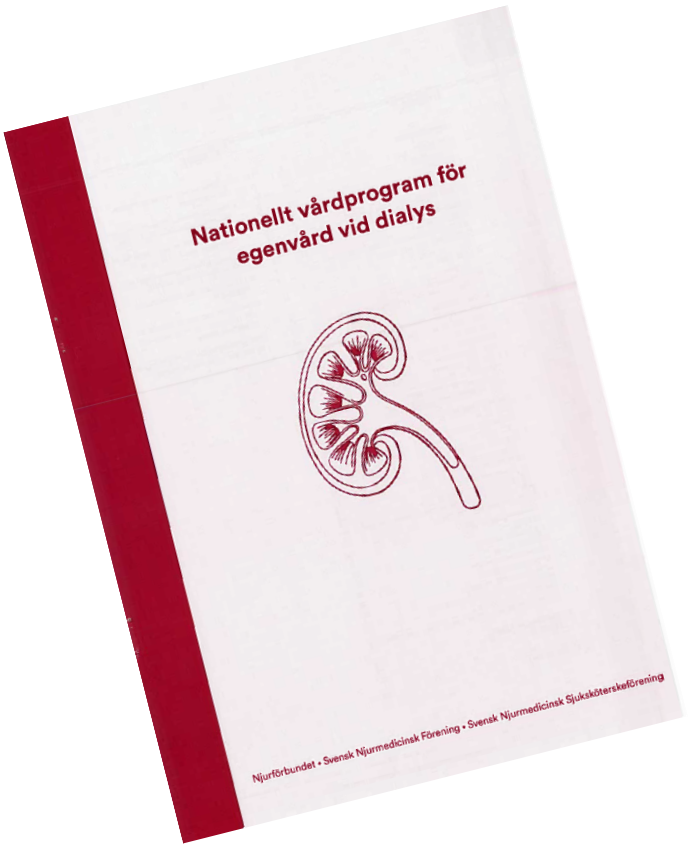
National care program for self-care in dialysis. (Sweden 2019)



Swedish Kidney Association, Swedish Society of Nephrology and Swedish Nephrology Nurses Association

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Appendices 6 and 7 are separate documents that can be downloaded from www.dialys.nu.

Summary

According to the National Board of Health and Welfare (Socialstyrelsen) definition, self-care refers to the situation in which licensed medical personnel have assessed that an individual, either alone or with assistance from someone else, is capable of carrying out a medical procedure. Self-care in dialysis has been practiced since the late 1960s when the first patients brought home their dialysis equipment. Self-dialysis with support from medical personnel, referred to as "limited care," was very common until the early 1980s, after which the practice declined.

Since 2000, self-dialysis with varying degrees of support from healthcare personnel has once again become more common. Many dialysis centers have self-dialysis units that provide patients with the opportunity to manage their treatment independently without involvement of medical personnel, a process referred to as self dialysis (SHD). Some patients also manage their dialysis treatment independently at home. But the proportion of patients who have chosen to conduct dialysis at home, either as hemodialysis (HHD) or peritoneal dialysis (PD), has leveled off and even declined over the past two decades.

The purpose of this care program is to reverse that trend so that more people who require dialysis will have the opportunity to choose self-care. The care program also aims to establish national guidelines for all dialysis-related self-care and to replace local and regional care programs to ensure equal care regardless of home community. The care program is primarily intended for affected medical personnel and healthcare decision makers.

An explicit goal of the care program work group is to increase the proportion of patients who practice self-care in dialysis from the current level of barely 30 percent up to 50 percent. Peritoneal dialysis (PD) should be the method of choice when possible. It should be possible to increase the proportion of patients who practice PD from the current 20 percent up to 30 percent. The assessment of the work group is that 10 percent of patients should be able to practice hemodialysis at home (HHD). Currently, barely 4 percent of patients at one dialysis center practice self-dialysis (SHD). This proportion should be 10 percent.

At the start of the care program project, a health economics study was conducted at Lund University (see appendix) which concluded that HHD and PD have a positive impact on employment, while reducing healthcare costs. This conclusion should provide clear incentive to increase self-care initiatives concerning dialysis.

Currently, several obstacles need to be removed in order to increase the number of patients who practice dialysis at home. Reimbursement of additional costs when initiating home dialysis

after the age of 65 has not yet been established and only a few healthcare authorities have a regulatory framework that reimburses older patients for the additional costs related to dialysis

treatment. The division of responsibilities between municipality and healthcare authority related to assisted PD is a problem which in some cases could preclude PD as an option for patients who need home healthcare services.

The care program stipulates the minimum requirements and conditions that need to be met, as well as the legal division of responsibilities, for patients who are partially or completely independent in managing their dialysis.

