

Guidelines for the care of kidney patients

From the Swedish Association for Kidney Patients

Foreword

Care of patients suffering from chronic kidney failure belongs to priority group 1 in accordance with the principles established by the Swedish Parliament governing health care in Sweden. This means that all kidney patients, no matter what age, will be provided with adequate specialist treatment, and will receive active uremia care, i.e. dialysis or transplant, if the kidneys have partially or totally ceased to function.

A patient suffering from chronic kidney failure becomes dependent on the resources of the medical services for the remainder of his or her life. Optimal medical care for kidney patients involves cooperation between several different resources within the health services and other social services, on both local and regional levels.

Over recent decades the number of patients requiring dialysis or transplant has shown an annual increase of 5-10 percent, the equivalent of 125 per million inhabitants. Comparative studies show that the quality of kidney care varies considerably in different clinics and health authorities in Sweden.

Recent scientific research in kidney treatment shows that the early treatment of kidney patients at a specialist level can often delay or even avert the need for dialysis or transplant. Early diagnosis and early treatment can probably also delay or prevent complications related to kidney failure, for instance various types of cardiovascular disease. An increased awareness of the significance of the early adequate treatment of kidney failure is vital, particularly among those responsible for providing primary care. This is probably an extremely cost effective measure.

This document is a summary of the publication "*Guidelines for the provision of good medical care for kidney patients*" from the Swedish Association for Kidney Patients and assumes the patient's perspective. The document has been produced in cooperation with representatives of the various professional groups working in kidney care. An important objective has been to reach a common standpoint so that the same quality of kidney care may be provided throughout Sweden no matter where a patient lives.

This document does not cover paediatric kidney care as this patient category has specific needs that differ from the care of adult kidney patients.

Sundbyberg, February 2006

Riksförbundet för Njursjuka
Swedish Association of Kidney Patients

Kidney medical care

If kidney patients are to receive good medical treatment and care from the patient's perspective, a number of important criteria outlined on pages 11-21 must be met. In this version of Guidelines for good medical care for kidney patients, the Swedish Association for Kidney Patients wants to highlight important issues characterising medical care for kidney patients in Sweden today.

Background

From the mid 1960's onwards patients suffering from chronic kidney failure have survived thanks to dialysis and transplants. An important breakthrough came in 1960 when for the first time a permanent access to the blood supply could be established. This made chronic dialysis treatment possible. Another breakthrough came in 1964 when the first kidney transplant was carried out in Sweden. Since then over 10,000 kidney transplants have been carried out.

An increase in the number of patients

There are more than 70 renal units in Sweden and four transplant units. From 1990 to 2004 the number of patients in active uremia care almost doubled. Every year around 1100 new patients (125 per million inhabitants) require treatment for uremia. The annual net increase is around 5%. The average age on commencement of dialysis or for transplant is 57. Two thirds of the patients are men and one third women. At the beginning of 2005 just over 3,800 patients had a functioning kidney transplant and around 3,400 were receiving some form of dialysis treatment. Few children suffer from chronic kidney failure and only 1% of patients in active uremia care were under the age of 15.

(Source: SRAU, Svenskt Register Över Aktiv Uremivård 2005).

Highly specialised care

Patients suffering from any stage of chronic kidney disease require specialist or highly specialist care. Early remittance to specialist care and, for instance, adequate treatment for hypertension can delay the progress of kidney failure and even prevent future need for dialysis or transplant. Unfortunately there is still low awareness among primary care doctors and many kidney patients are still being remitted to specialist care far too late.

Comprehensive quality register needed

The Swedish Register for Active Uremia Care (SRAU) and the Swedish Dialysis Database (SDDB) are two national registers for active uremia care. To assess and develop treatment and care a further two national quality registers are needed, for chronic kidney failure and for kidney transplants respectively.

Treatment of chronic kidney failure

Objective

All patients with chronic kidney failure will receive medical treatment of such quality that the need for dialysis or transplant is delayed or prevented.

Common causes leading to chronic kidney failure are diabetes, inflammation of the the kidneys (nephritis), hereditary kidney diseases, hypertension and systemic diseases such as SLE.

Early treatment can delay future dialysis or transplant

The early discovery and diagnosis of chronic kidney failure increases the chance of successful treatment. A patient with diagnosed kidney failure should therefore be immediately remitted to a specialist renal unit. Adequate medication to reduce blood pressure and other treatment can in many cases delay the progress of kidney disease and even prevent the need for dialysis or transplant. Early treatment can also prevent or delay complications related to kidney failure such as coronary and vascular diseases.

