Working group of the Finnish Society of Nephrology

TREATMENT GUIDANCE OF SEVERE CHRONIC KIDNEY DISEASE

Finland's strategy



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FOREWORD

Kidney failure affects the life of the patient and the close relatives in many ways. Although the treatment for this serious disease has evolved, a great deal of healthcare resources and needed at significant societal costs. Treatments are used differently in different parts of Finland, and a national treatment recommendation has been lacking.

The task of the working group set up by the Finnish Society of Nephrology (for members, see Chapter 9) was to identify common objectives and to consider means of reaching them and ways to monitor the results.

This strategy will hopefully guide and harmonise the treatment practices in our country. At the same time, it is important that they are taken into account in our current hospital districts and in the future wellbeing services counties and collaborative areas for healthcare and social welfare. It is also important for policy makers to be aware of these objectives so that the healthcare and social welfare legislation may be developed with the intention to achieve them.

1 CURRENT SITUATION AND FUTURE PERSPECTIVES FOR FINLAND AND THE WORLD

Chronic kidney disease (CKD) is a major global public health problem, which has recently been estimated to affect more than 10% of the population (1). In 2017, there were 3.9 million patients living with a functioning kidney transplant or on dialysis. The number of these patients, who are undergoing so-called renal replacement therapy, is projected to increase by 40–50% by 2030 (1).

CKD is estimated to have caused the death of 130,000 patients in Europe in 2019. Therefore, it is the eighth most common cause of death (2). The main causes of severe chronic kidney disease are diabetes, glomerulonephritis and polycystic kidney disease (3).

In Finland, approximately 500 patients are admitted for renal replacement therapy each year, and the number has not changed much in recent years. However, the number of patients on treatment has increased significantly. In 2009, there were 4,175 patients on renal replacement therapy in our country. Ten years later, the number of patients had risen to 5,190, i.e., the number had increased by almost 25%. This is, above all, due to improved survival.

Of the patients undergoing renal replacement therapy, approximately 60% live with a functioning kidney transplant and approximately 40% are on dialysis. According to the Finnish Registry for Kidney Diseases, in 2019, one quarter of the patients were on home dialysis three months after the start of the treatment and 5% had received a kidney transplant. This means that approximately one third of all patients were treated at home, but the differences between the hospital districts in Finland were significant. The proportion of patients on home dialysis varied between 0% and 45% of all patients.

Efforts have been made for a long time to increase the share of home dialysis, but progress has been slow. Significant efforts have also been made in recent years to increase renal transplantations, and patients may, in some cases, receive a renal transplant without prior dialysis.

In Finland, the number of people who need renal replacement therapy is also projected to increase by several tens of per centage units over the next 10–15 years (4). In addition, the share of patients over 75 years of age will increase to almost one third of all new patients. Consequently, provision must be made not only for an increase in the number of patients, but also for the treatment of elderly patients. On the other hand, as the population ages and as the burden of disease increases, more effort is needed for palliative care (5).

Severe kidney disease affects the patient's life in many ways. Optimal treatment selection can affect health outcomes and the patients' quality of life but it also affects costs – dialysis is one of the most expensive medical treatments used regularly. Therefore, the patient must be referred to specialised medical care in a timely manner, where the treatment intent is decided together with the patient and renal replacement therapy is started in time. Simultaneously, good palliative care must be provided.

The working group set up by the Finnish Society of Nephrology has agreed on a national practice for directing patients with CKD to dialysis, kidney transplantation or palliative care. This publication

describes the treatment methods of CKD, the course of treatment planning, the treatment targets, the quality criteria and a proposal for monitoring how well goals have been met.

REFERENCES

- 1. Jager KJ, Kovesdy C, Langham R, et al. A single number for advocacy and communication worldwide more than 860 million individuals have kidney diseases. Nephrol Dial Transplant 2019; 34:1803–1805.
- 2. Vanholder R, Annemans L, Bello AK, et al. Fighting the unbearable lightness of neglecting kidney health: the decade of the kidney. Clinical Kidney Journal 2021 (in print).
- 3. Finnish Registry for Kidney Diseases. Report 2019; 1–44. https://www.muma.fi/liitto/suomen_munuaistautirekisteri/finnish_registry_for_kidney_diseas_ es.
- 4. Finnish Registry for Kidney Diseases. Report 2017; 1–50. <u>https://www.muma.fi/liitto/suomen_munuaistautirekisteri/finnish_registry_for_kidney_diseas_es.</u>
- 5. Verbene WR, Geers ABM, Jellema WT, et al. Comparative survival among older adults with advanced kidney disease managed conservatively versus with dialysis. Clin J Am Soc Nephrol 2016; 11: 1–8.

2 CHRONIC KIDNEY DISEASE AND TREATMENT TO SLOW ITS PROGRESSION

CKD refers to a condition where there has been evidence of kidney damage for at least three months. The evidence may consist of an abnormal finding at urinalysis (persistent albuminuria, haematuria of renal origin), a pathological finding of a renal function test (determined from a blood sample), a pathological radiological finding (for example, polycystic kidney disease) or a combination of these (1).

The severity of CKD is classified according to the glomerular filtration rate (Table 1).

Stage	Severity of	GFR (ml/min/1.73	
	dysfunction	m ²)	
G1	Normal GFR	>90	
G2	Mild	60–89	
G3	Moderate	30–59	
G4	Severe	15–29	
G5	Failure	<15	

Table 1. Severity of chronic kidney disease and classification by glomerular filtration rate (GFR)

CKD significantly increases the risk of cardiovascular diseases. The progression of CKD is affected by factors, such as the presence of an underlying nephrological disease, the amount of protein in the urine and, especially, blood pressure.

The state of the kidney disease must be monitored regularly. The frequency of monitoring depends on, among other things, the severity of the kidney dysfunction and the patient's overall prognosis.

The cornerstones of treatment to slow the progression of CKD are

- good treatment of the primary renal disease (such as glomerulonephritis)
- stringent blood pressure management (office target < 130/80 and target at home < 125/80, for elderly < 150/80 and < 140/85, respectively) (2)
- treatment to reduce proteinuria (ACE inhibitors, sartans)
 - for the elderly, renal function must be taken into account and drug doses must be scrutinised

– patients must be instructed to interrupt this medication if they experience dehydration

• SGLT2-inhibitors. The indication of this group of medicines is expanding from diabetes to include the treatment of CKD.

In addition, therapy to prevent/treat comorbidities must be instituted:

- effective, individualised treatment of dyslipidaemia (at GFR 30–59: target LDL < 1.8 mmol/l, at GFR < 30 and/or diabetes: target LDL < 1.4 mmol/l) (3)
- smoking cessation.

It is also essential to

- treat diabetes well
 - a recent national recommendation outlines the management of diabetic nephropathy (4)
- prevent bone disease by instituting a low-phosphorus diet and the appropriate medication (5).

In case of diagnostic and treatment problems (e.g., difficult-to-treat hypertension, nephrotic syndrome), a nephrologist should be consulted.

The guidelines presented in this publication focus on the management of patients with CKD stage G4–5.