The work group that formulated the care program included representatives from the Swedish Kidney Association, the Swedish Society of Nephrology (SNF) and the Swedish Nephrology Nurses Association (SNSF). The project was financed by the National Board of Health and Welfare through funds earmarked for chronic diseases, as well as funding from the Swedish Kidney Association.

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Terms and abbreviations

- HD – hemodialysis.
- HHD – home hemodialysis, hemodialysis conducted independently at home, or with assistance from a family member or other person.
- PD – peritoneal dialysis carried out at home or as assisted PD with help from healthcare personnel employed within the municipality.
- SHD – self-hemodialysis, hemodialysis carried out completely independently at a dialysis center without assistance from medical personnel.
- SHDLC – self-hemodialysis (limited care) at the dialysis center with assistance from medical personnel.

1. Introduction

1.1 Background

In 2015 the Swedish Kidney Association initiated a collaborative effort with the Swedish Society of Nephrology (SNF) and the Swedish Nephrology Nurses Association (SNSF) to arrange a workshop on self-care in dialysis. The common perception was that substantially more people undergoing dialysis should be capable of managing their treatment either completely independently, or with minimal assistance from medical personnel, than is currently the case. The dialysis centers do not always take advantage of these opportunities. The proportion of individuals who manage their own dialysis at home has remained constant for many years.

The workshop was held March 10-11, 2016. All relevant personnel categories from various parts of the country participated, along with individuals with personal experience of dialysis. External speakers participated during parts of the workshop and held talks on legal issues, health economics and person-centered care.

The workshop revealed large regional differences with respect to procedures and involvement with self-dialysis (SHD), home hemodialysis (HHD) and peritoneal dialysis (PD). These differences were clearly confirmed in the annual report of the Swedish National Kidney Registry.

The discussions also brought to light ambiguities regarding who is legally responsible for the treatment when patients manage dialysis themselves at the unit within the care provider's building, in the patient's home, or elsewhere. Furthermore, the insurance issue is unclear should a treatment injury occur, or if someone dies due to malpractice. The question of whether supplementary insurance is required in cases that are not covered by the Swedish patient insurance system was discussed and remained unresolved.

Everyone agreed that many people who undergo dialysis have untapped potential to manage their own treatment, either through PD, SHD or HHD. Opinion was unanimous that a national care program for self-care in dialysis is needed.

There was consensus among workshop participants to form an expert panel and task it with developing a care program for self-care in dialysis treatment. In the first six months of 2016, the Swedish Kidney Association appointed representatives from the Swedish Kidney Association, the Swedish Society of Nephrology (SNF) and the Swedish Nephrology Nurses Association (SNSF) to serve on the expert panel.

The National Board of Health and Welfare allocated two rounds of project funding in 2016 and 2017, totaling SEK 463,500, to develop the care program as part of the Government initiative to improve care for people with chronic diseases.

A health economics study was conducted within the framework of the project in late 2016 in collaboration with researcher Johan Jarl at Lund University

1.2 Aim

The care program shall be a national care program for self-care and patient involvement in dialysis. The purpose is to create national guidelines to replace the many regional and local care programs currently in place. The goal is to achieve equal care regardless of regional affiliation. Such a national care program should take the needs and desires of the patient into account and promote a stronger partnership.

1.3 A person-centered approach is essential for good quality of life

In many cases, the realization that chronic renal failure is becoming life-threatening unless treatment such as transplantation or dialysis is initiated usually comes as a shock to the patient. Such information almost always triggers an existential crisis in the patient. Not until the new orientation phase does the individual become receptive to constructive solutions (Crisis and Development by Johan Cullberg). This knowledge is extremely important if the patient is to enter into partnership with the healthcare system and assume responsibility for self-management of a large portion of the treatment. This implies that self-care in dialysis (PD, HHD or SHD) is only a realistic alternative for patients who have passed beyond the existential crisis and started looking for their own solutions.

Patients for whom dialysis is being planned can become involved in their own treatment in many ways.

Everything hinges upon providing patients with knowledge and understanding of their renal disease, a process for which the groundwork should be laid long before the first dialysis treatment begins. Meeting people who are successfully undergoing dialysis may reduce fear and discomfort prior to starting their own dialysis treatment. Individual field trips to self-dialysis units and PD centers, as well as meeting people on home hemodialysis should be routine preparatory educational measures.

Knowledge about dialysis and how the equipment functions promotes self-esteem and quality of life, while allowing a partnership to develop between dialysis patients and medical personnel. Incremental learning and involvement aimed at ultimately gaining full control over dialysis treatment raises self-esteem and reduces dependence on medical personnel. A person-centered approach that views the dialysis patient as a partner increases quality of life while encouraging more people to opt for self-management of their treatment either in the unit or at home.