Dialysis treatment

Objective

In accordance with their individual needs, all dialysis patients must receive treatment of good quality that will minimise complications and prevent premature mortality.

There are two types of dialysis:

- *Peritoneal dialysis (PD) is administered by the patient at home. The peritoneal membrane serves as a dialysis filter to cleanse the blood through the continuous exchange of dialysis fluids in the abdomen.*
- *Hemodialysis (HD) means that the blood is cleansed outside the body using a dialysis filter. HD is usually carried out in a hospital three times weekly, but can also be done in the home when the patient administers the treatment.*

Better quality dialysis increases long-term longevity

The high mortality among dialysis patients, which in 2004 reached 27.4 percent, is a serious problem. The high average age in the dialysis population is one of the reasons, but not the only one. Better quality dialysis and access to more frequent dialysis treatments per week, preferably daily, can lower the number of complications and contribute to increased quality of life and longevity. Better quality dialysis leads to a sharp drop in the need for emergency and elective medical care and also to a lower use of medication which in turn leads to savings in health care costs.

Dialysis closer to the patient's home is more cost effective

Travelling distances to dialysis units should be kept as short as possible. Greater resources should be given to establishing smaller dialysis units closer to the patient. With modern technology and simple means satellite units for single patients or a handful of patients can easily be established at health centres in areas of low population. Travelling costs are minimised and the kidney patient experiences a higher quality of life if the dialysis unit is closer to his or her home.

Cost effective self-dialysis/home dialysis

Dialysis patients should be encouraged to take responsibility as far as they are able for their own treatment. The patient who takes charge of his or her dialysis can more easily determine when dialysis takes place and can fit dialysis into his or her daily life, work, education etc. Patients with patient-administered home dialysis can also increase the number of dialysis treatments. Self-dialysis at a unit or alternatively home dialysis are cost effective treatment forms as they demand little or no staffing. More self-dialysis units should be established and at the same time greater resources should be devoted to training home dialysis patients when and if the patient is able to administer the treatment.

Dialysis on contract demands specification of requirements and consultation

As health service authorities have chosen to invite tenders for dialysis treatment there must always be a clear specification of requirements with a starting point in the patient's needs of good care and continuity. The regional kidney patient association must always be consulted whenever a new dialysis unit is established whether or not this is on contract or under the national health service. To assure patients of continuity when a contractor is replaced, the health service authority must supply dialysis premises so that patients do not risk changing both premises and care staff.

The right to guest dialysis

Access to guest dialysis is essential if a dialysis patient is to fully participate in society and to live as normal a life as possible. This is a self evident right which must never be curtailed.

Kidney transplants

Objective

All kidney transplant patients must have access to specialist care so as to minimise the risks of complications and early mortality and to establish the pre-conditions for maximum transplant survival.

Around 300-350 kidney transplants are carried out annually in Sweden, of which 20-40 percent are live donor transplants. Around 550 patients are on the waiting list. Lack of cadaver organs limits the number of transplants.

Without organ donation – no transplants

The number of kidney disease patients wanting a kidney transplant is increasing while the availability of cadaver kidneys has steadily dropped. Waiting lists can therefore be long, several years, for a patient who cannot receive a kidney from a live donor. Powerful measures are needed if more cadaver organs are to be available. Information is needed to heighten awareness among the general public of the importance of making one's wishes regarding organ donation known. Furthermore every single health authority must have exclusive resources at every emergency hospital for retrieving organs and tissues for transplant purposes.

Cost effective

Not only does the patient most often achieve a good quality of life, kidney transplants are a cost effective treatment. It has been calculated that every completed kidney transplant means a saving equivalent to SEK 2-3 million in reduced medical care costs.

Live donors must be acknowledged

A live kidney donor makes a fantastic gift beyond all comparison. It is therefore important that the donor be acknowledged by the health service for his or her gift. Financial compensation should be made for all expenses and loss of income in connection with assessment and the actual transplant. Compensation for lost working hours should not be limited to 7.5 basic amounts geared to price index, but should match the actual total loss of income. The Swedish Association for Kidney Patients does not recommend any further financial compensation. However it is the association's opinion that a lifelong free card for all future medical care should be granted in appreciation.

