National
Kidney
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Council of Nephrology
Social Workers

STANDARDS OF PRACTICE FOR NEPHROLOGY SOCIAL WORK

Sixth Edition

6th Edition Edited By:
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Dear Colleagues,

On behalf of the National Kidney Foundation's Council of Nephrology Social Workers (CNSW), we would like to introduce the sixth edition of the **Standards of Practice for Nephrology Social Work**. In addition to updating the material already in the book, it was also updated to include the language of the new Conditions for Participation.

I wish to thank the editors of this edition, Teri Browne, PhD, MSW, NSW-C (CNSW Chair 2005-2009); Leanne Peace, MSW, LCSW, MHA (CNSW Chair 2013-2015), and Diane Perry, LICSW, NSW-C (CNSW Region III Representative 2012-2014), and the rest of the CNSW Executive Committee who took time to review this manual in great detail in the commitment to have it as best as it can be for the CNSW membership.

Nephrology social work continues to be an exciting and expanding field. In addition to dialysis and transplant social workers, we continue to see growth in other areas of practice such as pre-dialysis patient educators, social workers in management of dialysis companies, and research in university settings. We hope this updated edition will continue to offer information and resources beyond just the clinical setting. CNSW hopes you will find this a useful resource in your social work practice.

Sincerely,
Stephanie Stewart, LICSW, MBA
CNSW Chair, 2011-2013

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Council of Nephrology
Social Workers

Council of Nephrology Social Workers Mission Statement

The Council of Nephrology Social Workers (CNSW) functions as a professional membership council within the framework of the National Kidney Foundation (NKF) and networks with other organizations, including the Centers of Medicare and Medicaid (CMS), state and local governments, and private groups. CNSW's purpose is twofold: one, to assist patients and their families in dealing with the psychosocial stresses and lifestyle readjustments and facilitate a treatment program that will maximize rehabilitation potential; two, to support the federal regulations governing ESRD reimbursement in regard to standards for social work practice and in the definition of a qualified social worker.

Council of Nephrology Social Workers Strategic Goals

- Develop and promote patient and public education.
- Support and promote the profession and education of nephrology social work.
- Impact regulatory and legislative issues.
- Ensure the use of the qualified social work in the ESRD setting.
- Provide ongoing support and education to the kidney disease patient.

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1. UNDERSTANDING CHRONIC KIDNEY DISEASE

NKF Kidney Disease Outcomes Quality Initiative (NKF KDOQI)™

In 1995, the National Kidney Foundation (NKF) began the development of what would become the first broadly accepted clinical practice guidelines in nephrology, now known as KDOQI—Kidney Disease Outcomes Quality Initiative. The first guidelines were published in 1997, and today there are 13 guidelines, which have made a major difference in the quality of care for kidney patients in the United States and worldwide.

With the publication of the Clinical Practice Guidelines and Clinical Practice Recommendations for Diabetes and Chronic Kidney Disease in February 2007, KDOQI achieved its primary goal of producing evidence-based guidelines on the thirteen aspects of CKD care most likely to improve patient outcomes. We now seek to apply the knowledge acquired in the development and refinement of the KDOQI processes to improve clinical practice through a broader range of activities.