REFERENCES

- 1. KDIGO 2012. Clinical practice guideline for the evaluation and management of chronic kidney disease. Kidney Int. 2013; 3:1–150.
- 2. Hypertension. Current Care. Duodecim 2020. https://www.kaypahoito.fi/hoi04010.
- 3. Dyslipidaemias. Current Care. Duodecim 2020. <u>https://www.kaypahoito.fi/hoi50025</u>.
- 4. Diabetic kidney disease. Duodecim 2020. https://www.kaypahoito.fi/hoi50060.
- 5. Keronen S, Martola L, Honkanen E. Munuaispotilaan luustosairauden uudet hoitosuositukset. Duodecim 2019; 25–32

3 TYPES OF TREATMENT

3.1 Assisted in-centre haemodialysis

Haemodialysis through vascular access at the clinic (in-centre HD) is suitable for many patients, but in terms of time, it is the most binding type of treatment, with significant treatment-related societal costs. In addition, the possibilities for taking individual wishes into account, for example in relation to treatment schedules, are limited. The risks of infections and the spread of resistant bacteria increase.

In-centre HD is always necessary in acute situations. As maintenance therapy, it may be used by patients who are unable to undergo self-care or assisted home dialysis (see 3.4) for physical or psychological reasons or if they do not have a suitable assistant.

As far as possible, in-centre dialysis must support the patient's self-care, and the facilities of the dialysis unit must be designed to support and encourage self-care (see 3.2 and 3.3).

The treatment targets vary among individuals.

- Special attention must be paid to guarantee metabolically adequate dialysis to ensure transplantability for patients aiming at renal transplantation. This usually means that the minimum number of hours of dialysis per week will be exceeded (i.e., more than 12 hours/week) but depends on the degree of residual renal function.
- Kidney transplantation is not possible for most patients because of limitations due to underlying diseases. In this case, the target of treatment is to provide control of the symptoms caused by the renal disease and to prevent comorbidities so that the patient's quality of life is affected as little as possible by the treatments.
- Rather than a minimum number of HD-hours, the focus is on an appropriate rhythm of treatments and on adapting the treatments to the patient's schedules and wishes.

Patients attending for in-centre HD should be provided with the opportunity to have *personal discussions* with the treating nephrologists, nurses and, if necessary, other staff, e.g., social worker and nutritional therapist. This means that a separate opportunity for consulting privately with the dialysis staff at least 1–2 times per year should be provided. At the these consultations, the patient's current health and other issues raised by the patient are discussed and the treatment plan is updated. Someone close to the patient may also be present.

A *treatment agreement* is also recommended when in-centre dialysis is started. The agreement should define the responsibilities of the unit and of the patient regarding treatment schedules, treatment progress and the comfort of other patients.

In all forms of dialysis, there is a significant *palliative aspect* (see 3.7). The relative proportion of palliation is emphasised when the patient's condition and prognosis deteriorate. Nephrological units should, therefore, work in close collaboration with the regional palliative care unit.

The treatment and medical records describing the dialysis must aim to record timely and consistent key information on the patient's functional ability and treatment targets.

3.2 Self-care in-centre haemodialysis

Training patients to participate at least partially in carrying out their own HD will increase their commitment to treatment and improve outcomes (1). Self-care also expedites dialyses, reduces waiting times and reduces the need for nursing. In the preparatory phase of dialysis and transplantation, the patient must be informed, as far as possible, that they can participate in carrying out their own dialyses.

Self-care haemodialysis (shared haemodialysis care) can vary greatly: It may mean that the patient measures her/his weight and blood pressure and records certain treatment data. Many patients can learn how to set up the starting table and the dialysis machine, how to regulate the operation of the dialysis machine and how to conclude the dialysis session. Patients may also be able to cannulate their vessels for dialysis on their own and self-administer the required medicines during the dialysis. Training these capabilities lasts between 6 and 8 weeks, depending on the patient and target level of training.

When planning the type of treatment for a patient, it may be beneficial to have a separate area (or a reserved space) in the dialysis unit for self-care patients. At the beginning of the treatment, it is important to assess the extent of self-care that each patient starting HD treatment is able to carry out. The feasibility and success of self-care should be monitored as treatment continues.

REFERENCES

1. Wilkie M, Barnes T. Shared hemodialysis care. Increasing patient involvement in centerbased dialysis. Clin J Am Soc Nephrol 2019; 14:1402–1404.

3.3 Kiosk haemodialysis

A significant part of the benefits of home HD compared to in-centre HD is related to the possibility of the patient performing dialysis frequently (short daily dialysis) or prolonged dialyses during the night (long slow dialysis).

Due to practices and resource limitations, short daily HD treatment (e.g., 5–6 times a week) is not always possible in the hospital setting. However, in some dialysis units, self-care by short daily HD is made possible by separate space arrangements ("kiosk HD", "OmaHemo"): In a "kiosk", the patient can perform dialysis independently at any time of the day (e.g., after work or at night) and often sufficiently often (3–6 times a week).

Kiosk HD in a hospital can be an alternative to home HD if the patient does not want to take the HD device home due to the patient's living conditions or life situation. Although home care has been proven to be safe, some patients feel that kiosk HD is safer in a hospital surrounding.

The indications and contraindications for kiosk HD are the same as for home HD.

There is very little scientific evidence on the effect of kiosk HD on patient prognosis, and the patient numbers in the few follow-up studies that have been published have been small (1). There is no research data on the effect of this type of treatment on the quality of life of patients compared to patients undergoing home HD or in-centre dialysis (2).

REFERENCES

- 1. Marshall MR, van der Schrieck N, Lilley D, Supershad SK, Ng A, Walker RC, Dunlop JL. Independent community house hemodialysis as a novel dialysis setting: an observational cohort study. Am J. Kidney Dis. 2013; 61(4):598–607.
- Budhram B, Sinclair A, Komenda P, Severn M, Sood MM. A Comparison of Patient-Reported Outcome Measures of Quality of Life. By Dialysis Modality in the Treatment of Kidney Failure: A Systematic Review. Can J. Kidney Health. Dis. 2020; 7:2054358120957431 <u>https://journals.sagepub.com/doi/10.1177/2054358120957431</u>.

3.4 Home dialysis

Home dialysis refers to peritoneal dialysis (PD) and haemodialysis (home HD) in the patient's home, usually managed by the patient without external aid.

During the predialysis phase, the primary goal is to direct the patient to home dialysis. At the same time, even before dialysis is started, the possibility of kidney transplantation is examined. It is essential that home dialysis and kidney transplantation are planned in good coordination (see 5.8).

Home dialysis makes it possible for the patient to adapt the treatment schedule to her/his daily activities and to adapt the effectiveness of the treatment to meet the patient's needs. The costs for home dialysis are usually lower than for in-centre haemodialysis (1).

Key factors for selecting home dialysis include the possibility for the patient to continue her/his professional life, to maintain working capacity and to pursue studies. Transportation costs, which are much lower for home dialysis than dialysis managed by the dialysis centre, are also an important consideration. These variables comprise the total cost to society.

The choice between the different forms of home dialysis must be made together with the patient after adequate provision of information. For some patients, only one form of home dialysis is suitable. If the form of home dialysis initially selected has to be discontinued due to problems, the possibility of switching to another form of home dialysis is to be considered first.

It is important that the entire treatment team understands the benefits of home dialysis and supports the choices made by the patients. Referral to home dialysis is a team effort. It is important that the benefits of home care are communicated consistently by all professional groups involved in managing dialysis services.

The Finnish Kidney and Liver Association provides rehabilitation courses to support patients on home dialysis and their relatives. If the unit's own resources are limited, patient training provided by dialysis companies may also be used.

Peritoneal dialysis

The start of PD must be planned sufficiently well in advance to allow the dialysis catheter to be put in place in time (2–4 weeks before treatment start) and to have any hernias repaired. Still, treatment can be started immediately after catheter placement, if needed.

