcomes when patients are enabled to make free choice. The first, and largest, comes from the NECOSAD study (11); this was set up to perform a randomised study of HD compared to PD; only 38 patients agreed to enter the study. Of the remaining 1347 patients, about a third was deemed not to be suitable for medical or social reasons to be able to make a choice. Of the 64% who could make a choice, half chose peritoneal dialysis and half chose haemodialysis. The other study comes from Toronto (12); in this group of patients, 58% of those assessed as able to make an informed choice of dialysis modality selected peritoneal dialysis. The results of these 2 studies are therefore similar, suggesting that around 50% of informed patients able to make a choice of dialysis modality will select peritoneal dialysis.

Which patients select peritoneal dialysis? The NECOSAD study looked at this in detail and showed that patients choosing haemodialysis tended to be older, live alone, have vascular renal disease, have more comorbidity, be less likely to have predialysis care, be unemployed

and have lower educational level. These are the same categories of patients who are often assessed as unable to make a choice of their dialysis modality.

Despite all the above observations, past experience of members in the working party suggests that education does not always enhance selection of home treatment by patients. This was thought partly due to information overload, inappropriate style of education (written and oral), and discrepant information given about peritoneal and haemodialysis.

There are a number of qualitative studies examining specifically how patients make choices and their perceived role in the process (13). All highlight how choice changes over time, the importance of trust and the need for accurate information, but also the importance of understanding the patient's perceptions and roles they want to play which clinicians need to identify and review regularly. Some studies have also identified the role physicians play in guiding decisions (14).

**CONCLUSION:** With appropriate education, studies show that 50% of patients will choose peritoneal dialysis and up to 80% will select home dialysis (peritoneal and home haemodialysis). There was considerable concern that there are no UK standards for dialysis education. It was felt that patient education should focus on home versus hospital based treatments, and then discuss peritoneal dialysis versus haemodialysis once patients have discussed where they would prefer their treatment to take place.

### **Patient awareness of the complications of peritoneal dialysis and haemodialysis**

The main complications of peritoneal dialysis and haemodialysis should be discussed with patients before they make a choice of dialysis modality as patients and their relatives have complained in the past that they were not fully informed about the major complications of both modalities e.g.

All patients considering opting for PD should be aware of:

1. risk of peritonitis (one episode of peritonitis every 20 months of PD in Scottish audit 2002-2007)
2. 50% risk of technique failure and switching to HD after 2 years
3. possible development of Encapsulating Peritoneal Sclerosis during or after stopping PD (incidence of 3.5% after 3-4 years of PD and 8% after 4-5 years of PD in incident Scottish peritoneal dialysis patients 2000-2007)

Similarly all patients thinking of opting for HD should be aware of:

1. risk of local infection of the vascular access and bacteraemia, especially with the use of central venous dialysis catheters (1 episode of catheter related bacteraemia every 12.6 catheter months in a prospective audit at Glasgow Royal Infirmary 2005-2007)
2. risk of developing infective endocarditis and metastatic bacterial infection of the spine and joints if develop a local infection of the vascular access or bacteraemia.
3. small risk of technique failure and switching to PD
4. risk of bleeding complications from the regular use of anticoagulation during HD

Encapsulating Peritoneal Sclerosis (EPS) is well recognised as a severe complication of long-term peritoneal dialysis, occurring in around 5% of patients who have been on PD for more than 5 years. Haemodialysis also has severe complications (complications of line

infections, e.g., endocarditis, discitis; venous thrombosis, need for multiple and increasingly complex vascular access procedures), though their rates are not as well documented as for PD. EPS is increasingly being used as a reason for not putting patients on peritoneal dialysis, partly because many nephrologists see the few inpatients with EPS in each unit much more frequently than the many more healthy outpatients on peritoneal dialysis.

**CONCLUSION:** Patients should be told that both dialysis modalities have complications which can be severe and life-threatening. EPS, itself, is not a reason to avoid using PD. The majority of patients will be transplanted, will have transferred to HD or will have died by 5 years. PD teams are also being much more pro-active by providing appropriate guidance to PD patients as they approach 5 years. How the information is given needs to be carefully considered therefore written information needs to be consistent and appropriate.