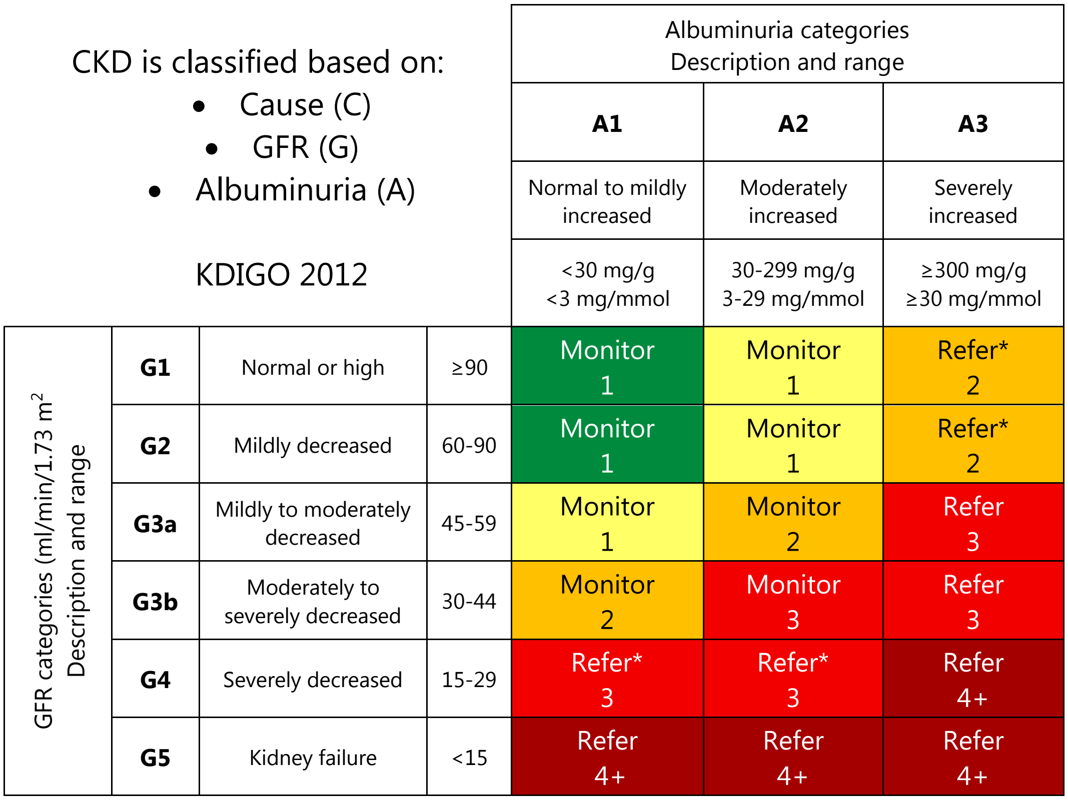
> All KDOQI Guidelines and Commentaries are published in the ***American Journal of Kidney Diseases (AJKD)***, NKF's premier journal, and can be accessed online at the **NKF KDOQI™ website**.
>
> ### Guidelines
>
> The National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF KDOQI)™ has provided evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD) and related complications since 1997. Recognized throughout the world for improving the diagnosis and treatment of kidney disease, the KDOQI Guidelines have changed the practices of numerous specialties and disciplines and improved the lives of thousands of kidney patients.
>
> ### Commentaries
>
> KDOQI convenes a small work group of U.S. based experts to review the international guidelines and write a commentary to help the U.S. audience understand the applicability and importance of the guidelines in their local clinical environment. These commentaries will form the basis for U.S.-specific implementation tools and programs, which will be produced under the KDOQI brand.

In 2009, Kidney Disease: Improving Global Outcomes (KDIGO) convened a controversies conference in 2009 and then organized an international work group to review and update the 2002 NKF-KDOQI CKD guideline. After the international KDIGO guideline was published in 2013, NKF-KDOQI organized its own work group to provide the **KDOQI US Commentary on the 2012 KDIGO Clinical Practice Guideline for the Evaluation and Management of CKD**.

The NKF also offers a free **Speaker's Guide**, which explains the KDIGO 2012 Clinical Practice Guideline for CKD in simple, practical diction; helps you educate large or small groups of professional learners; and can also be viewed by individual clinicians for self-learning. Slides are available in English, Spanish, French and German.

Definition and Classification of CKD

CKD is defined as abnormalities of kidney structure or function, present for >3 months, with implications for health. KDIGO proposes classification of CKD by **C**ause, **G**FR and **A**lbuminuria, respectively referred to as **CGA staging**. It can be used to inform the need for specialist referral, general medical management, and indications for investigation and therapeutic interventions. It will also be a tool for the study on the epidemiology, natural history, and prognosis of CKD.



CKD is classified based on:

- Cause (C)
- GFR (G)
- Albuminuria (A)

KDIGO 2012

GFR categories (ml/min/1.73 m^2) Description and range				Albuminuria categories Description and range		
				A1	**A2**	**A3**
				Normal to mildly increased	Moderately increased	Severely increased
				<30 mg/g <3 mg/mmol	30-299 mg/g 3-29 mg/mmol	≥300 mg/g ≥30 mg/mmol
	G1	Normal or high	≥90	Monitor 1	Monitor 1	Refer* 2
	G2	Mildly decreased	60-90	Monitor 1	Monitor 1	Refer* 2
	G3a	Mildly to moderately decreased	45-59	Monitor 1	Monitor 2	Refer 3
	G3b	Moderately to severely decreased	30-44	Monitor 2	Monitor 3	Refer 3
	G4	Severely decreased	15-29	Refer* 3	Refer* 3	Refer 4+
	G5	Kidney failure	<15	Refer 4+	Refer 4+	Refer 4+

Adapted with permission from KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. *Kidney Int*. 2013;Suppl.3:1-150.