PD must also be kept in mind as an option in case of acute dialysis needs, if the type of treatment has been planned already at the predialysis stage or if PD has been found to be a good form of long-term dialysis for the patient. Less than a week's training is usually enough for the patient to learn how to run home PD. PD can be carried out through manual exchanges (CADP, continuous ambulatory peritoneal dialysis) or at night with a machine (APD, automated peritoneal dialysis).

The survival prognosis of patients on PD is the same as for patients on in-centre HD, or even better (2). A well-motivated treatment team and rapid access to help when needed enable safe implementation of home dialysis.

If the patient needs hospital care, successful treatment at a regular ward must be ensured by sufficient training of the staff and by consulting the nursing staff of nephrological wards.

Recurrent infections are a common reason for discontinuation or interruption of peritoneal dialysis. It is essential that the patient is reminded of the importance of good hygiene.

Assisted PD

may allow home treatment for elderly patients or patients who have a reduced functional ability.

Home haemodialysis

It takes, on average, about 6 weeks for patients to learn home HD. During this time, the patient typically attends for training provided by home haemodialysis nurses in the hospital three or four days a week.

The patient's dialysis access must be prepared well in advance of home dialysis training and dialysis start. It takes several weeks from creation to maturation of the AV fistula. Still, dialysis can be started acutely through a neck catheter and permanent vascular access may be created later. Home dialysis training can be provided at this time, as well, but primarily permanent vascular access should be prepared well in advance.

Home HD through a catheter may also be an option before kidney transplantation from a living donor.

It is recommendable to have home HD patients treated and in training at the dialysis unit continuously. If this activity is intermittent, the quality of treatment and training may suffer.

The patient's training period binds staff resources and this may affect the availability of nursing efforts in other dialysis operations. But if home dialysis is a continuous, permanent activity, less

staff is needed at home dialysis units than at in-centre dialysis units and the available staff may provide service to a larger number of patients (3). Although the aim is to identify patients who are eligible for home haemodialysis already during the predialysis phase, patients who have long been on in-centre HD can also be referred to home HD, especially if they have previously been successfully referred to a period of self-care training (see 3.2 and 3.3).

The patient's return to her/his professional life is an important goal. Since home HD can be highly individualised (for example, provided as short treatments 4–5 days or evenings per week or as long treatments 3–5 nights per week while the patient is asleep), it is suitable for most people.

Patients on home HD have a better survival prognosis and a better quality of life than patients on in-centre HD, and home HD carries the lowest societal costs of all forms of dialysis treatments.

Assisted home haemodialysis

may be considered if the patient is no longer able to carry out self-care. The treatment may then continue either at the patient's home or, for example, at a health care centre.

REFERENCES

- Howell M, Walker RM, Howard K. Cost Effectiveness of Dialysis Modalities: A Systematic Review of Economic Evaluations. Appl Health Econ Health Policy 2019 Jun; 17(3):315– 330.doi: 10.1007/s40258-018-00455-2.
- Mehrotra R, Devuyst O, Davies SJ, Johnson DW. The Current State of Peritoneal Dialysis. J Am Soc Nephrol 2016 Nov; 27 (11):3238–3252. doi: 10.1681/ASN.2016010112. Epub 2016 Jun 23.
- 3. Rauta V. Kotidialyysien lisääminen kannattaa. Lääkärilehti 2019; 42:2376–2380.

3.5 Kidney transplantation

The patient's prospect of undergoing kidney transplantation are evaluated for all who have severe chronic kidney disease (eGFR < 30 ml/min/1.73 m²) and whose renal function is deteriorating (eGFR < 15 ml/min/1.73 m²) (1). The matter is discussed with the patient who is thus informed. Once a joint decision has been reached it is recorded in the medical report and in the quality register (if a register is in use).

Kidney transplantation must be considered for all patients with kidney failure who are judged to tolerate the risks of transplant surgery and the anti-rejection medication. Contraindications for kidney transplantation include

- most of the active malignant diseases, uncontrolled chronic infection, morbid obesity, severe cardiovascular disease, severe lung disease, unstable psychiatric illness, persistent heavy drug abuse and a persistent lack of adherence to treatment
- any other disease that reduces the patient's prognosis or impairs the general condition too much (1, 2).

When assessing the eligibility of elderly patients for kidney transplantation, the patient's functional capacity, degree of frailty and chronic diseases are considered (1).

For patients eligible for transplantation, kidney transplantation is associated with improved life expectancy and quality of life compared to dialysis (3, 4). In Finland, the results of kidney transplantation are good: 95% of transplants are functioning one year after transplantation and approximately 65–70% ten years after transplantation.

The main cause of transplant loss is the patient's death while the transplant is still functioning. The proportion of deaths as the cause for transplant loss is likely to increase in the coming years, as more and more elderly patients are admitted to the transplantation list. The best results of kidney transplantation are obtained when the origin of the transplant is from a living donor and when the transplantation can be performed pre-emptively without prior dialysis (1).

In Finland, 85–90% of kidney transplants in recent years have originated from a deceased donor. The average waiting time on the transplant list is currently around 1.5 years.

The number of kidney transplantations in Finland has increased in recent years. In the future, special emphasis will be put on increasing the number of transplantations from living donors. Some patients with type 1 diabetes who need a kidney transplant are eligible for combined pancreas-kidney transplantation, which has the advantage of restoring simultaneously the blood glucose balance as well as the renal function of the patient. Although there are many complications associated with pancreas-kidney transplantation, the results of these transplantations are excellent in Finland (5).

REFERENCES

- 1. Chadban SJ, Ahn C, Axelrod DA, et al. KDIGO Clinic al Practice Guideline on the Evaluation and Management of Candidates for Kidney Transplantation. Transplantation 2020; 104:S11–S103.
- 2. HUS Abdominal Center, Nephrology and transplantation and liver surgery: Munuais- ja haimansiirrot indikaatiot, lääkehoito ja seuranta. 2016.
- 3. Oniscu GC, Brown H, Forsythe JL. Impact of cadaveric Renal Transplantation on Survival in Patients Listed for Transplantation. J Am Soc Nephrol 2005; 16:1859–65.
- 4. Cameron JI, Whiteside C, Katz J, Devins GM. Differences in quality of life across renal replacement therapies: a meta-analytic comparison. Am J Kidney Dis 2000; 35:629–37.
- 5. Bonsdorff A, Sallinen V, Räihä J, et al. First-day plasma amylase detects patients at risk of complications after simultaneous pancreas-kidney transplantation. Clin Transplant 2021; Jan 27: e14233.

3.6 Financial impact of renal replacement therapy

The overall cost of renal replacement treatment is very significantly dependent on the form of treatment and under what circumstances renal replacement therapy it is carried out.

Dialysis

Based on studies conducted in different countries, including Finland, assisted in-centre HD is the most expensive form of treatment (approximately €60,000–€70,000/year). The lowest cost is

associated with home HD and CAPD (approximately $\leq 30,000 - \leq 50,000$ /year, or approximately 60% of the costs of assisted in-centre HD). The cost of the other forms treatment is in between (1–2). Training patients for self-care, at least partially, also reduces treatment costs (3).

In Finland, significant cost differences are caused by travelling expenses to and from treatment sessions. In a study conducted by Kela, the annual travel costs for a patient going to a hospital for HD treatment were over €11,000 (5). Therefore, increasing the use of home dialysis has a particularly positive impact on overall societal costs (6).



Results: On average, home haemodialysis is the most affordable type of treatment Average annual costs for different forms of dialysis

Figure 1. Average annual costs for different forms of dialysis (Arponen 2021)

Kidney transplantation

As well as improving life expectancy and quality of life, kidney transplantation saves costs to society compared to dialysis. According to a fairly recent Finnish study, the costs of specialised medical care, medication and travel one year after kidney transplantation total about one third of the costs associated with dialysis before transplantation.