Care and rehabilitation

Objective

Multi-professional care for kidney patients putting the individual's needs and requirements first. Chronic patients must be offered support to enable them to make the most of their remaining good health and live as full a life as possible.

The importance of the care team

A chronic kidney patient is dependent on medical resources for the remainder of their life. Many kidney patients also have other diagnoses. For optimal treatment a kidney patient often requires contact with other specialists. The care team has a central significance for the patient's quality of life and must view the patient's life as a whole. Besides doctors and medical staff, a kidney patient may need to consult physiotherapists, counsellors, dieticians, psychologists and in some cases occupational therapists.

Increased resources needed for rehabilitation

Very little rehabilitation help is available for kidney patients in specialist care and more is needed. After a stay in hospital there is often a need for convalescence care with access to dialysis treatment. Special rehabilitation centres, adapted to kidney patients' particular needs must be set up in every health authority. Contracts must be made with the few rehabilitation clinics with specialised care for kidney patients.

The need to coordinate with dental care

The side effects of medication and the complications from kidney diseases can affect dental health. Close coordination must be established between dental care, renal units and transplant units. Kidney patients must be regularly remitted to preventive treatment free of charge. This is especially important prior to an impending transplant.

Patient education

Objective

Chronic kidney patients throughout the country must receive the same high level of quality information about their condition and available treatments.

Kidney information for all kidney patients

Early information in cases of chronic kidney failure helps the patient take a more active role in the treatment and can in some cases contribute to delaying the progress of the disease so that future dialysis or transplant can be avoided.

Active uremia care comprises dialysis in various forms and kidney transplant. Education programmes are significant in giving the patient support to actively influence the choice of treatment.

Kidney education programmes should be under the charge of the health services in cooperation with the regional association of kidney patients. The same curriculum should be used throughout the country to ensure that the same level of care is achieved.

Research and development

Objective

Resources must be allocated for qualified scientific research aimed at improving quality of life for kidney patients.

To ensure optimal care for chronic kidney patients and to minimise the risks of serious complications the Swedish Association for Kidney Patients holds that there is a need for a large increase in resources for research and development in nephrology and transplants. Similarly health authorities must allocate resources for further education and staff training for all staff categories participating in the care of chronic kidney patients. The founding of a chair in nephrology at every teaching hospital can encourage more doctors to specialise in the field and even stimulate more research and development.

Minimum requirements to be met for good kidney medical care

Care

Objective

Multi-professional care for kidney patients putting the individual's needs and requirements first.

Requirements:

- Individually adapted care plan, to be regularly overviewed, to be set up in cooperation with the patient at every stage of the patient's condition and treatment.
- Care to be characterised by warmth, respect and consideration.
- Every patient with kidney failure to be entitled to a doctor responsible for the patient and at least one nurse who can be contacted whenever necessary.
- A multi-professional care team with doctor, nurse, dietician, physiotherapist and counsellor. If necessary the team is to include occupational therapist, psychologist, hospital priest/welfare worker and other resources.
- Readiness and experience in dealing with people in crisis situations.

Patient Education

Objective

Chronic kidney patients throughout the country must receive the same high level of quality information about their condition and available treatments.

Requirements:

- All patients with chronic kidney failure on diagnosis to receive education and information about how kidney failure can be delayed or prevented.
- Education about different forms of treatment to be offered to chronic kidney patients well before dialysis treatment or transplant is commenced.
- Information to be objective and given both orally and in writing, and be repeated on several occasions.
- Information to be given by the doctor treating the patient and if necessary by other representatives of the professions included in the care team.
- Information to be adapted in case of disabilities or language difficulties. Approved interpreters to be used when needed.
- If the kidney patient so wishes next of kin are to participate in the kidney education programme.
- Every new patient is to be informed about the regional kidney patient association and have access to information from the Swedish Association for Kidney Patients.
- Routines for informing the children of kidney patients.
- Chronic kidney patients and patients who have received transplants are to be informed of the importance of regular visits to dentists and dental hygienists.

Treatment of chronic kidney failure

Objective

All patients with chronic kidney failure must receive medical treatment of such quality that the need for dialysis or transplant is delayed or prevented.