Key to Figure:
Colors: Represents the risk for progression, morbidity and mortality by color from best to worst. Green: low risk (if no other markers of kidney disease, no CKD); Yellow: moderately increased risk; Orange: high risk; Red, very high risk.
Numbers: Represent a recommendation for the number of times per year the patient should be monitored.
Refer: Indicates that nephrology referral and services are recommended.
*Referring clinicians may wish to discuss with their nephrology service depending on local arrangements regarding monitoring or referral.

Role of the Nephrology Social Worker in KDOQI and KDIGO

The nephrology social worker plays an important role in helping the patient meet the outcomes as outlined in the K/DOQI & KDIGO guidelines. Through a focused assessment, the social worker can identify the psychosocial issues that are a barrier to achieving optimal treatment outcomes and can implement clinical interventions to reduce these barriers. Patient education, advocacy, cognitive and behavioral interventions, quality of life measurements and resource referrals as well as other interventions can be used by the social worker to resolve barriers.

The **Comprehensive Interdisciplinary Assessment Document (CIPA)** was developed by CNSW in 2008 to assist social workers in the assessment of barriers that have an impact on treatment outcomes. It covers barriers related to obtaining hemodialysis and peritoneal adequacy, attaining vascular access guidelines, meeting anemia management guidelines, attaining nutritional guidelines, and addressing adherence issues such as understanding emotional/behavioral processes, resources and problems during treatment.

2. NEPHROLOGY SOCIAL WORK

THE ROLE OF THE NEPHROLOGY SOCIAL WORKER

Nephrology social work services support and maximize the psychosocial functioning and adjustment of chronic kidney disease patients and their families. These services are provided to improve social and emotional stresses resulting from the interacting physical, social, and psychological concomitants of chronic kidney disease which include shortened life expectancy, altered lifestyle with changes in social, financial, vocational, and sexual functioning, and the demands of a rigorous, time-consuming, and complex treatment regimen.

The nephrology social worker is a part of an interdisciplinary team and provides collaboration with other team members to help them in understanding the biopsychosocial factors that can impact treatment outcome. The major interventions provided by nephrology social workers include:

- Pre-dialysis education and assessment
- Ongoing Biopsychosocial Assessment (including quality of life measurement)
- Casework (counseling and conferences with patients, families, and support networks; crisis intervention goal-directed counseling; discharge planning)
- Group work (education, emotional support, self-help)
- Mediation
- Information and Referral
- Facilitation of community agency referrals
- Interdisciplinary care planning and collaboration
- Advocacy on patients' behalf within the setting and with appropriate local, state and federal agencies and programs
- Patient and family education

The major categories of problems addressed by nephrology social workers include:

- Adjustment to chronic illness and treatment as they relate to the patient's quality of life
- Physical, sexual, and emotional relationship problems
- Educational, vocational, and activity of daily living problems
- Conflict resolution
- Problems related to treatment options and setting transfers
- Resource needs, including finances, living arrangements, and transportation
- Decision making with regard to advance directives

The nephrology social worker and management must work together in establishing mutually agreed-upon goals and responsibilities. Many tools are available through the National Kidney Foundation's Council of Nephrology Social Workers to assist in this process; see, for example, **Comprehensive Interdisciplinary Assessment Document (CIPA)**.

Adapted from the "NASW/NKF Clinical Indicators for Social Work and Psychosocial Services in Nephrology Settings," (1994) Washington, DC: NASW Press.

ESRD REGULATIONS: DEFINITION OF SOCIAL SERVICES AND QUALIFIED SOCIAL WORKERS

Position Paper of the NKF Council of Nephrology Social Workers

Position: The Council of Nephrology Social Workers of the National Kidney Foundation, representing over 700 nephrology social workers in dialysis and transplant facilities, strongly supports enforcement of the current federal regulations governing ESRD reimbursement regarding standards for Social Services and the definition of a qualified social worker.

Historical Overview: The Changing Patient Population

As part of the Social Security Amendment of 1972, Congress extended Medicare coverage to persons diagnosed with ESRD. The following summer, on July 1, 1973, enrollment of ESRD patients began (Federal Register, 1976). At that time, only about 11,000 patients were receiving chronic dialysis treatments, and it was believed that the extension of Medicare coverage would help to save those lives, as well as the lives of future patients, while reducing the financial burden of their illness. When the regulations were first issued, it would have been difficult to predict the numbers of future patients who would be stricken with ESRD and the often overwhelming medical, social, and psychological problems these patients would confront. In 2010, there were 116,946 new patients diagnosed with ESRD, and 594,374 total prevalent patients with ESRD in the U.S. It is projected that by 2030 the number of ESRD patients will increase to 2.24 million (U.S. Renal Data System, 2012).