Self-care should be a goal for all patients undergoing renal care, not just those undergoing dialysis. This approach increases independence, while reducing dependence on healthcare resources. The use of modern digital technology for communication and monitoring can help more individuals to achieve self-management of their disease.

1.4 Goal

The proportion of patients who independently manage their dialysis, either at home or as self-dialysis at a dialysis center, has remained constant for many years. A reasonable goal is for about 10 percent of all patients who require dialysis to have HHD, about 30 percent PD and at least 10 percent SHD.

1.5 Course of care in chronic renal failure

Chronic renal failure can be divided into five stages, in which stage five ultimately requires treatment with renal transplantation or dialysis, known as active uremic care. Investigations and medical preparations for these treatments should usually begin during stage four or five, depending on how rapidly renal failure progresses. The renal failure coordinator should provide information and patient education, as well as initiate discussions concerning renal failure, dialysis and transplantation at an earlier stage. A few patients may choose to refrain from dialysis and renal transplantation, in which case they continue to receive medical treatment with follow-up at the renal clinic.

Patients who are healthy enough for renal transplantation may receive a kidney from a living donor, or be placed on a waiting list for transplantation from a deceased donor. Assuming favorable medical circumstances, renal transplantation should be a primary goal and should preferably be carried out prior to initiation of dialysis if the patient has a living donor.

Comprehensive patient information on various methods of dialysis should be provided well in advance, either in a group or individually, and should include how patients can actively participate and independently manage their dialysis at home or at a self-dialysis center. Self-care should be presented as an option that is well-suited to achieve treatment goals and well-being.

For the majority of patients, dialysis will be the first and only type of treatment. Patients who are planned for peritoneal dialysis require a peritoneal dialysis catheter to be surgically implanted in the abdominal cavity.

This procedure can advantageously be undertaken a few weeks before dialysis needs to be started. Patients who are planned for hemodialysis need to have an arteriovenous (AV) fistula created well in advance to access the bloodstream. Several months may be required before it can be used for dialysis. Concerning patients who do not have time for creation of an AV fistula, or who have problems with fistula maturation, dialysis may begin using central dialysis catheter access, which increases the risk of serious infections.

Patient education should be provided to individuals who plan to self-manage their peritoneal dialysis or hemodialysis well before dialysis becomes an absolute necessity.

Patients who present with acute renal failure, or who have had chronic renal failure unknown to the nephrology clinic, require immediate initiation of dialysis. Most of them will then receive inpatient hemodialysis using a central dialysis catheter. One challenge for the future is to increase the use of peritoneal dialysis in the acute setting and to help these patients transition to some form of self-dialysis following initiation of acute dialysis.

2. Self-care

2.1 Definition

According to the National Board of Health and Welfare (Socialstyrelsen) definition, self-care refers to the situation in which licensed medical personnel have assessed that an individual, either alone or with assistance from someone else, is capable of carrying out a medical procedure.

2.2 Self-care in dialysis - concept definitions

This care program has been limited to three different types of care in the field of dialysis with the following definitions of terms according to the Swedish National Kidney Registry (SNR):

- HHD – Home hemodialysis, hemodialysis conducted independently at home, or with assistance from a family member or other person.
- PD – Peritoneal dialysis carried out at home or as assisted PD with help from healthcare personnel employed within the municipality.
- SHD – Self-hemodialysis, hemodialysis carried out completely independently at a dialysis center without assistance from medical personnel.

2.3 Background and regulations

All health care, except for services provided under legislation concerning compulsory care, is voluntary and the patient has the right to refuse to receive care. Health care refers to interventions to medically prevent, investigate and treat illnesses and injuries. Health care includes services that are deemed to require personnel who are trained to provide healthcare services, or such personnel in collaboration with other staff. In general, it is not possible to identify what interventions constitute self-care because this depends on the circumstances in each case. According to the National Board of Health and Welfare's self-care regulations, the assessment must be carried out in consultation with the patient, based on the physical and mental health of the patient, while taking into account his or her life situation in general. This means that the result depends on whether circumstances enable the patient to safely manage self-care, or whether the patient can instruct someone else to help. If the individual is unable to assume responsibility for self-care, the result of the assessment depends on the nature of the available support and assistance. Self-care may be an option if the intervention can be safely carried out by someone else, such as a family member or personal assistant.

2.4 Requirements

One way to distinguish between health care and self-care is to assess whether or not the intervention requires personnel with medical training. If medically trained personnel are required, the situation involves health care and is therefore subject to healthcare legislation. However, under certain circumstances family members may have gained sufficient knowledge about the needs of an individual patient to be able to carry out interventions that usually require trained medical personnel. In such cases, the situation involves self-care. For example, this may be the case when parents help their children.

