**Training patients and their carers to manage Peritoneal Dialysis**

**A Pan-LKN Report**

E**xecutive Summary**

There is variation across London in the training patients and carers receive to manage their peritoneal dialysis (PD). The Home Therapies Workstream of the London Kidney Network has produced recommendations on what good training should look like. These recommendations were developed by clinicians working in home therapies and those with lived experience of PD. The minimum standard of care and treatment is described.

**Recommendations**

1. Those being trained on PD and receiving PD are involved and informed at all stages of training; expectations are explored, rationales are given and where possible indications of timings are provided. Confirmation of understanding is sought at all stages.
2. There is a clear pathway with timelines for starting PD and adequate resources, in particular nursing, to support the pathway.
3. Exit site care training is delivered within 3 days of when it is deemed appropriate for self-management to commence.
4. There is the capacity to start training to administer PD within 14 days of a functional catheter and fully healed exit site.
5. Training and information are provided on all aspects of PD management which are required for safe care at home.
6. The training program is flexible and individualised for the patient / carer with the option of increased time to allow people to become competent and confident, and the ability to train at home if this is required for the patient.
7. For those who require an urgent or unplanned start there is access to assisted APD.
8. Support and surveillance are provided at home when first starting PD, as a minimum, contact is made within the first 2 days of starting dialysis and a home visit within the first 2 weeks by a nurse or appropriately trained nursing assistant, ideally who is known to the patient. There is someone who can be contacted for advice and support and in the event of an emergency.
9. PD technique reviews take place at home. As a minimum these take place every 6 months and: after peritonitis, on the first sign of exit site infection, if there are concerns regarding hygiene or there has been an event / change in circumstances which is likely to impact on PD management.

**Background**

Starting peritoneal dialysis (PD) is a major life event for many people affecting virtually every aspect of life including relationships, work, hobbies, and everyday routines. A good experience in the early stages can help support this transition, help build partnerships between the renal team and the patient and their families / support network and ultimately contribute towards better outcomes. An important part of this initial experience is the gaining of knowledge and skills to enable the person and / or carer to manage their dialysis independently and safely. With this in mind, The London Kidney Network has produced this document describing what good training for peritoneal dialysis should look like, taking into account clinical standards and patient experience. It has been developed by those involved in PD training across London including PD nurses, nephrologists working in PD and those with lived experience of PD.

It describes the minimum care / standard of treatment as agreed by the experts involved in the care of people being trained to perform PD. It is not the aim of this document to give specifics about the content of the training program; the ISPDGuidelines, A syllabus for teaching PD to patients and care givers, provides recommendations on the content of the training program. It is recognized that practice may vary from unit to unit and good evidence to suggest one training pathway over another is lacking. For this reason, some units are working to tighter criteria, but all have agreed to the minimum description of the ‘good’ training pathway as described here.

**Recommendations:**

1. Those being trained on PD and receiving PD are involved and informed at all stages of training; expectations are explored, rationales are given and where possible indications of timings are provided. Confirmation of understanding is sought at all stages.

The partnership between the patient and the renal unit is key to a good relationship and better outcomes. Those with lived experience tell us how important it is to have ownership of their treatment and be involved at all stages. Having a better understanding of the reasons for processes will help with concordance. Providing timings allows patients to plan, limits disruption to their life and helps to reduce anxiety. It is important to use a variety of strategies to confirm understanding and employ these frequently during all stages of training.

1. There is a clear pathway with timelines for starting PD and adequate resources, in particular nursing, to support the pathway.

The pathway encompasses all aspects of starting PD from shared decision making on the choice of dialysis modality, to successful dialysis at home. It includes the catheter placement and training on all aspects of PD, initial and ongoing training. There is consideration of the resources required, in particular, nursing expertise and nursing time to support the pathway and ensure timelines are achievable. There is flexibility in terms of the pathway and resources to allow adequate support for people who need a more individualised approach (high risk patients). People being trained on PD are given clear information on these timelines and what to expect and when.

1. Exit site care training is delivered within 3 days of when it is deemed appropriate for self-management to commence.

Units have local protocols regarding the timings of self-care of the exit site, and timing may vary depending on the individual and method of placement. Once it is safe for the patient to start self-care training should be provided promptly within 3 days. The rationale for the timings should be discussed with the patient.