In addition to the ESRD population growing in numbers, information from the U.S. Renal Data System (USRDS) indicates that patients are also growing older. In 1977, the median age of new ESRD patients was 54 with 27% over age 65. In 2008, the median age had risen with 36% of the population over age 65 (USRDS, 2010). The rates of elderly patients, age 75 and older, have doubled since 1997 (USRDS). The aging process alone often leads to other more complex medical and psychosocial dilemmas. For example, elderly individuals are often faced with declining physical and emotional capabilities, loss of emotional and social support systems, shrinking income, increasing health problems, increasing occurrence of dementia, as well as housing and transportation difficulties.

While increasing numbers and the aging process present potentially serious problems in the ESRD population, other growing problems also exist. One problem is the increasing prevalence of other disease entities. According to the USRDS, the incidence of diabetes and hypertension in ESRD patients is more than 50% above average (1989). Another patient group whose numbers are growing are those infected with AIDS. For at least three years (1985-1987), the annual Health Care Financing Administration (HCFA; now Centers for Medicare & Medicaid Services, or CMS) survey of dialysis facilities reported an annual increase in the number of patients infected with the AIDS virus. While true incidence and prevalence data are not available for the ESRD population, the Centers for Disease Control and Prevention (CDC) estimates (based on the incidence of AIDS in the general population) that 10,000 to 15,000 persons will develop renal disease in association with AIDS (Schoenfeld & Feduska, 1990). Mortality rates are also higher in the ESRD population than in the general population. The life expectancy of ESRD patients is 75% lower than similar individuals without ESRD (Moss, 2005).

Some of the other serious psychosocial issues which arise in the ESRD population are cited in the 1989 USRDS report:

> Kidney failure is a devastating medical, social and economic problem to the patient and his or her family. The initial experience may leave the patient feeling vulnerable, dependent, and at death's door. After replacement therapy is initiated, the other problems become more prominent. Social adjustment to the dependency, the reduced quality of life, the low likelihood of returning to work, genuine higher mortality rates, and the dramatically lowered economic standard are all part of the problems. If the patient was not poor before kidney failure, it is very likely that he/she will be after.

In addition to issues cited above are the demands of a rigorous time-consuming treatment regimen; the financial disincentives to successful vocational rehabilitation (i.e., losing disability payments, etc.); diminishing community resources; as well as a whole range of psychosocial responses to illness and treatment, including anger, frustration, anxiety, and depression. Addressing these psychosocial stresses and the lifestyle readjustment demanded of patients and their families is an essential part of the therapeutic process in order to facilitate the effective use of a costly treatment program and to maximize treatment potential.

Review of Current ESRD Regulations: Definition of Social Services

Almost four decades ago when regulations governing ESRD settings and professionals serving in these settings were being formulated, general knowledge of the relatively new field of ESRD treatment was limited among policy makers and professionals alike. Even less was understood about how increasingly complex individuals' lives would become medically, socially, and psychologically as a result of the diagnosis and treatment of ESRD. The federal government, as early as 1976, acknowledged that the ultimate goal of ESRD treatment is to not only extend life but to extend meaningful and productive life. To that end, the Centers for Medicare and Medicaid (CMS) regulations governing reimbursement for dialysis and transplantation were written mandating that social work services be an integral part of patient care. The Standard for Social Services, effective September 1, 1976, was specified in the Final Regulations 405.2163 (b) (Federal Register, 1976):

> Social Services are provided to patients and their families and are directed at supporting and maximizing the social functioning and adjustment of the patient. Social Services are furnished by a qualified social worker who has an employment or contractual relationship with the facility. The qualified social worker is responsible for conducting psychosocial evaluations, participating in team review of patient progress and recommending changes in treatment based on the patient's current psychosocial needs, providing casework and group work services to patients and their families in dealing with the special problems associated with ESRD, and identifying community social agencies and other resources and assisting patients and families to utilize them.

By 2008, the CMS Conditions for Coverage for ESRD Facilities (CfCs) were revised for both the dialysis and transplant settings (Federal Register, 2007, 2008). The conditions both mandated an emphasis on the importance of attending to psychosocial barriers to kidney disease. CNSW compiled a chart for its members, which outlines all aspects of the 2008 CfCs for the dialysis setting that attend to psychosocial aspects of ESRD. This chart includes the actual language in the document, as well as the language from the document's preamble. The chart is available **HERE**.