Should a patient have sufficient support so that the intervention can be safely carried out, it could also be considered to be self-care in situations such as when a few personal assistants are assigned to and become familiar with the needs of the individual patient.

2.5 Assessment

Assessment according to the National Board of Health and Welfare regulations for assessment of self-care (SOSFS 2009: 6):

The treating licensed medical professional shall, within the limits of his or her area of responsibility, assess whether a medical intervention can be carried out as self-care. In other words, the healthcare provider determines what interventions can be carried out as self-care in each individual case. The person making the assessment must analyze whether any risks are associated with classifying the intervention as self-care. It must be determined whether the patient can safely carry out the relevant medical intervention as self-care, or whether the patient can accomplish the intervention with assistance from someone else.

The patient may need practical assistance in order to carry out the intervention as self-care. In such cases, the care provider responsible for the assessment must first consult with the person who is to assist regarding the regulations concerning confidentiality. A medical intervention must not be assessed as appropriate for self-care if the analysis shows that there is a risk that the patient will be injured.

The self-care assessment and planning must be documented in the patient's medical records.

The patient must receive information about what self-care entails. This means that the care provider making the assessment must inform the patient that the intervention to be carried by the individual alone or with help from a family member is not considered to be health care, and is therefore not covered by healthcare legislation.

2.6 Planning

It is important to plan self-care so that it can be carried out safely. For example, everyone involved must clearly understand what to do should the patient's situation change, whom to contact if the patient is at risk of injury and who should give instructions. If the patient is personally responsible for self-care, in relevant cases someone must be available who can be contacted should the patient's condition worsen and if the patient needs help.

Self-care planning should clarify:

- The intervention assessed as self-care
- Whether the patient will carry out self-care alone or with assistance from someone else.
- How information and instructions will be provided to those involved in delivery of self-care.
- What measures should be taken and whom to contact, should the patient sustain or be placed at risk of injury or disease in conjunction with self-care.
- What measures should be taken and whom to contact, should the patient’s situation change.
- How and when to follow up the assessment to permit self-care.
- When the assessment to permit, self-care should be reconsidered.

2.7 Legal responsibility in relation to self-care

The legislator views self-dialysis as one of the more advanced care interventions that may be appropriate for self-care. The self-care decision means that the intervention can no longer be considered as health care within the meaning of the law. Therefore, interventions following such a decision are not covered by the regulatory system that applies to health care. The logical consequence of this is that the person in such cases who helps the patient to carry out the self-care intervention is not subject to supervision. Therefore, any error committed by such a person can only be legally addressed within the framework of criminal or labor law. The potential to intervene against the individual within the framework of these rules will be strongly dependent on the individual circumstances in each case. However, a licensed individual who assists the patient with self-care, which in some cases may be a family member, should be considered to be subject to supervision, regardless of whether assistance is provided privately or professionally.

The implications of the legislation and the National Board of Health and Welfare regulations entail requirements for licensed personnel to be responsible for educating and training patients and other individuals who participate in dialysis self-care.

The self-care decision means that the intervention can no longer be considered as health care. The logical line of reasoning is that the requirements of the Health Care Act do not apply to self-dialysis carried out in hospitals. The patient is to a certain extent responsible for incidents and events that may cause personal injury. However, an incident shown to occur as a consequence of a self-care decision made by licensed healthcare personnel based on erroneous grounds may still result in criticism aimed at the doctor. It is the responsibility of licensed healthcare personnel to ensure that the patient is not subjected to greater risk as a consequence of self-care compared with the same intervention carried out by healthcare personnel.

As a start, it can be concluded that SOSFS 2009:6 says nothing about where a self-care intervention should take place, even though the assumption is that such interventions are generally carried out in the patient's home. The point of departure should therefore be that a self-care intervention can be carried out wherever it becomes relevant. However, further analysis should be undertaken concerning whether other sections of the law within the legal medical regulatory system are affected.

The general requirement for safety and appropriateness of premises and equipment are described in Chapter 5, Section 2 of the Health Care Act (2017:30, HSL), as follows: “Premises in which healthcare services are provided must be staffed by the appropriate personnel and equipped as necessary so as to provide good care." It has been established above that the self-care decision means that the intervention can no longer be considered as health care. The logical line of reasoning is that the requirements of the Health Care Act do not apply to self-dialysis carried out in hospitals.

The fact that self-dialysis is considered to be self-care does not limit the responsibility of the care provider or healthcare personnel under SOSFS 2008:1 concerning the use of medical devices. In other words, the regulations governing both self-care and the use of medical devices apply to self-dialysis. The head of services is responsible for ensuring that the medical device used in self-dialysis on the hospital premises and in the patient's home must meet the same safety, service and maintenance requirements as equipment within the healthcare system at large.