Requirements:

- All patients with suspected chronic kidney failure must be remitted to a nephrologist for suitable treatment. Children with suspected chronic kidney failure to be remitted to a nephrologist at a paediatric clinic.
- A patient with chronic kidney failure is to receive at an early stage information, individually and in a group, about the importance of the medical treatment and life style changes which may delay or prevent the need for dialysis treatment or kidney transplant.
- Education, individually or in a group, is to be provided before starting dialysis treatment or before a transplant, so that the patient is equipped to choose the method of treatment.
- When treatment with protein reduced nutrition is to be started a dietician must be consulted and the treatment may only continue so long as it achieves the intended effects.
- At an early stage the patient must consult a dietician and a physiotherapist and if necessary a counsellor, psychologist and dentist.
- The nephrologist must cooperate with specialists at other specialist clinics if the patient has other chronic conditions.
- Transplant assessment must commence at an early stage to avoid, or to shorten the length of, dialysis treatment.
- A national quality register must be compiled over patients with kidney failure to assess and develop care and treatment.

Dialysis Treatment

Objective

In accordance with their individual needs, all dialysis patients must receive treatment of good quality that will minimise complications and prevent premature mortality.

Requirements peritoneal dialysis (PD):

- PD-catheterising (access) must be carried out well before dialysis is started.
- Each patient must be entitled to individually adjusted dialysis treatment with APD or CAPD, to be available according to need or request. Financial factors must not determine choice of method or material.
- All dialysis patients must have a satisfactory haemoglobin level (Hb) and receive the necessary medication to achieve this.
- Patients receiving PD must have 24-hour access to nephrology staff.
- All aids and goods, including deliveries necessary for treatment must be free of charge for the patient. This also applies to equipment needed when travelling.
- The local authority or health authority must, without cost for the patient, take charge of packaging and other refuse in connection with PD.
- When necessary local authority home carers must be trained to assist patients with PD-treatment.
- Contact with physiotherapist and dietician must be offered and encouraged. If necessary patients must be referred to a counsellor.
- There must be routine house calls on patients when PD-treatment is started up.

Requirements home dialysis (HD):

- Permanent access to blood supply must be made at least three months prior to starting dialysis.
- The number of dialysis treatments per week, the length of the treatments, material used during the treatments and medical technology safety must be determined in accordance with the most up to date research and medical theories, in relation to the individual's needs, and must not to be influenced by financial considerations.
- All dialysis patients must have a satisfactory haemoglobin level (Hb) and receive the medication necessary to achieve this.
- Repeated headaches, nausea, drop in blood pressure and fatigue during and after dialysis must lead to adjustment of the dialysis management until these symptoms have ceased.
- The objective must be to offer each patient a flexible dialysis timetable adjusted to that individual's needs and work, studies and leisure time.
- The patient must be encouraged to take an active part in his or her dialysis. Every patient who wishes, and is able, must be offered self-dialysis at a renal unit or in the home.
- The patient must have access to regular private consultations with his or her dialysis doctor.
- Regular contact with physiotherapist and dietician must be offered and encouraged. Meals during dialysis treatment must be seen as part of the treatment and must be composed by a dietician and free of charge for the patient.
- The local authority must provide an assistant for patients using hemodialysis at home.
- Every health authority must offer education and training before starting HD in the home.
- Patients using HD in the home must have 24- hour access to the responsible nephrology medical staff.
- All transport to and from dialysis units must be free of charge and arranged to avoid delays due to shared transport. Dialysis patients staying at a temporary address must be entitled to transport to and from their own dialysis unit.

Kidney transplants

Objective

All kidney transplant patients must have access to specialist care so as to minimise the risks of complications and early mortality and to establish the pre-conditions for maximum transplant survival.

Requirements:

- All patients about to enter active uremia care, who have the medical pre-conditions, must be offered kidney transplants.
- All patients must be given detailed information well in advance of transplant about the operation, the significance of the medication, life style guidelines and possible complications, which may arise following immune suppressing treatment.
- Patients not accepted for transplants must be informed about their right to a new assessment, so called “second opinion”. A new assessment must be carried out at a different transplant centre.
- The option of possible live donors must always be raised when a patient has been accepted for transplant and the assessment must be completed within three months. If there is no donation, the assessment period must be included in the time the patient has been on the waiting list.
- The patient must be informed about the waiting list regulations, the estimated waiting period for transplant and about complications that may affect the waiting period.
- Next of kin must, for as long as there is a need, be entitled to compensation for transport and accommodation costs if the transplant is carried out at a distance from the home address.
- Check ups and follow up must be carried out by a nephrologists specialised in transplant medicine. The patient must have 24-hour access to specialist doctors. Should complications arise, or if the patient wishes, the patient must be remitted to the hospital where the transplant was carried out.
- When a kidney transplant patient is treated for other conditions, continuous contact must be maintained with the transplant specialist and the renal care team.