An effective kidney transplant saves approximately €40,000/year/patient compared to dialysis (7). A recent Swedish study arrived at similar figures and estimated that kidney transplantation carries 66–79% lower costs than the health care costs of dialysis. Over a 10-year period, the average savings compared to dialysis are €380,000/kidney transplant (8).

By far the largest share of post-transplantation costs are due to costs for medicines. This proportion of costs may be reduced in the future by wider use of generic medicines. The costs of pre-transplant dialysis could be avoided by increasing pre-emptive transplantations.

Costs to the patient

A patient on HD in a hospital/dialysis unit pays a serial treatment fee for 45 treatments per year. The problem is that some hospital districts have also charged home HD patients this fee. PD patients are not charged this fee.

A payment cap applies to medicine expenses, medical treatment expenses (outpatient clinic, ward care) and travel. The sum of these expense items is very significant (the total payment cap amounts to almost €1,600 per year) and applies to many people with chronic illnesses.

The form of renal replacement therapy has a significant impact on the patient's costs: many patients on in-centre HD have to travel for treatment to the centre by taxi, and the annual co-payment liability for travel expenses for the patient is currently €300. The difference between home dialysis and in-centre dialysis is significant as concerns the cost for transportation, as patients undergoing home dialysis only visit the hospital for check-ups, and their travel costs are low.

Whenever possible, dialysis treatment should primarily be carried out in the patient's home. However, home dialysis is more expensive for the patient than dialysis in the hospital, for example due to water, electricity and waste charges.

In some hospital districts, home dialysis can be carried out in the patient's home under the assistance from municipal home nursing. In this case, the patient is generally charged a home nursing client fee, which is income-related and exempted from the payment cap.

REFERENCES

- 1. Arponen I. Cost-effectiveness analysis of dialysis modalities for end-stage renal disease patients from a Finnish payer perspective using Markov modelling. 2021. <u>https://aaltodoc.aalto.fi:443/handle/123456789/109282</u>
- 2. Beaudry A, Ferguson TW, Rigatto C, et al. Costs of dialysis therapy by modality in Manitoba. Clin J Am Soc Nephrol 2018; 13. doi. <u>https://doi.org/10.2215/CJN.180917</u>.
- 3. Malmström RK, Heikkilä A, Roine RP, et al. Cost analysis and health-related quality of life of home and self-care satellite dialysis. Nephrol Dial Transplant 2008; 23:1990–1996.
- 4. Klarenbach SW, Tonelli M, Chui B, Manns BJ. Economic evolution of dialysis therapies, Nature Review Nephrol 2014; 10:644–652.
- 5. Tillman P, Maunula N, Kela, Tutkimusosasto 2015; (Työpapereita 73/2015).
- 6. Rauta V. Kotidialyysien lisääminen kannattaa. Lääkärilehti 2019; 42:2376–2380.
- 7. Helanterä I, Isola T, Lehtonen T, et al. Association of clinical factors with the costs of kidney transplantation in the current era. Ann Transplant 2019; 24:393–400.
- 8. Jarl J, Desatnik P, Hansson UP, et al. Kidney transplantations save money? A study using a before-after design and multiple register-based data from Sweden. Clin Kidney J. 2018; 11(2):283–288. doi: 10.1093/ckj/sfx088.

3.7 Palliative care

Palliative care refers to active, holistic treatment of a patient with a terminal illness which aims at preventing and alleviating suffering and preserving the quality of life. Palliative care involves also

close relatives to the patient. Palliative care is not defined in relation to the time of death, although the need for palliative care increases toward the end of life (1–4).

Terminal care is the part of palliative care that takes place in the final days or weeks of the patient (2, 5).

Patients with kidney failure in palliative care refrain from dialysis. They may, however, have dialysis at reduced intensity for symptom relief alone.



Figure 2. Treatment intent during different stages of an illness (Lehto J, Marjamäki E, Saarto T. Elämän loppuvaiheen ennakoiva hoitosuunnitelma. Duodecim Medical Journal 2019; 135(4):335–42)

Patients with chronic kidney disease are one of the most demanding and multiproblematic groups of patients. As renal function deteriorates and renal replacement therapy is not started in terminal care, the overall symptoms of the kidney disease are often as intense as those of some terminal cancer diseases.

Every patient has the right to proper symptomatic treatment regardless of disease severity.

REFERENCES

- Palliative and end-of-life care. Current Care Guideline. Working group set up by the Finnish Medical Society Duodecim, Finnish Association for Palliative Medicine. Helsinki: Finnish Medical Society Duodecim, 2019 (accessed 30 May 2021).<u>https://www.kaypahoito.fi/hoi50063</u>
- 2. Lehto J, Marjamäki E, Saarto T. Elämän loppuvaiheen ennakoiva hoitosuunnitelma. Duodecim 2019; 135(4):335–42.
- 3. Davison S, Levin A, Moss A, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. Kidney International 2015; 88:447–459.

- 4. Gelfand S, Scherer J, Koncicki H. Kidney Supportive Care: Core Curriculum 2020. Am J Kidney Dis 2020; 75(5):793–806.
- 5. Munuaisten vajaatoimintaa sairastavan saattohoito. Finnish Kidney and Liver Association. 2017.

4 RECOMMENDATIONS FOR SELECTION OF TREATMENT

The European Kidney Health Alliance (EKHA) is a joint body of organisations for physicians (ERA-EDTA), nurses (EDTNA/ERCA) and patients (ECBF) involved in the care of patients with nephrological conditions. EKHA published recommendations for sustainable kidney care in 2015 (1).

The recommendations emphasise the importance of prevention and early treatment of kidney diseases.

- The EU must support the member states in increasing the availability and use of home dialysis, which has advantages such as improved well-being and quality of life, the possibility to go to work and lower costs.
- Palliative care must also be considered as a treatment option.
- Kidney transplantation from living and deceased donors must be promoted as much as possible.

In Sweden, nephrologists, renal nurses and representatives of patient organisations published in January 2019 national guidelines on the importance of self-care in dialysis (2).

- Many dialysis units offer the possibility of self-care, but the use of home dialysis has not increased in recent years. The aim is to reverse this trend.
- The aim is to harmonise and equalise treatment in the country and to get rid of local treatment guidelines.
- A significant increase in the number of self-care patients is desired.
- PD treatment is considered to be the primary form of home treatment, and efforts are being made to increase home PD from the current level of around 20% to 30%. The proportion of home HD and of self-care in-centre HD is targeted at 10% of all patients on dialysis.
- The financial problems associated with home dialysis, particularly assisted PD therapy, must be resolved.

In the US, new national targets were published in 2019 (3). According to these, end-stage kidney disease must be reduced by a quarter by 2030. By 2025, 80% of new patients should either be on home dialysis or have a functioning kidney transplant. There are stringent grounds for these objectives.

- The cost of treatment for patients with end-stage kidney disease is seven times higher than their proportion of patients in the treatment system.
- Home dialysis offers many advantages over in-centre haemodialysis. Nevertheless, only about 2% of all dialysis patients in the US were on home dialysis in 2018 although home dialysis would be suitable for a large proportion.

The publication emphasises patient-centred therapies and promotes new, innovative technologies. Efforts, including elimination of financial barriers, are being made to increase kidney transplantation from both brain-dead and living donors. Similarly, an "optimal time to start" is required: preparing the patient for a possible kidney transplant even before dialysis is started and presenting the different forms of dialysis, in particular home dialysis. A maximum possible number of patients should have their vascular access ready for use when they start on haemodialysis.