Regarding self-dialysis, when the intervention is to be carried out in the home of the patient, the head of services is responsible for ensuring that the equipment provided to the patient is safe and traceable. The information that ensures traceability must be documented in the patient's medical records. In addition, the head of services is responsible for assessing what skills are required by professionals who prescribe the equipment, and the prescriber must possess that skill.

(Information in section 2.7 from Institutet för Medicinsk Rätt AB)

2.8 Insurance coverage in conjunction with self-care

Society covers patients who suffer personal injury in conjunction with care and treatment through the Patient Injury Act (1996:799). However, this legislation only applies to injuries that occur in conjunction with healthcare services provided by personnel covered by Chapter 1 of the Patient Safety Act (primarily people who are licensed by the National Board of Health and Welfare to provide health care). Since self-care is not carried out by such personnel, there is a gap in the law concerning insurance coverage for people who self-manage their dialysis.

All care providers, both public and private, are obliged to take out insurance that covers their liability to pay compensation in such cases. Patients are covered through the care provider insurance policy. Each healthcare region in Sweden carries patient insurance through Löf (Landstingens Ömsesidiga Försäkringsbolag), which thereby insures about 90 percent of Sweden’s care providers. In its capacity as an insurance company, Löf reviews each reported case. Since no case of hemodialysis-related injury has yet come under review, there is no precedent.

It is important to assess private insurance coverage, such as household insurance, sickness and accident insurance and life insurance. These are taken out privately and premiums and terms vary among different insurers.

As a rule, it is not possible for people to insure themselves against a known illness (pre-existing condition) when the policy is taken out. The insurance companies carry out their own risk assessment of the state of health of the individual, but it can be difficult to insure against sequelae of the illness. This applies to both health insurance and life insurance. Accident insurance offers protection for a sudden external unforeseen event caused by something over which the policyholder has no control. People who have a mortgage have the option to take out loan protection insurance as an alternative to life insurance.

Since a dialysis machine requires water and water lines in the home, there is a risk of accidents such as leaks that may damage interior furnishings. People who live in a single-family home or a condominium should have a supplement to their home insurance that covers any damage to the residence.

An umbrella policy covers sudden unforeseen events. The liability insurance included in the home insurance policy provides protection for lawsuits against the insured, for example if water damage in a condominium causes damage in a neighboring residence.

3. Prior to initiation of dialysis

3.1 Information about different dialysis options

The renal failure coordinator should provide the patient with information concerning self-care options well in advance of starting dialysis. If dialysis needs to be started emergently, the patient should be provided with support and information as soon as possible regarding the respective advantages of SHD, PD and HHD.

Both patient and family should receive information about the various treatment options at hand well in advance of starting dialysis. PD should be considered the method of choice when deemed medically feasible and where the patient considers him/herself to have the resources to successfully manage such treatment. PD provides the greatest freedom of movement and because treatment is continual it results in an even exchange of waste products and excess fluid, for which reason PD is to be considered the dialysis method of choice.

Patients with residual function who are undergoing HD that was started emergently should have the right to receive support and information about the possibility of changing their treatment to PD.

3.2 Support functions related to self-care

3.2.1 Care team

People who require dialysis, regardless of self-care, shall have access to a care team, in which the patient is viewed as a participating member of the team. A care team should comprise a doctor, nurse, social worker, dietician, physical therapist and, if necessary, medical technician, psychologist and occupational therapist.

3.2.2 Home modifications

Home improvement grants can be applied for through the municipality when dialysis is carried out at home. The purpose is for people with disabilities to be able to remain in their homes and live as independently as possible. Specifically, the home infrastructure must be adapted to meet the needs of the disability. In some cases, investments in the plumbing system may be necessary in order to carry out dialysis. For the grant to be approved, an occupational therapist, doctor or other expert must certify that the modification is necessary. People who rent an apartment must obtain permission from the landlord to allow the modification to be carried out. Condominium owners may also require permission from the homeowner’s association. Grants are only approved for modifications to a permanent residence in which the applicant intends to live permanently. Application procedures for the grant vary by municipality.

3.2.3 Support from social worker

The social worker who is part of the care team must provide the patient with information concerning the financial support to which the patient is entitled to cover additional costs and, if necessary, to provide counseling. In cases where the patient is not entitled to disability benefits from the Social Insurance Agency, for example as a result of the 65-year rule, the healthcare authority shall provide similar financial assistance to cover the additional costs incurred as a result of home dialysis treatment. Currently, the rules applied by the various healthcare authorities differ in regard to

reimbursement for additional costs, which in some cases may prevent the patient from receiving treatment at home.

3.2.4 Support from dietician

Diet is an important part of all dialysis treatment. Each dialysis patient, regardless of whether treatment occurs at home or at a dialysis center, should be given the opportunity in conjunction with training and while under treatment to receive dietary counseling from a dietician who is a member of the care team.