### **Patient selection for home dialysis**

In all studies, it is recognised that various medical and social factors are barriers to home dialysis and that therefore not all patients can be realistically given choice. It is well recognised that there are more barriers preventing peritoneal dialysis than haemodialysis. Social factors preventing home dialysis are more frequent amongst older patients (e.g., lack of social support, availability of assistance if the patient is unable to do dialysis independently because of impaired manual dexterity, cognitive problems or physical frailty) and in areas with poor housing accommodation with overcrowding and lack of space to perform the dialysis or store supplies. In published studies (11,12,15), 20-36% patients were designated as not suitable for peritoneal dialysis for such reasons. Inevitably there will be significant variation among units depending on social factors, e.g., age and social mix of population, proportion of ethnic minorities with poor English living in crowded accommodation, availability of home assistance with treatment. Bias for or against home treatment will also impact on proportion of patients thought to be unsuitable for home treatment (16,17).

**CONCLUSION:** Although studies show that only a third of patients are not suitable for peritoneal dialysis, allowance needs to be made for areas of the UK where there are large numbers of ethnic minorities, poor housing and a high proportion of frail elderly. The opinion of the working party was that in such areas, 50% of patients would not be suitable for home dialysis.

### **Impact of pre-emptive transplantation**

It is often suggested that the increase in pre-emptive transplantation is one of the reasons for the observed decline in patients starting on peritoneal dialysis. This in fact is not necessarily true as many of the units with high rates of pre-emptive transplantation in the UK Renal Registry Report (2007) also achieved an average or even above average percentage of incident patients starting on peritoneal dialysis.

**CONCLUSION:** Pre-emptive transplantation will lower the number of patients who may otherwise start on peritoneal dialysis but is not a reason for a low uptake of PD.

### **'Crashlanders' and acute start PD**

Up to 30% of patients starting dialysis do so unexpectedly, either because of late referral and/or presentation, or because of more rapid decline in renal function than expected. Such

patients are mostly started on haemodialysis with central venous dialysis catheters. Some units are proactive about subsequent education and choice of modality but in the majority of units such patients are given little or no education about dialysis in the haemodialysis unit and therefore have no or little choice of modality. Although haemodialysis is the optimal modality for patients with a severely metabolically disturbed acute presentation of end-stage kidney disease, there is no reason why more stable patients could not be started directly on peritoneal dialysis. Historically, this happened very successfully, and a few units are introducing a programme of “acute start peritoneal dialysis”. The evidence is that outcomes are identical for late presenting patients starting on peritoneal and haemodialysis (18). The main factor limiting the use of acute peritoneal dialysis is the difficulty of catheter insertion, especially in units where nephrologists do not insert catheters themselves and are therefore dependent on surgical colleagues.

**CONCLUSIONS:** Enabling late presenters with irreversible renal failure to start directly on peritoneal dialysis will increase the number of patients eventually choosing PD. All patients who present late and start dialysis urgently should receive individualised education within 3 months of starting treatment.

### **Restarting dialysis after transplant failure**

It is well recognised that patients with failing grafts are often not as well managed as patients with similar levels of renal function in low clearance clinics. In particular, it is often assumed that they know about dialysis and choice of modality is not discussed with them. Some will not have been on dialysis previously and for many dialysis will have been many years previously. The majority therefore are started on haemodialysis.

**CONCLUSION:** Patients with failing transplants should have access to education about dialysis modality choice.

### **Elderly and assisted PD**

The median age of patients presenting with end-stage kidney disease in the UK is now 65 years. Many such patients will have barriers to peritoneal dialysis as discussed by Oliver et al (12). These include medical factors (e.g., visual and hearing problems, arthritis, frailty) and psychosocial factors (e.g., depression, needing residential care, cognitive problems). Using a multidisciplinary approach, it is possible to overcome many of these barriers so that the majority of patients can be considered as eligible for home treatment and therefore enabled to choose peritoneal dialysis (19). In Oliver’s experience, access to home care assistance increases eligibility further with up to 80% patients (median age 72 years) considered as suitable for peritoneal dialysis. This has been standard practice in France, where peritoneal dialysis at home with the assistance of community nurses, is considered as the optimal method of providing dialysis to frail older patients, with the result that the age distribution of peritoneal dialysis is considerably skewed to over 70 years and upwards (20). Assisted peritoneal dialysis is slowly being introduced into the UK utilising healthcare assistants from a private healthcare agency. This greatly increases the cost of peritoneal dialysis to nearly the same as centre haemodialysis, though it saves the cost of transport which can be considerable as many frail patients would need ambulance transport to the main centre dialysis unit rather than to a local satellite unit. These costs are currently not recognised by the commissioning process.