REFERENCES

- 1. European Kidney health Alliance 2015. http://ekha.eu/aboutus/accomplishments/recommendations-sustainable-kidney-care/
- Njurförbundet (SE): Nationellt vårdprogram för egenvård vid dialys. <u>https://njurforbundet.se/wp-content/uploads/2019/09/Nationellt-vårdprogam-för-</u> <u>egenvård-vid-dialys.pdf</u>
- 3. Executive Office of the President: Advancing American Kidney Health. Department of Health & Human Services, USA. <u>https://www.federalregister.gov/documents/2019/07/15/2019-15159/advancing-american-kidney-health</u>

5 OPERATIONAL PRINCIPLES AGREED ON BY THE WORKING GROUP



Figure 1. Referral of a patient to specialised medical care

As the kidney disease progresses and approaches stage CKD G5, it is important to make preparations in advance for renal replacement therapy or to plan for palliative care. This requires good cooperation between primary health care and specialised medical care, multi-professional activity, common objectives and suitable methods to monitor the results.

5.1 Patient referral from primary health care to specialised medical care

- A nephrologist must be consulted at the latest when the patient's calculated GFR (eGFR) is less than 20 ml/min/1.73 m² on at least three measurements within three months. If renal function deteriorates rapidly, consultation must be performed earlier.
- Specialised medical care must also be consulted (e.g., electronically) for patients in primary care who are considered not to benefit from renal replacement therapy and for whom palliative care is planned. Regional nephrological specialist care will provide the necessary instructions.

5.2 Treatment decision

- When kidney function is declining (eGFR< 20 ml/min/1.73 m²), the treatment intent (renal replacement therapy or palliative care) is decided.
- The decision is recorded in the patient's medical report, and if palliative treatment is decided on together with the patient, the reasons for the decision are recorded.
- In the future, the aim is to enter all treatment decisions in the Finnish Registry for Kidney Diseases. Currently this is not possible.



5.3 Initiation of renal replacement therapy planning

Figure 2. Planning renal replacement therapy (1)

- When the decision on starting renal replacement therapy is taken, it is time to decide whether the patient is eligible for kidney transplantation or not. If transplantation is considered possible, the possibility of transplantation from a living donor should be assessed as early as possible.
- Renal replacement therapy must be individually planned taking into account, for example, the rate of renal disease progression and the severity of the kidney disease at the time of the treatment decision.
 - If the disease progresses slowly and the patient will not receive a kidney transplant, the patient may be referred back to primary health care and a nephrologist may be consulted again as needed.

 If the disease progresses (eGFR is then usually < 15 ml/min) and kidney function will apparently be lost within 6–12 months, preparations for dialysis and possible kidney transplantation are initiated.



5.4 Investigations related to the planning of renal replacement therapy

Figure 3. Planning of renal replacement therapy (2)

- Before dialysis is started, a series of laboratory and imaging studies are needed (Appendix 1). If necessary, a nutritional therapist, social worker and possibly also a physiotherapist and diabetes nurse will be consulted at this stage (see 5.6).
- In addition to what is listed in Appendix 1, examinations related to kidney transplantation include
 - either a cardiac stress test, stress echocardiography or a cardiac nuclear stress test, as is the practice of the unit,
 - if needed, coronary angiography, if latent coronary artery disease is suspected.
- A cardiologist should be consulted for studying cardiac function and structure imaging.
- If a pancreatic transplantation is planned, additional examinations are carried out in accordance with Appendix 1.

5.5 Informing and guiding the patient

- Information on dialysis and kidney transplantation is to be provided at the latest when GFR falls to 30 ml/min and the patient has progressive kidney disease.
- Information is given orally at the appointments. In addition, the patient is guided to explore the contents of the Munuaistalo service.
- The aim is to provide a digital care pathway (for example, the digital care pathways of Health Village's Munuaistalo) to all eligible patients. Digital care pathways can be used to ensure that patients and, if the patients so wish, their close relatives can explore the treatment options and current guidelines at their leisure.
- An appointment with a nurse and/or group counselling on these matters can be arranged for each patient hospital wise. The patient is welcome to bring a family member/close relative to the nurse's appointment and/or for group counselling.
- The patient is referred to a social worker and other professionals described in section 2.7.
- Information is given individually so that the patient
 - understands the significance of dialysis
 - is able to participate in choosing the form of treatment
 - is supported in taking an active role when the treatment is carried out
 - understands the importance of kidney transplantation, of the benefits of kidney transplantation and of regular medical treatment.
- The guidance material of the Finnish Kidney and Liver Association (<u>https://www.muma.fi/files/458/munuaispotilaan_opas.pdf</u>) also provides helpful information. The material contains also information on the services provided by the Finnish Kidney and Liver Association (rehabilitation courses, peer support, advocacy).

The working group stresses the importance of informing all patients. Even when patients have required acute dialysis (see section 5.7), the provision of information and planning of the form of treatment must start as soon as the situation permits.

5.6 Consulting professionals, role of patient organisation

• Dentist

- Dental examinations and treatment must be carried out at an early stage when planning dialysis and especially kidney transplantation.
- The hospital district must decide whether to refer the patient to specialist dental consultation or to dental care within the primary health care.
- Nutritional therapist

- A patient at the planning stage of renal replacement therapy must be referred to a nutritional therapist/dietician.
- Nephrological nurses must also be familiar with the main features of nutritional therapy.

• Social worker

 A patient at the planning stage of renal replacement therapy must be referred to a social worker. The social worker is an expert in questions related to the patient's benefits and the service system and cooperates with various professional groups.

• Physiotherapist

- The working group recommends referring the patient to a physiotherapist at the planning stage of renal replacement therapy.
- The patient is also individually guided to exercise actively.

• Psychological support

- The patient must receive psychiatric/psychological support when the need for this treatment is identified and/or when the patient wishes.
- Continuation of the professional or student life of the patient must be supported whenever possible.

• Finnish Kidney and Liver Association

- The Association raises public awareness of chronic kidney disease. It also provides advice and guidance, conveys peer support and experience and promotes rehabilitation of patients in different stages of the disease.
- The Association is the advocacy organisation of these patients and provides counselling services on matters of social security at all stages of the disease.
- Each unit treating kidney patients must have a contact nurse/doctor to whom the Association can direct information and campaign material.
- Each patient undergoing renal replacement therapy for whom home dialysis is planned must be provided with the Association's information package.

5.7 Patients for whom dialysis has been initiated acutely

- Some patients are put on renal replacement therapy without having had the opportunity to plan treatment in advance. This can happen when
 - an acute kidney disease leads to severe chronic kidney disease
 - the patient has a chronic kidney disease that has not been identified for some reason
 - the patient's referral to specialised medical care has been delayed.
- These patients are typically on assisted in-centre HD, rarely on peritoneal dialysis. It must be ensured that they get the guidance presented in section 5.5 as early as possible.
- It is essential to establish whether the patient is eligible for home dialysis and kidney transplantation.

5.8 Coordination of dialysis and kidney transplantation planning

• Although kidney transplantation is planned for a patient, the planning of dialysis must progress at the same time, since there are uncertainties surrounding kidney transplantation and its timing is usually unknown in advance. In particular, patients eligible for home dialysis must be identified at the same time as transplantation planning is initiated. If the transplantation cannot be carried out pre-emptively, the primary dialysis treatment is home dialysis, and the patient needs to be instructed well in advance.

- If so-called pre-emptive transplantation from a living donor is being planned, the patient will not need an AV fistula (or graft).