3.2.5 Support from physical therapist

Each dialysis patient, regardless of whether treatment occurs at home or at a dialysis center, should be in contact with a physical therapist who is a member of the care team in order to create a personalized exercise program aimed at maintaining or improving physical fitness.

3.2.6 Support from occupational therapist

To plan housing modifications and assess the need for assistive devices related to home dialysis, PD or HHD, the patient should have access to an occupational therapist who is a member of the care team.

3.3 Organization for self-care in relation to dialysis

To ensure continuity and expertise, HHD training and education should be concentrated to larger home dialysis centers or to closely collaborating smaller centers. Collaboration with a center that is well-organized to handle HHD is preferable. PD can advantageously be based at the same center as HHD. A single location offering both HHD and PD may be advantageous to patients, in the event that the type of dialysis needs to be changed. Patients and personnel are already acquainted with one another, which contributes to a sense of security. The home dialysis center can advantageously be located outside the traditional hospital campus in order to emphasize the healthy aspects of these patients. When training is provided at a general dialysis center, it should be conducted in a private room.

4. Peritoneal dialysis (PD)

4.1 Background

Just over one quarter of the dialysis population uses PD, which is the second most common form of dialysis. Three-quarters of patients who self-manage their dialysis have chosen PD. This is a mobile treatment that can be conducted exclusively in the home or wherever else the patient may be. Use of PD varies significantly across the country, but in general it is underused. One goal is for about 30 percent of all dialysis patients to use PD.

4.2 Method description

In PD, the peritoneum functions as a dialysis membrane. About 2 liters of dialysis fluid are pumped in and out of the abdomen through an implanted dialysis catheter. Through the processes of osmotic pressure and diffusion, an exchange of metabolic waste products and excess fluid, normally filtered by the kidneys, occurs between the peritoneum and the dialysis fluid.

The treatment can either be conducted manually 4–5 times during daytime, known as continuous ambulatory peritoneal dialysis (CAPD), or by using a machine that automatically turns the dialysis fluid on and off at night (APD). Assisted PD is used in cases where the person is unable to self-manage dialysis. In these cases, treatment is administered by specially trained personnel within municipal home health care.

4.3 Organization

PD services at a dialysis center should be staffed by specially assigned personnel. PD services can be advantageously integrated with other self-care options at the dialysis center. Patients should be informed about where they can obtain additional information and support should treatment-related complications arise. Since many patients carry out their treatment at night, advice should be available to them round the clock.

4.4 Catheter placement

Catheter placement should be undertaken well in advance of the planned start of dialysis. The surgeon should be experienced to ensure proper function and minimal risk of complications. If there is a lack of experienced surgeons at the center in question, catheterization should be undertaken at a center where expertise is available.

4.5 Dialysis training

Patients who are planned to have PD should, together with a family member or friend, receive information from the renal failure coordinator or the PD nurse well before the estimated start of dialysis regarding the treatment process and how it may affect lifestyle and the family situation, as well as about what requirements need to be met in the home. Manual (CAPD) and/or automatic dialysis fluid management using the machine at night (APD) should be discussed during the initial phase. Provided there are no medical obstacles, patients should be given the opportunity to select the method of choice best suited to their lifestyle. Planning prior to PD catheter placement is important since too long a delay in a uremic patient has negative consequences on training time. Similarly, experience shows that placing a PD catheter too early may cause more technical problems, such as changes in catheter position.

Training and education should begin as soon as the PD catheter is assessed to function. If it is still too early to begin using the PD catheter at the start of training/education, a training apron can be used. Home visits should be planned to resolve any additional issues prior to the start of dialysis. A social worker should be contacted regarding the grant application for additional costs well in advance of the anticipated start of dialysis. Should assistive devices and housing modifications be needed, an occupational therapist should be included in the team to prepare for discharge to the home.

During the training period, patients should be offered housing at a patient hotel or regular hotel, unless they are able to stay at home.

4.6 Assisted PD

If it has been determined that the patient is unable to manage PD independently, municipal home health care should be contacted to ensure that specially trained personnel who can assist the patient are available. The district nurse may delegate the task to assistant nurses who have received special training and who will collaborate with the patient's own PD nurse. In certain cases, initial assistance with PD may serve as support and a continuation of training with the ultimate aim of enabling the patient to manage treatment independently.

4.7 Home modifications

PD usually does not require any special modifications to the home. There should be sufficient room to store materials since the liquids occupy a large amount of space. Support from the social worker should be provided since it may be necessary to move to a different residence. An occupational therapist should be involved under special circumstances in conjunction with home modifications. Should the home need to be remodeled, the patient must contact the municipality to apply for a housing modification grant.