ESRD Regulations: Definition of a Qualified Social Worker

In describing the Social Services which are required in the ESRD setting, a qualified social worker must be available to provide such services in order for a facility to bill Medicare for services. The **2008** ESRD regulations for **dialysis units** define a qualified social worker as (**Federal Register, 2008, §494.140(d)(1)**):

> *The facility must have a social worker who—*
>
> *(1) Holds a master's degree in social work with a specialization in clinical practice from a school of social work accredited by the Council on Social Work Education; or*
>
> *(2) Has served at least 2 years as a social worker, 1 year of which was in a dialysis unit or transplantation program* ***prior to September 1, 1976****, and has established a consultative relationship with a social worker who qualifies under §494.140(d)(1).*

The **2008** dialysis ESRD regulations also mandate (Federal Register, 2008, § 494.180):

> *All dialysis facility staff must meet the applicable scope of practice board and licensure requirements in effect in the State in which they are employed. The dialysis facility's staff (employee or contractor) must meet the personnel qualifications and demonstrated competencies necessary to serve collectively the comprehensive needs of the patients. The dialysis facility's staff must have the ability to demonstrate and sustain the skills needed to perform the specific duties of their positions.*

Furthermore, the **2008** ESRD dialysis regulations mandate (Federal Register, 2008, § 494.140):

> *The governing body or designated person responsible must ensure that—*
>
> *(1) An adequate number of qualified personnel are present whenever patients are undergoing dialysis so that the patient/staff ratio is appropriate to the level of dialysis care given and meets the needs of patients; and the registered nurse, social worker and dietitian members of the interdisciplinary team are available to meet patient clinical needs;*
>
> *(2) All employees have an opportunity for continuing education and related development activities.*

The 2008 regulations replaced the **1976** ESRD regulations for dialysis centers, that defined a qualified social worker in a dialysis unit as (Federal Register, 2008, § 405.2102(r)(6):

> *A person who is licensed, if applicable, by the State in which practicing, and:*

> *(i) Has completed a course of study with specialization in clinical practice at, and holds a master's degree from a graduate school of social work accredited by the Council on Social Work Education; or*
>
> *(ii) Has served for at least 2 years as a social worker, 1 year of which was in a dialysis unit or transplantation program prior to effective date of these regulations, and has established a consultative relationship with a social worker who qualifies under item (6) (i) of this section.*

The **2007** ESRD regulations for **kidney transplant centers** define a qualified social worker as (**Federal Register, 2007, § 482.94(3)(ii)(d)**) as:

> *A qualified social worker is an individual who meets licensing requirements in the State in which he or she practices; and*
>
> *(1) Completed a course of study with specialization in clinical practice and holds a master's degree from a graduate school of social work accredited by the Council on Social Work Education; or*
>
> *(2) Is working as a social worker in a transplant center as of the effective date of this final rule and has served for at least 2 years as a social worker, 1 year of which was in a transplantation program, and has established a consultative relationship with a social worker who is qualified under (d)(1) of this paragraph.*

The knowledge base and skills required by a nephrology social worker in order to effectively evaluate and treat ESRD patients and families are multi-faceted. Areas of knowledge include an understanding of individual behavior, family dynamics and the environmental context within which the patient/family interact; the psychosocial impact of chronic illness and treatment on patient/family functioning; treatment team interaction and communication patterns; and the existence and utilization of family and community resources. Social work skills required include interviewing and assessment; treatment expertise in individual, family, and group counseling; identifying, using and/or developing needed community resources, including those which can facilitate successful social and vocational rehabilitation; and effective communication with and participation in team review of patient care. Increasingly, the nephrology social worker must have the ability to assess the appropriateness of a patient and family's home care plans. This social work assessment is essential in helping to formulate treatment plans which can ultimately decrease the cost of both prolonged hospitalizations and nursing home placements. Finally, the nephrology social worker frequently serves as an advocate for patients and families, assisting them to work within systems which may be overwhelming and extremely confusing.

The Qualified ESRD Social Worker: Educational Preparation

The mandate from the federal government to provide patients with access to qualified social work services is even more critical today than when the regulations were first enacted more than 35 years ago. The complexity and increasing severity and multiplicity of problems of ESRD patients requires highly-developed and sophisticated social work skills.

A study conducted by CNSW in 1988 clearly illustrates this point. The study was conducted because of concerns about the quality and accessibility of social work services provided in dialysis facilities.