- The HUS Abdominal Center has published instructions on the eligibility of patients for transplantation and on preparation and monitoring patients for kidney and pancreas-kidney transplantation: <u>https://www.hus.fi/ammattilaiselle/elinluovutustoiminnan-ammattilaismateriaalia.</u>
- The eligibility for transplantation is assessed for patients with progressive chronic kidney disease when the eGFR falls below 20 ml/minute.
 - The patient is informed of the option of a living donor.
 - Those who may be eligible for combined pancreas-kidney transplantation are informed.
- Examinations aiming at transplantation are initiated at the same time in accordance with the rate of progression of the chronic kidney disease. The goal is to enrol a patient on the transplant list when eGFR is below 15 ml/min and continues to decline.
- The timing of the examinations is the same regardless of whether the transplant originates from a living donor or a deceased donor or if a combined transplantation is in sight.
- The aim is to schedule the transplantation from a living donor to a stage when the patient is asymptomatic and has an eGFR of 10–12 ml/min. Some patients manage at GFR levels of 10–15 ml/min and the kidney disease may not necessarily progress.
- In elderly patients, problems caused by immunosuppression and infections must be taken into account when planning transplantation.

5.9 Selection of the form of dialysis



Figure 4. Principles of selecting the form of dialysis

- Discussions with the patient on the selection of the form of dialysis begin at the latest when eGFR is 20–30 ml/min/1.73 m² (1).
 - The decisions are recorded in the patient's medical report and in the quality register (if a register is in use).
 - The patient is provided with information in a multi-professional manner and is guided to use digital care paths and/or electronic materials.
 - If dialysis has to be initiated acutely without prior monitoring and guidance, the patient must be provided with the corresponding information on the forms of treatment.
 - The agreed plan for the form of dialysis is recorded in the patient's medical report and in the quality register (if a register is in use).
- The possibilities for transplantation are considered for all patients whose renal failure may progress and renal function may cease (eGFR <15 ml/min/1.73 m²) (2).
 - The matter is discussed with the patient, and the possibility of transplantation from a living donor is examined.
 - If there is no living donor, the possibility of referring the patient to the kidney transplant list pre-emptively, i.e., before dialysis is started, is considered.
- When the dialysis form is planned, the aim is to direct the patient to home dialysis (PD or home HD) because of its benefits.

• When the selection of the form of home dialysis is being considered, the patient is informed in a variety of ways and comprehensively about the pros and cons of the different forms of dialysis available (see Table 2). Here, medical, social and other factors are to be taken into account so that the decision on the treatment form can be recorded as a joint decision (shared decision making).

Table 2. Comparison of forms of home dialysis

(the more stars***, the better in comparison)

	Home HD	CAPD	APD
Skills requirements	*	***	**
Training time	*	***	***
Individual planning (<i>personalisation</i>) possible	***	*	**
Effect on residual renal function	*	**	**
Risk of bacterial infection	**	*	*
Survival (<i>comparison: in-centre HD</i>)	***	*	**
Possibility to continue working	**	*	**
Costs to society (<i>comparison: in-centre HD</i>)	***	***	*
Additional costs to patient <i>(comparison: in-centre HD)</i>	*	**	**
Easy to travel (comparison: in-centre HD)	**	**	**

- Providing information on home dialysis should be started early, so that the patient has time to embrace the idea.
- Principles for the selection of the renal replacement therapy method must be understood by the entire treatment team (see figure above).
- If home dialysis is not possible, the patient must be encouraged to choose self-care incentre HD or kiosk HD.
- If transplantation is not considered possible due to the patient's health condition, the patient should be informed by the medical staff about the palliative nature of dialysis and the prognosis (1).

REFERENCES

 Chan CT, Blankestijn PJ, Dember LM, Gallieni M, Harris DCH, Lok CE, Mehrotra R, Stevens PE, Wang AY, Cheung M, Wheeler DC, Winkelmayer WC, Pollock CA, Conference Participants. Dialysis initiation, modality choice, access, and prescription: conclusions from a Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference. Kidney Int. 2019 Jul; 96(1):37–47. Chadban SJ, Ahn C, Axelrod DA, et al. KDIGO Clinical Practice Guideline on the Evaluation and Management of Candidates for Kidney Transplantation. Transplantation 2020; 104: S11– S103.

5.10 Dialysis access

Haemodialysis

The primary goal is to construct a so-called native AV fistula as peripherally as possible from the patient's own blood vessels.

- The AV fistula is planned at the latest when eGFR falls to < 10–15 ml/min. Consideration is also given to the rate at which renal function is declining (rate of decline of GFR).
- The aim is to perform the fistula operation well in advance (about 6 months before the start of the dialysis), especially if there is a plan for self-care/home HD.
- In slowly progressing, asymptomatic renal failure (e.g., an elderly patient's atherosclerotic kidney disease) predicting the renal prognosis is difficult.
 - Atherosclerotic renal disease often progresses slowly, and patients may manage for a long time despite a minimal renal clearance.
 - An agreement on treatment start is possible only when symptoms have progressed sufficiently.
 - Treatment can be started by using a tunnelled catheter. A re-evaluation of the access is made after treatment start.
- Close cooperation with vascular surgeons on treatment goals and plans is necessary (as well as joint fistula monitoring and statistics).

Peritoneal dialysis

- The method and timing of catheter placement are planned when it is obvious that dialysis needs to be started in the coming months.
- The unit must have a plan and care instructions available for situations where peritoneal dialysis has to be initiated acutely, e.g., due to fluid accumulation.
- The functionality of the different types of catheters used in the unit must be monitored. It is also necessary to monitor and collect statistics on catheter infections.

5.11 Treatment start

Dialysis is started

- when the patient has symptoms of renal failure, such as
 - swelling

- loss of appetite/nausea
- fatigue
- when, in spite of appropriate medical treatment, laboratory tests show changes that indicate significant kidney failure, such as
 - anaemia
 - hyperkalaemia
 - acidosis
 - hyperphosphataemia
 - signs of malnutrition (for example, progressive hypoalbuminaemia).
- In practice, the eGFR in these situations is always <15 ml/min/1.73 m², usually <10 ml/min/1.73 m².
 - According to the Finnish Registry for Kidney Diseases, the average eGFR in adults who started renal replacement therapy in 2019 was 8.2 ml/min/1.73 m² just before the start of the treatment.

5.12 Implementation of palliative care



Figure 5. Palliative care

- An important part of palliative care is to refrain from renal replacement therapy.
- The decision to start palliative care must be made individually in cooperation with the patient and the patient's close relatives, who must be provided with adequate information on the estimated impact of the different treatment options on life expectancy and quality of life (1–4).