4.8 Equipment prior to returning home

Once patients are fully educated and ready to begin home dialysis, the PD center should provide them with the necessary equipment to use at home. Should the patient require additional assistive devices/technical solutions in order to manage their PD treatment, the PD center along with, for example, the medical engineering department, should offer assistance.

4.9 Distribution and disposal of consumables

Distribution of consumables and disposal of empty packaging must be done according to an individually tailored plan. Consumables should be delivered directly to the patient's home or other address.

Patients should be informed of any changes to the range of consumables offered, and if necessary, be given new instructions on proper use. Patients should be able to place orders online or by phone.

4.10 Travel in conjunction with PD

One of the advantages of PD is that the patient is significantly more mobile compared with other types of dialysis and the treatment can be carried out wherever the patient may be. Regarding longer trips in Sweden and abroad, the PD center should help the patient to order sufficient fluids.

5. Home hemodialysis (HHD)

5.1 Background

Over three quarters of all dialysis patients use hemodialysis. This treatment is generally carried out at a dialysis center. The patient may manage treatment independently, either as self-dialysis (SHD) at a special center or at home (HHD).

Both SHD and HHD are underused with less than four percent use of each among people on dialysis. One goal is for about 10 percent or more of all dialysis patients to be able to carry out dialysis at home.

5.2 Method description

In hemodialysis, the blood is purified outside the body for which good access to the bloodstream is required, known as vascular access. This can be accomplished through an arteriovenous fistula (AV fistula), which means that an artery and vein are connected through a surgical procedure in order to achieve high blood flow. Another common alternative is placement of a central dialysis catheter (CDC). In both cases, blood is continuously pumped through tubes from the patient's vascular access to the dialysis machine, which serves as an artificial kidney in which waste products and water are filtered through a semipermeable membrane. The purified blood is then returned to the patient.

5.3 Dialysis access

An AV fistula should be placed by an experienced surgeon well in advance of starting dialysis in order to minimize the risk of complications. Should such expertise be unavailable at the home hospital, the patient should be referred for this procedure to a center that is staffed with a specialist in dialysis access.

5.4 Home dialysis training

Training prior to discharge to the home should be carried out at a dialysis center, home dialysis center, or in the patient's own home. To enable a timely return home, patients should be offered training five days per week. This also provides the patient with an idea of how it feels to carry out dialysis more often, thereby increasing motivation for more frequent dialysis. If the dialysis center is far from home, patients should be offered the opportunity for overnight accommodation at a patient hotel or the like during the training period.

All information should be documented and signed by both the patient and trainer(s). A written manual with instructions and measures to be taken for various alarms and error codes that may arise should be provided for treatment with the dialysis machine. The manual can advantageously be made available on a digital tablet which can be provided to the patient as needed.

5.5 Home modifications

Some home modifications are usually required for HHD. There should be sufficient space where the treatment is to be carried out, as well as for storage of consumables. Support from the social worker should be provided since it may be necessary to move to a different residence. An occupational therapist should be involved if modification of the residence is required.

Should the home need to be remodeled, the patient must contact the municipality to apply for a housing modification grant. There should be a list of requirements that the home must meet to carry out HHD. Patients are encouraged to contact their insurance company to check that their home insurance and property insurance policies cover any costs that may arise in the event of damage.

5.6 Equipment prior to returning home

Once the patient is fully trained and ready to begin home dialysis, the home should be equipped with a dialysis machine along with the necessary water purification system. It is extremely important that the patient have a blood leak detector that provides an alert in case blood leaks around the patient's vascular access. There should also be an alarm for potential water leaks. If the dialysis machine is not equipped with a built-in alarm, several external blood leak detectors are available on the market. Should anything else be needed for the patient to be able to safely carry out home dialysis, help with practical solutions should be provided.

5.7 Assistance and support after returning home

Telephone support should be available to the patient outside of regular working hours. Concerning technical support, this may be a collaborative service shared by many centers. When relief is required or in case of illness, patients should have the opportunity to receive dialysis at their dialysis center. All patients who carry out their treatment at home should receive assistance as needed in the home either through home services/home health care, or from family members who are reimbursed for their efforts.

5.8 Follow-up of procedures

Patients who carry out home dialysis are members in their care team. Patients should be provided with continuing education through the home dialysis center, which must also ensure patient compliance with all procedures. This should be achieved by visiting the patient at home or in the dialysis center. Patients should be provided, as needed following lengthy hospital stays, breaks, or incidents, with the opportunity to refresh their home dialysis training. Contact and meetings with others who carry out home dialysis and family members should be considered to be an important part of monitoring and arranged through the home dialysis center.

5.9 Distribution and disposal of consumables

Distribution of consumables and disposal of empty packaging must be done according to an individually tailored plan. Consumables should be delivered directly to the patient's home or other address.