Responses from 345 social workers representing approximately 25,000 ESRD patients were obtained. A comparison with 1987 HCFA data indicated that responses were representative of the types of facilities in operation (CNSW, 1988).

From the data obtained, information was gathered on caseload and types of problems the ESRD social worker encounters. A full-time social worker (FT = 32-40 hrs. weekly) carried an average caseload of 102 patients. In this "average" caseload of 102, 20 patients are diabetic, 3 live in nursing homes, 3 are so debilitated that they require ambulance transportation to treatment, 3 have general transportation problems, 10 patients have inadequate support systems, 17 need financial assistance to pay for medications, and 27 receive Medicaid benefits and are financially indigent. All of these situations can present serious problems for patients and would require the intervention of a skilled social worker.

Almost twenty-five years later, CNSW determined that caseloads remain high for dialysis and kidney transplant social workers in national surveys of thousands of social workers (Merighi, Browne, & Bruder, 2010). **To view poster, visit Appendix A (p. 147).**

Between 2007 and 2010, outpatient dialysis social workers experienced increases in mean caseload size from 73 to 79 (up 8.2%) for those employed 20–31 hours per week, 113 to 121 (up 7.1%) for those employed 32–40 hrs/wk, and 117 to 126 (up 7.7%) for those employed 40 hrs/wk. To read more, visit the article by Merighi, Browne, and Bruder in the ***Journal of Nephrology Social Work* (*JNSW*), Volume 34, Winter 2010**.

Each of the problems cited above are serious and require highly-skilled social work intervention. Educational preparation as outlined by the Council on Social Work Education (CSWE) clearly calls for a master's-prepared social worker to assess and intervene in these problem areas. The CSWE defines the BSW, or baccalaureate degree, as the first level of professional education for entry into the profession of social work. Bachelor's-level social work training provided by a CSWE-accredited college or university is meant to provide a social worker with a "beginning level of proficiency in the self-critical and accountable use of social work knowledge" (CSWE, 1987, p.124). A bachelor's degree in social work educates students for general practice. The master's degree in social work, on the other hand, is directed toward preparing the individual for concentration in a specialized field. Health and mental health are designated as such fields. Students who graduate from MSW programs are to have "advanced analytic and practice skills sufficient for self-critical, accountable, and ultimately autonomous practice" (CSWE, p.124). Clearly, MSW training is unique because it prepares the worker to intervene where both social and psychological problems exist. Such skills are essential for the nephrology social worker who practices independently in a very specialized and complex field where patients frequently experience stress of both a social and psychological nature.

Support for the Regulations

It is critical to note that during the comment period prior to the enactment of the previous and current federal regulations defining Social Services and the qualified social worker in ESRD settings, the largest number of comments received were on the qualifications of the social worker. To quote, "many commentaries expressed the opinion that the need of the ESRD patient is for psychosocial evaluations and for recommending changes in treatment based on the patient's current psychosocial needs and for direct social work interventions. This activity is considered to require the background for master's degree with specialization in clinical practice; the usual baccalaureate programs in social work were not felt to provide the requisite background in counseling of ESRD patients" (Federal Register, 1976). As a result of these comments, the regulations were written to ensure that patients have access to quality social work services. Social work commentaries supporting the MSW-trained social worker included both MSW and non-MSW social workers. The National Association of Social Workers (NASW), consisting of 128,900 professional members, supports the regulations as they stand and states its support in its "NASW Standard for Social Work in Health Care Settings." Requiring appropriately-trained social workers in the kidney disease setting is the first step toward assuring quality social services to ESRD patients. In response to the 2008 regulations update, CNSW provided members with a literature-based sample response for members to include when submitting comments to the proposed Conditions for Coverage.

Summary and Conclusions

In the years that have elapsed since the enactment of federal regulations governing the provision of social services by a qualified social worker, the picture of ESRD has changed. The patient population is growing both larger and older and is exhibiting a broader range of medical and psychosocial problems.

It is apparent that these potentially severe psychosocial stressors require trained and independent social work practitioners who possess the essential assessment and intervention skills. Clearly, non-MSW-level training is not sufficient to work with the many and complex problems of ESRD patients. Any consideration given to lowering educational requirements of ESRD social workers would mean that the psychosocial needs of patients would not be addressed and ultimately treatment outcome would be poor. Therefore, it is imperative to maintain the current requirement for MSW prepared social workers who are trained to intervene in an autonomous and highly-skilled manner. Since technology has advanced to the point of prolonging life in patients, many of whom would surely have died just a few short years ago, it is essential that they have access to qualified social work services which can enhance the outcome of treatment and the quality of the years prolonged.