1. There is capacity to start training to administer PD within 14 days of a functional catheter and fully healed exit site.

There may instances where a decision has been made to delay training, e.g., for clinical reasons or due to patient choice, however there should be the capability to train within 14 days.

1. Training and information are provided on all aspects of PD management which are required for safe care at home.

In addition to technique and care of the catheter, this training includes, but is not limited to, disposal of waste, placing orders, delivery dates, storage, recording of output of CAPD and weight, special considerations if there is a day off dialysis e.g. draining out. The impact or likely impact of PD on the individual’s lifestyle is discussed, aspects such as washing and showering, activity and exercise, occupation, relationships, diet, and bowels are included. The impact on other co-morbidities such diabetes and hypertension are discussed, consider any changes in medications or management which might be necessary. It is important to ensure the patient knows how to identify potential complications in particular peritonitis and exit site infection and knows what action to take.

Chronic kidney disease and starting dialysis can have a significant impact on emotional wellbeing and mental health. As part of the training this should be discussed, acknowledged and where necessary sign posting to support.

We recommend using a training check list which is shared with the patient and the wider PD team to ensure all areas are covered. The patient should be made aware that changes might be required in the future and that an explanation for these changes will always be communicated.

1. The training program is flexible and individualised for the patient / carer with the option of increased time to allow people to become competent and confident, and the ability to train at home if this is required for the patient.

Flexibility is important, the standard training will not meet everyone’s needs. Having a flexible responsive service will increase access to PD and help reduce inequalities of care.

1. For those who require an urgent or unplanned start there is access to assisted APD.

Ideally assisted APD is provided at home, but this could be in house until the patient is fully trained. For those who are starting dialysis with a lower kidney function, dialysis before training has the benefit of reducing ureamia and fluid overload, hopefully the patient will feel better and be able to engage more with the training.

1. Support and surveillance are provided at home when first starting PD, as a minimum, contact should be made with the person within the first 2 days of starting dialysis and a home visit within the first 2 weeks by a nurse or appropriately trained nursing assistant, ideally who is known to the patient. There is someone who can be contacted for advice, support and in the event of an emergency.

The initial contact within the first 2 days could be a phone call, video call or home visit. However, it is important that the patient is visited at home by a nurse or appropriately trained nursing assistant within the first 2 weeks of starting dialysis and their technique observed. This provides support and reassurance, allows for identification of incorrect technique, and contributes to reducing infection. The reasons and benefits for this home visit should be explained to the patient and carer, emphasising that even those who feel confident with the technique will benefit from a visit. At all times it must be kept in mind that one of the reasons for choosing home therapies is to promote self-care, independence and reduce the impact of dialysis on lifestyle. Wherever possible visits and calls should be booked in advance and if possible, the observation should fit in with the patient’s usual dialysis times. Ideally, a nurse who is known to the patient will provide this support and surveillance. There should always be someone who can be contacted for advice, support and in the event of an emergency.

1. PD technique reviews take place at home. As a minimum these take place every 6 months and after: peritonitis, the first sign of exit site infection, if there are concerns regarding hygiene or there has been an event / change in circumstances which is likely to impact on PD management.

PD technique reviews are an important part of ongoing training and surveillance and should take place at home. As a minimum there should be a review every 6 months. Technique should also be reviewed after peritonitis or at the first sign of exit site infection. Additional reviews should take place if there is concern regarding hygiene or a significant health or life event which may affect PD. Below is a list of ‘red flags’ which will trigger a technique review, this is not exhaustive:

* Patient has dirty hands or dirty fingernails
* Multiple changes of extension line
* After a long hospital admission
* If usual support system is disrupted e.g., divorce, carers away
* Change of housing,

**Suggested Monitoring**

It is important to monitor the training provision to allow for continual improvement. We suggest the following metrics:

Number of patients (%) waiting longer than agreed time to start training (planned starters)

Number of patients unable to access aAPD whilst waiting for training

Number of avoidable inpatient days due to suboptimal training pathway

Number of people deemed not competent at training at first PD check

Patient experience measure

Starting haemodialysis as unable to provide PD

Early peritonitis – within 3 months

Coming off PD within 90 days due to technique failure