- The treatment intent can be made by a primary health care physician, but in case of doubt, the patient must always be evaluated by specialised medical care.
 The specialised medical care unit which has been consulted about the treatment decision records the decision.
- International treatment recommendations and risk scores may be used to aid the assessment of the risk of death before the renal function ceases of elderly and multimorbid patients (5, 6).
 - Kidney Failure Risk Equation (4 variables): (7) <u>https://www.qxmd.com/calculate/calculator_308</u>
 - Kidney Failure Risk Equation (8 variables): (7)
 <u>https://qxmd.com/calculate/calculator 125/kidney-failure-risk-equation-8-variable</u>
 - Predicting 6 and 12 Month Mortality in CKD patients: (8)
 <u>https://qxmd.com/calculate/calculator_446/predicting-6-and-12-month-mortality-in-ckd-patiens</u>
 - Clinical Frailty Scale: (9) <u>https://www.bgs.org.uk/sites/default/files/content/attachment/2018-07-</u>05/rockwood_cfs.pdf
 - Karnofsky Score/Performance Status: (10)
 https://qxmd.com/calculate/definition_14/karnofsky-score-performance-status
- In principle, renal replacement therapy is not considered appropriate for patients (1)
 - with functional impairment due to underlying diseases to such an extent that the risks and burdens associated with renal replacement therapy outweigh the outlook for a longer life expectancy
 - who have previously unequivocally expressed their advance decision that excludes renal replacement therapy
 - with any other end-stage condition (severe neurological or cardiovascular disease, malignancy, severe dementia or chronic malnutrition) that is being treated by palliation alone.
- Palliative treatment and management must be developed in cooperation with a palliative unit to draw on the expertise of both specialties (nephrology and palliative care).
 - Sufficient support from the palliative and the primary care unit must be provided for patients who will be managed palliatively.
 - A nephrologist must always be available for consultations.
- When the condition of a patient undergoing maintenance dialysis worsens, adequate dialysis must be secured and the proportion of palliative care increased. Terminal care is ultimately instituted. Sufficient preparations are needed for decisions in a timely manner.
 - A proactive management plan can be used to prepare for this process. The plan should be drawn up already before the decisions on renal replacement therapy are taken (11).
- The palliative care decision is recorded in the patient's medical record, and the diagnosis code Z51.5 (palliative care) should be noted.

- The diagnosis of palliative care (Z51.5) is used for patients with severe chronic kidney disease (eGFR less than 20 ml/min), and a decision not to initiate dialysis for the patient is made.
- In this situation, the diagnosis code of palliative care is supplemented with the information that the decision on palliative care applies only to refraining from renal replacement therapy. The same entry is made in the risk information section of the patient's medical record.
- Dialysis is provided only to the extent needed for palliation (it may be discontinued altogether).
- The patient is transferred to a unit for palliative treatment, e.g., a palliative outpatient clinic.
- The activity of patient organisations is important both for sharing background information related to treatment decisions and for supporting patients and their families during the time that palliative and terminal care are topical.

Matters to consider for palliative treatment are described in more detail in Appendix 2.

REFERENCES

- Davison SN, Levin A, Moss AH, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. Kidney Disease: Improving Global Outcomes. Kidney Int. 2015; 88(3): 447–59.
- 2. Gelfand SL, Scherer JS, Koncicki HM. Kidney Supportive Care: Core Curriculum 2020. Am J Kidney Dis 2020; 75(5):793–806.
- 3. Moss AH. Revised Dialysis Clinical Practice Guideline Promotes More Informed Decision-Making. Clin J Am Soc Nephrol 2010; 5:2380–2383.
- 4. Farrington K, Covic A, Nistor I, et al. NDT Clinical Practice Guideline on management of older patients with chronic kidney disease stage 3b or higher (eGFR<45 ml/min/1.75 m²): a summary document from the European Renal Best Practice Group. Nephrol Dial Transplant 2017; 32:9–16.
- Bansal N, Katz R, De Boer IH, et al. Development and Validation of a Model to Predict 5 Year Risk of Death without ESRD among Older Adults with CKD. Clin J Am Soc Nephrol 2015; 10:367–71.
- 6. Couchoud CG, Beuscart J-BR, Aldigier J-C, et al. Development of a risk stratification algorithm to improve patient-centred care and decision making for incident elderly patients with end-stage renal disease. Kidney Int 2015; 88: 1178–86.
- 7. Tangri N, Stevens LA, Griffith J, et al. A predictive model for progression of chronic kidney disease to kidney failure. JAMA: The Journal of the American Medical Association 2011; 305 (15):1553–9.
- 8. Cohen LM, Ruthazer R, Moss AH, Germain MJ. Predicting six-month mortality for patients who are on maintenance hemodialysis. Clinical Journal of the American Society of Nephrology: Clin J Am Soc Nephrol 2010; 5 (1): 72–9.
- 9. Rockwood K, Song X, MacKnight C, et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005; 173:489–495.

- 10. Karnofsky DA, Abelmann WH, Craver LF, Burchenal JH. The Use of the Nitrogen Mustards in the Palliative Treatment of Carcinoma with Particular Reference to Bronchogenic Carcinoma. Cancer. 1948; 1(4):634–56.
- 11. Lehto J, Marjamäki E, Saarto T. Elämän loppuvaiheen ennakoiva hoitosuunnitelma. Duodecim Medical Journal 2019; 135(4):335–42.

5.13 Current problems

Pressures on outpatient treatment and providing dialysis

- Compared to in-centre haemodialysis, efforts to increase home dialysis and early renal transplantation require more work from the entire nephrological community in the stage before kidney transplantation and in the beginning of dialyses.
- Since the choice of treatment has a major impact on costs and on patients' quality of life, the awareness and commitment of the nephrology staff and patients must be increased through active information and training.
- The management teams of the nephrological units have a profound responsibility for making the strategy successful.
- Increasing home dialysis requires sufficient human resources for selecting, informing, training and monitoring patients.
- In the long term, home dialysis saves resources significantly, especially compared to assisted in-centre HD.
- Bottlenecks may arise, for example
 - in vascular access operations, which may lead to the use of temporary dialysis catheters
 - for access to dental care, which may delay placements to the kidney transplant list
 - for treatment of severe obesity (BMI > 35) prior to transplantation; associated lifestyle guidance and treatment must be initiated early.

These factors should be taken into account already before renal replacement therapy has been started.

Costs of home dialysis to the patient

Patients currently incur unreasonable costs for home dialysis, in particular home haemodialysis (see 2.12). The main problems are:

- According to the prevailing practice of disability benefits, the types of home treatment (PD and home HD) are unequal for the patient (KELA grants less care and disability allowance to a person carrying out home HD treatment than to a person carrying out PD treatment).
- Serial treatment fees for dialysis complicate the use of home haemodialysis in some hospital districts.

- Assisted dialysis involves home nursing client fees that are excluded from the patient's copayment liability. Because treatments are needed several times a week (HD) or daily (PD), fees often become a hindrance to assisted dialysis. The different forms of dialysis must be scrutinised with respect to cost and resolved in such a way that the treatment does not entail additional costs to the patient.
- The patient's co-payment liability and payment cap policy (see 3.6) apply to medicine expenses, medical treatment expenses and travel expenses. The combined payment cap of these is very significant.

Development of palliative care

• Palliative treatment care must be developed in close and expanding collaboration between palliative care units and the primary health care. Currently, there are no operational care paths that cover all parts of Finland where the responsibility for care would be clearly defined.

Challenges related to monitoring (follow-up) and quality control

- Different ICT systems in hospitals do not allow for sufficiently simple data collection. Manual recording is still needed, and often the same piece of information must be recorded in several places.
- The activities of the Finnish Registry for Kidney Diseases should be expanded.
 - It should be possible to send treatment decisions taken in different parts of Finland to the registry without the patient's written consent. This would make it possible to monitor national practices and the impact of decisions on important variables like mortality. This will be possible only once this process becomes statutory.
 - It should be possible to monitor the success of the strategy often enough. This would require a change in the way the registry is used and stringent maintenance of the entries as up to date as possible.
 - Improved resourcing would enable, among other things, automatic and timely monitoring of the quality of operations and of the achievement of objectives.