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PRE-DIALYSIS EDUCATION: THE SOCIAL WORKER'S ROLE

There is ample evidence that educating patients prior to the initiation of dialysis is beneficial. Medicare regulations mandate that dialysis patients be provided with treatment options, which are best presented prior to the start of dialysis. Patients who are prepared for lifestyle changes tend to have improved outcomes after dialysis is initiated. The education process is optimized when patients receive ongoing education, starting early in the disease process

The master's-trained social worker is uniquely qualified to provide pre-dialysis education to CKD patients. The social worker can discuss treatment options, job retention strategies, rehabilitation potential, family adjustment issues and insurance concerns. Social workers are trained to assess mental health issues that facilitate or impede adjustment to chronic illness and dialysis. Social workers combine these skills with a systems, rather than symptom, approach that addresses the total functioning of the patient and family.

The social worker can also be the team leader in developing a pre-dialysis education program. Existing resources include the following:

- **Missouri Kidney Program Patient Education Program**
- **ESRD Network resources**
- **Renal Support Network resources**
- **Medical Education Institute's Kidney School**
- **American Association of Kidney Patients education materials**

CNSW participated in the creation of the National Kidney Foundation program "**Your Treatment, Your Choice**" to educate patients before they need treatment for kidney failure. This program can be used to educate patients as part of the **Medicare Improvements for Patients and Providers Act of 2008 (MIPPA) Kidney Disease Education Benefit**.

When the social worker involves the entire health care team in the educational process, there is the added benefit of increased cohesiveness on the part of the team. Pre-dialysis education leads to empowerment of the patient; the patient develops understanding and confidence that can be optimized by the social worker in helping the patient to cope. The benefit of having an informed patient extends to the entire health care team, providing an effective marketing device to encourage team involvement.

Initially authored by Ed Gray, 2002
Revised by T. Browne, 2012

TEAMWORK

This practice guide is directed toward the social worker who is providing services to patients with chronic kidney disease; the guide contains much information and many resources. The social worker in his/her physician's clinic, dialysis unit, or transplant unit may feel overwhelmed both by the scope of the practice guide and nephrology social work in general.

Fortunately, the social worker does not have to "know it all." One of the advantages of the clinic or dialysis/transplant unit setting is the opportunity to work as a member of an interdisciplinary team, consisting of physicians, advanced practitioners, nurses, dietitians, technicians and other professionals as well as social workers. It is important to recognize and use the unique perspective of nephrology social work, which focuses on the entire person and not just on the "patient" with chronic kidney disease. It is equally important to develop a working relationship with fellow team members, with the goal of providing well-rounded patient care.

Other team members have their own perspectives on the patient. They may have valuable insights into the patient's daily life, because they spend so much time interacting with and listening to the patient. Team members can informally alert the social worker to needs and concerns voiced by the patient, enhancing the formal social work assessment.

Social workers need to be aware of the importance of defining their role to other team members. This can be done not only through day-to-day social work services provided in the clinic or unit, but also through in-services that educate staff about the unique psychosocial needs of the patient with chronic kidney disease.

Social workers can play a vital role in helping kidney disease teams manage stress and conflict. They can also help team members with issues related to professional boundaries, particularly in the age of social media such as Facebook, where patients and staff may request that they "friend each other" and complicate the professional relationship. Some resources to help with boundary issues include:

- **Social Networking and the Medical Practice: Guidelines for Physicians, Office Staff and Patients**
  Ohio State Medical Association
- **Where to Draw the Line: Professional Boundaries in Social Networking**
  Joseph D. Tariman, RN, MN, APRN-BC
- **Professional Boundaries in a Virtually Boundary-Less E-environment**
  Kathryn B. Chernack, DSW, LCSW (NASW Illinois Chapter)
- **Establishing Healthy Workplace Boundaries**
  Jan Alexander, RN MSN (Children's Hospital Association of Texas)
- **Social Networks May Blur Professional Boundaries**
  John M. Grohol, PSy.D.