- When a transplant is expected to be unsuccessful, the conditions for a new transplant must be immediately assessed. The patient must also be offered support from a psychologist for the trauma often arising from a return to dialysis.
- Live donors must be offered full insurance cover, full compensation for loss of income and other expenses, as well as a lifelong free card for all health care as compensation.
- When a patient is assessed for transplant, preventative dental care must be included in preparing the patient.
- To minimise the risk of skin tumours, all kidney transplant patients must be examined regularly by a dermatologist. Women must be regularly referred for examination by gynaecologist.
- A quality register for treatment of kidney transplant patients must be compiled, in order to achieve the same standard of care throughout the country with the highest possible transplant survival.

Family life and relationships

Objective

The kidney patient's next of kin must always be given the opportunity to participate, and must receive the support they require.

Requirements:

- Kidney patients' children or younger siblings must be given special attention and receive suitable information.
- Next of kin must be offered information about kidney conditions and treatment and about how social and private life may be affected.
- The kidney patient must be given information about how his or her sexuality may be affected and about possible treatment.
- Next of kin must be offered support counselling if needed.

Rehabilitation

Objective

Chronic patients must be offered support to enable them to make the best of their remaining good health and live as full a life as possible.

Requirements:

- Rehabilitation for every stage of the kidney disease must be included in the care plan and the care team must offer individual support with physical and psychological rehabilitation from the start.
- Care must be planned so that the patient who is able can take part in working life or study.
- Dialysis treatment at other locations in Sweden and abroad must be available without limitations or increased costs for the kidney patient.
- Special rehabilitation centres must be available within reasonable distance for every kidney patient in this country.

Research

Objective

Resources must be allocated for qualified scientific research aiming to improve quality of life for kidney patients.

Requirements:

- Research and development resources must be allocated to renal and transplant units for the use of professional groups working with the care of chronic kidney patients.
- Priority must be given to medical research focusing on delaying and preventing the development of chronic kidney failure, and minimising the risks of premature mortality among kidney patients undergoing active uremia care.
- Teaching hospitals must be allocated sufficient staff resources, so that continuous medical research of high quality can be carried out without affecting the level of care for kidney patients.
- All research and development must take account of a gender perspective.

Care at life's close

Objective

The decision to cease treatment must always be taken together with the patient, next of kin, and only when all possibilities of starting or continuing treatment have been investigated.

Requirements:

- Information that life maintaining dialysis treatment may not be started or may be ceased must be given by the responsible nephrologist. The information must be given in such a way that all those involved can understand the implications of the decision, so there are no doubts as to which alternatives are medically viable.
- To cease life maintaining dialysis treatment must be discussed together with the patient and/or next of kin, if the patient cannot participate for health reasons.
- The decision not to start, or to interrupt dialysis treatment, must be thoroughly investigated so that the decision is not made on erroneous grounds. When necessary, counselling with hospital priest, counsellor and care staff must be offered. The decision must always be taken by the nephrologist responsible for the patient.
- Care at the close of life must always be sympathetic, respectful and considerate.
- Palliative care in the home must be closely coordinated with the nephrologist responsible for the patient and the nurse. It must always be possible to transfer the patient immediately to hospital care should the need or wish arise.

The Swedish Association for Kidney Patients, RNj

www.rnj.se

The Swedish Association for Kidney Patients, RNj, was founded in 1969 to safeguard the interests of kidney patients in society, and above all regarding questions in the care of kidney patients. Further the association spreads information, works with recreation and rehabilitation for members and supports research and development. RNj has an established cooperation with other associations for the disabled in Sweden through the co-operative body The Swedish Disability Federation, HSO and through sister organisations in Scandinavia and Europe.

RNj is composed of thirteen regional associations covering all Sweden with a total of around 5000 individual members. Within RNj there are children and parent sections and a youth section with specific activities for each target group.

Comprehensive information about the activities and organisation of the association can be found in the association's various publications.