Patients should be informed of any changes to the range of consumables offered, and if necessary, be given new instructions on proper use. Patients should be able to place orders online or by phone.

6. Self-hemodialysis (SHD)

6.1 Background

If a patient is unable or unwilling to have HHD, then SHD becomes an option. In such cases, the patient may independently conduct dialysis treatment within the premises of the dialysis center by following the same procedure as at home. Patients should be offered a flexible dialysis schedule and be able to adapt their dialysis to their needs. If possible and by special agreement, patients should be able to have access to the premises outside regular working hours in order to independently carry out their treatment.

Training for SHD is provided in the same way as for HHD (5.4).

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Appendix 1

Proposal for description of responsibility for home hemodialysis patients

Recommendation of the Steering Committee for Home Hemodialysis in Sweden. To be used with consideration taken to department procedures.

The patient is responsible for:

- Prepare dialysis machine for treatment, start and end dialysis treatment and deal with any alarms.
- Record batch numbers of concentrate, bicarbonate, filters and tubing at each dialysis session.
- Carry out self-puncture in the AV fistula/graft or prepare the central dialysis catheter according to procedure.
- Follow given dialysis orders.
- Ultrafilter a max of…… ml of fluid per hour.
- Document each dialysis session according to procedure.
- Always disinfect the machine after treatment according to procedure, or at least every three days, and wipe the machine down.
- Blood samples are taken as agreed.
- Water samples are taken according to procedure.
- A phone must be available during treatment.
- The dialysis room and storage space for materials must be kept clean.
- Report any incidents/deviations to the nurse.

If the patient does not follow any of the above points, responsible staff at the dialysis clinic have an obligation to reconsider the decision to allow the patient to manage dialysis treatment at home.

The above refers to dialysis system: .....

Date ……..

Patient

Signature ……

Print name .....

Doctor

Signature ……

Print name ……

Nurse

Signature ……

Print name ……

Appendix 2

Proposal for additional costs that can be addressed when applying for reimbursement of additional costs for HHD

- Water consumption Record the number of hours that the machine or water purification system is running May vary by machine Include use of electricity for water pump if the patient has his or her own source of water
- Electricity, hours that the entire system is run. May vary depending on what machine is used.
- Dialysis diet based on dietician certificate. May vary by gender and by county council.
- Extra laundry.
- New purchase of bedding and towels.
- Increased amount of trash/garbage. Transportation costs to and from recycling center Larger trash container if necessary.
- Additional cost for home dialysis room/storage room. A larger residence may be needed, and thereby higher rent.
- Dues to patient association
- High-cost protection for medications.
- Medicines that are not covered by high-cost protection.
- Illness-related travel expenses, high-cost protection.
- Medical visits, high-cost protection
- Batteries needed for various alarms. For example, Venac, water alarm, etc.
- Exercise pass.
- Telephone expenses
- Disposal of materials to recycling center

Appendix 3

Proposal for additional costs that may be included when applying for reimbursement of additional costs for PD

- Electricity, hours that the entire system is run. May vary depending on what machine is used.
- Dialysis diet based on dietician certificate. May vary by gender and by county council.
- Extra laundry.
- New purchase of bedding and towels.
- Increased amount of trash/garbage. Transportation costs to and from recycling center Larger trash container if necessary.
- Additional cost for home dialysis room/storage room. A larger residence may be needed, and thereby higher rent.
- Dues to patient association
- High-cost protection for medications.
- Medicines that are not covered by high-cost protection.
- Illness-related travel expenses, high-cost protection.
- Medical visits, high-cost protection

Appendix 4

Home modifications

Possible requirements at start of HHD

- Grounded electrical outlets in the entire room
- Water and drainage to and from the machine.
- Circuit breaker
- Water leakage protection for machine and water purifier.
- Closet or similar for storage
- Separate fuse for dialysis machine and water purifier
- Set of charcoal particle filter holders.
- Surge protector

Possible requirements at start of PD

- Grounded outlet
- Closet or similar for storage

Appendix 5

Equipment

HHD

- Dialysis machine
- Floor protection against spills and flooding
- Blood leak detector
- Water purification
- Charcoal/particle filter

PD

- Machine
- Trolley
- Hot plate
- Stand for bag suspension
- Clamps
- Handheld scale

Requirements for both HHD and PD

- Hand disinfectant
- Skin disinfectant
- Disinfectant for machine
- Gloves
- Body scale
- Blood pressure cuff
- Water alarm for floor
- Storage unit such as closet or chest
- Waste basket with garbage bags
- Disposable washcloths
- Clamps/forceps and scissors

- Adjustable height bed with back support or armchair
- Centrifuge for blood samples Unless lab samples can be left at a nearby location, transport envelopes and containers for test tubes should be provided.

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