6 TARGETS FOR FINLAND

Monitored variable	Situation in 2019	Target 2023	Target 2025
Patients on the kidney transplant list or who have received a kidney transplant before dialysis was started	7%	<u>></u> 10%	<u>></u> 15%
Patients on the kidney transplant list or who have received a kidney transplant within 90 days after dialysis was started	12%	<u>></u> 15%	> 20%
Proportion of patients on home dialysis of all dialysis patients within 90 days after start of treatment	26%	<u>></u> 35%	<u>></u> 45%
Proportion of patients on home dialysis of all dialysis patients at the end of the year	22%	<u>></u> 30%	<u>></u> 40%
Proportion of patients beginning dialysis who have been monitored by a nephrologist and for whom starting dialysis has been planned	Not known	<u>></u> 65%	<u>></u> 70%

Table 3. Future targets in Finland

The targets for the future have been set on basis of the latest data from the Finnish Registry for Kidney Diseases compared to the situation in 2019.

- The main targets and monitored variables are
 - quick access to the kidney transplant list
 - sufficient proportion of patients on home dialysis
 - nephrological monitoring before dialysis start
 - systematic start of treatment.

The aim is to gradually increase the proportion of these patient groups in the coming years (Table 3.)

- The national targets also include
 - recording the realised treatment decisions
 - an effective care path between primary health care and specialised medical care, a clear division of responsibilities and smooth cooperation
 - organisation of palliative care.

7 MONITORING AND FOLLOW-UP

The operational principles and targets outlined in section 8 above require some changes to the current practices and it is, consequently, important to monitor regularly how they are implemented. The working group agreed on the following practices:

- The Finnish Society of Nephrology will establish a multidisciplinary subsection to coordinate and implement the treatment guidelines. The patient organisation (Finnish Kidney and Liver Association) will participate in the work of this subsection.
- The aim is that the updated data of the Finnish Registry for Kidney Diseases is reviewed approximately every six months. The specific catchment areas of the university hospitals and all hospital districts will be informed of the how well objectives have been achieved and of any possible shortcomings.
- The university hospitals will appoint a responsible nephrologist who is in touch with the hospitals of the region for coordination of the activities.

8 NEED FOR FURTHER INVESTIGATIONS AND ACTIONS

There are some open questions to be resolved and implemented regarding future activities.

1. Communicating this strategy

Communication target – responsible party/parties:

- administration of the hospital districts Finnish Society of Nephrology, chief physicians of nephrology
- KELA Finnish Society of Nephrology
- political decision-makers Finnish Kidney and Liver Association and Finnish Society of Nephrology
- Ministry of Social Affairs and Health (goal: to organise a meeting with the minister)
 - Finnish Kidney and Liver Association, Finnish Society of Nephrology

2. Regardless of the place of residence of persons concerned, digital patient guidance material must be as widely as possible available throughout Finland.

3. Institutionalising the status of the Finnish Registry for Kidney Diseases and securing its finances

- In this way, the operation of the registry can be improved and expanded to cover the stage before start of renal replacement therapy (including treatment decisions).
- The Ministry of Social Affairs and Health proposes that the status of the registry is made statutory. The related draft decree is currently being circulated for comment (5/2021).

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APPENDICES

Appendix 1

EXAMINATIONS RELATED TO THE PLANNING OF RENAL REPLACEMENT THERAPY

Dialysis

- Dental care
- Orthopantomography
- Chiropodist (diabetics)
- Social worker
- Nutritional therapist
- Diabetes nurse and physician, if necessary
- ECG
- Chest radiography
- Abdominal ultrasound
- Cardiac ultrasound
- Abdominal aortic calcification (AAC) score

For transplantation possibly also

- Cardiac stress test
- HLA typing
- Mammography
- PAP smear
- PSA
- Spirometry (smokers)
- Cerebrovascular MRI (if the patient has ADPKD)
- Glucose tolerance test
- Leukocyte antibodies
- HIV, hepatitis

In pancreas transplantation, also

- ENMG
- C-pept, fB-gluk
- Ophthalmologist's consultation
- Carotid ultrasound
- Abdominal vessels (CT scan, if necessary)
- Anaesthesiologist's consultation

Appendix 1

Predialysis/transplantation laboratory tests

- Blood count
- Plasma creatinine
- Plasma potassium
- Plasma sodium
- Serum ionised calcium
- Plasma urea
- Plasma inorganic phosphate
- Fasting plasma PTH
- Venous blood acid/base balance
- Plasma albumin
- Plasma aspartate aminotransferase
- Plasma alanine aminotransferase, Plasma alkaline phosphatase
- Lipids: fasting plasma cholesterol, fasting plasma cholesterol HDL, fasting plasma
- cholesterol LDL, fasting plasma triglycerides
- Fasting plasma glucose
- Blood HbA1c
- Plasma urate
- Plasma ferritin
- Fasting plasma transferrin saturation
- Plasma vitamin D-25
- Serum hepatitis B surface antigen
- Serum human immunodeficiency virus antigen antibody
- Serum hepatitis C virus antibodies
- Blood group (ABORh)
- Urinalysis
- Urine particle identification
- Urine bacterial culture
- Cytomegalovirus antibodies
- Epstein-Barr virus antibodies
- Serum cardiolipin antibodies
- Serum varicella antibodies

Appendix 2

TO CONSIDER IN PALLIATIVE CARE

- Treatment of dyslipidaemia
- Salt restriction
 - Sodium intake of less than 2 g/day should be sought; this should also help to control fluid accumulation
- Treating hyperkalaemia
 - Moderation of potassium intake
 - Potassium binders
- Treating anaemia
 - Correction of iron deficiency with either tablets or intravenous iron
 - EPO replacement therapy
- Treatment of disorders of calcium and phosphorus metabolism
 - Primary means is to moderate phosphorus intake
 - Secondary means is to use phosphorus binders
 - Vitamin D3 supplement
- Treatment of itching
 - Regular use of emollient creams and lotions
 - UVB phototherapy, if necessary
 - Low doses of hydroxyzine, gabapentin and tricyclic antidepressants may be tested
- Treatment of nausea and vomiting
 - Initially by changing eating habits (lower portions, more often)
 - Avoiding alcohol
 - Avoiding fatty foods
 - Medication, if necessary (ondansetron)
- Treating dyspnoea
 - Fluid restriction
 - Use of diuretics
- Analgesics
- Treating sleep disorders

Appendix 2

Treatment of patients with symptoms related to chronic renal failure			
Symptom	Treatment		
Swelling, dyspnoea	Salt and liquid restriction, diuretic (furosemide, metolazone if necessary), support stockings		
Nausea	Small meals, ondansetron, metoclopramide*, olanzapine, haloperidol*		
Itching	Treatment of hyperphosphataemia, emollients, avoidance of strong detergents, gabapentin*, pregabalin*, hydroxyzine*, other antihistamines		
Pain	Paracetamol, tramadol, opioids*, medicines for neuropathic pain		
Dry mouth	Good oral hygiene, saliva stimulants		
Constipation	Fibre preparations, lactulose, macrogol, sodium picosulfate, naloxegol for opioid constipation if necessary		
Diarrhoea	Loperamide, fibre preparations		
Sleep disorders	Sleep hygiene, treatment of sleep-disturbing symptoms, most sleeping pills are suitable		
Depression	Most antidepressants are suitable		
Anxiety	Quiet surroundings, benzodiazepines		
Restless legs, cramps	Sleep hygiene, exercise, pramipexole, gabapentin*, pregabalin*		
Neuropathy	Massage, hot baths, gabapentin*, pregabalin*		
Hiccups	Metoclopramide*, haloperidol*		

*Dose reduction according to the severity of renal insufficiency.

Adapted from Martola L, Wuorela M. Munuaisten vajaatoiminta. In Saarto T, Hänninen J, Antikainen R, Vainio A Ed. Palliatiivinen hoito, 3rd edition. Helsinki: Duodecim 2015; 483–488.