**CONCLUSIONS:** The potential advantages of home treatment for the quality of life for older patients should be recognised – particularly the avoidance of the need for transport to and from a haemodialysis unit, which is the commonest source of complaints from haemodialysis patients. Dialysis education should be tailored to the patient so that individual barriers can be discussed. The development of home assistance will enable more older and/or frail patients to dialyse at home, but this needs to be appropriately funded and recognised in the current development of “Payment by Results”.

### **Medical training in peritoneal dialysis**

It is generally recognised that many trainees have inadequate exposure to peritoneal dialysis and that this is one of the factors leading to a decline in its use. Many trainees only see inpatients with major complications of peritoneal dialysis and do not review fit outpatients on peritoneal dialysis. This problem was recently discussed by the peritoneal dialysis leads in London with a resulting document with training recommendations. These have now been endorsed by the North and South Thames training committees. The document was submitted to the SAC, but has not been taken up nationally.

**CONCLUSION:** Recommendations for PD training should be made to STCs who could then ensure that these were signed off by educational supervisors and asked about at RITAs

## SUMMARY OF RECOMMENDATIONS

### 1) Dialysis education for patients

- a) Appropriate education about transplantation and all modes of dialysis should be delivered to all patients – i.e. those from predialysis clinic and late presenters
- b) All patients (including patients with failing transplants) should have a one-to-one education session away from the predialysis clinic or dialysis unit
- c) The Renal Registry should be able to record the one-to-one education session so that this can be audited
- d) Written information should be based on nationally recognised and peer reviewed template.
- e) UK guidelines for delivery of dialysis and transplantation education should be developed

### 2) Percentage of patients starting home dialysis should be an audit measure of patient choice

- a) All patients suitable for home treatment should be offered this choice
- b) The majority of patients will select peritoneal dialysis as easier but some will have medical contra-indications or would prefer haemodialysis at home. Patients failing peritoneal dialysis should also be offered home haemodialysis to enable them to continue on home treatment
- c) 25% of incident patients on home dialysis is a realistic minimum figure for patients starting renal replacement therapy. This target figure is derived from data from the literature:
  - i) 10% patients may receive pre-emptive transplants
  - ii) 90% therefore will start treatment on dialysis; a minimum of 50% of these will be eligible for home treatment, i.e. 45% of total population
  - iii) 60% of patients eligible for home treatment will choose a home treatment if they are given appropriate education and an approach to overcoming barriers is adopted **i.e. 25% total population.**
- d) Many units in the UK are already starting more than 25% of their incident patients on home treatment, but the above approach will probably improve this further
- e) Units not achieving 25% of incident patients on home dialysis at 3 months after the start of renal replacement therapy should be encouraged by commissioners (? with financial incentives) to develop 3 year plan as to how they will improve
- f) Outlier units with low use of home dialysis for 2-3 years should be scrutinised by the audit processes already developed within the UK Renal Registry

### 3) Assisted Peritoneal Dialysis

- a) Development of this modality should be encouraged by an appropriate tariff being developed through the Payment by Results process

### 4) Medical Training in Peritoneal Dialysis

All trainees should:

- a) attend a minimum of 15 PD clinics during their training
- b) annually attend a national course or local dialysis training day which includes a component about PD
- c) complete a miniCEX and CBD (case based discussion) on PD annually

- d) complete the Renal Association sponsored PD e-module during first year of training and produce certificate at Year 1 RITA.
- e) complete a miniCEX and CBD (case based discussion) on PD annually
- f) visit a PD or home HD patient at home at least once during their training

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