ESRD FACILITY SURVEY

NEPHROLOGY SOCIAL WORK AND THE SURVEY PROCESS

The Centers for Medicare and Medicaid Services (CMS) Conditions for Coverage for ESRD Facilities (CfCs) **require that every dialysis facility is surveyed** by the local Department of Public Health. Surveys are performed routinely (the frequency varies in each state and region), or because of a complaint. Surveys are data-driven, and conducted in order to protect patient safety and improve patient outcomes. Surveyors make sure that every dialysis facility follows the CfCs, and use the ESRD Program Interpretive Guidance Manual in this endeavor. The **Interpretive Guidance Manual** has three parts: a computer identifier tag ("V-tag"); the wording of the regulation; and the guidance in interpreting the regulation. Surveyors use a Measures Assessment Tool (MAT) as a guide for their surveys and make sure dialysis units are following the (CfCs) in providing patient care.

The survey process has various components, one of which involves the Qualified Social Worker. For more details about every aspect of the survey process, you can visit the **National Forum of ESRD Networks** or ask your own ESRD Network.

Surveyors are trained by CMS on what constitutes a facility according to the CfCs. This person will ask for and have ready access to files, physical inspection of facility areas, patients, and staff. The date of the survey is unannounced. The reason for this is to observe the facility on a "usual" day, as opposed to a "we are ready for inspection" day.

Insofar as the Qualified Social Worker is concerned, the surveyor may review medical records of patients to assess the quality and completeness of psychosocial assessments, routine progress notes, patient care plans, and quality of life measurements. Such documentation should reveal the process of problem amelioration and outcomes of intervention. The surveyor may also interview the worker on working conditions, team process and involvement, caseload, administrative support for nephrology social work role, and involvement with patients.

Surveyors also interview patients at the clinic on the day(s) of the survey. If you provide home dialysis, surveyors will also speak to your home dialysis patients. The goal in patient interviews is to determine patient satisfaction with care and their participation in the care planning process. If concerns are recurring themes in the interviews, then a detailed inspection of records or further staff interviews may be necessary.

Other staff members are interviewed as well, that may include social workers. Again, the purpose is to obtain a view of the facility from as many sources as possible instead of only focusing on records and interviews with management.

The process is similar to that of Quality Assessment Performance Improvement (QAPI) in that if you are cited for deficiencies in the social work area, you have the opportunity to develop a plan of action and to develop an implementation schedule as a response to the citations. If there are no deficiencies in the social work area you will be advised of the outcome by the administrator or whoever is the responsible party receiving the reports.

This process is an opportunity to assess how you are doing on any given day and the outcomes of your interventions in light of your resources. The process is not punitive and encourages the team to collaborate on all aspects of care for the best patient outcomes.

It should be noted that high social worker caseloads may lead to citations for failure to comply with the CMS CfCs. Indeed, survey citations for V-tag 552 ("*The interdisciplinary team must provide the necessary monitoring and social work interventions*") have risen in the list of the top 25 citations among all U.S. dialysis facilities; specifically, from 21st place in fiscal year 2010 to 11th place as of the first quarter of fiscal year 2011. **Condition §494.180** states that:

> *The governing body or designated person responsible must ensure that—*
>
> *(1) An adequate number of qualified personnel are present whenever patients are undergoing dialysis so that the patient/staff ratio is appropriate to the level of dialysis care given and meets the needs of patients; and the registered nurse, social worker and dietitian members of the interdisciplinary team are available to meet patient clinical needs*.

The related **V-tag 758** states that:

> *If the facility "shares" the social worker or dietitian with multiple clinics or requires professional staff to perform non-clinical tasks, it must not negatively impact the time available to provide clinical interventions required to achieve the goals identified in the patient's plan of care.*

For further information, contact your local state health department or ESRD Network.

DOCUMENTATION FOR DIALYSIS SOCIAL WORKERS

Documentation for nephrology social workers in the dialysis setting focuses on three major areas: initial assessment, care plans, and progress notes.

The 2008 Dialysis Conditions for Coverage (**Federal Register, §494.80**) mandate that the patient assessment includes:

> *The facility's interdisciplinary team consists of, at a minimum, the patient or the patient's designee (if the patient chooses), a registered nurse, a physician treating the patient for ESRD, a social worker, and a dietitian. The interdisciplinary team is responsible for providing each patient with an individualized and comprehensive assessment of his or her needs. The comprehensive assessment must be used to develop the patient's treatment plan and expectations for care.*
>
> *(a) Standard: Assessment criteria. The patient's comprehensive assessment must include, but is not limited to, the following:*
>
> *(1) Evaluation of current health status and medical condition, including co-morbid conditions.*
>
> *(2) Evaluation of the appropriateness of the dialysis prescription, blood pressure, and fluid management needs.*
>
> *(3) Laboratory profile, immunization history, and medication history.*
>
> *(4) Evaluation of factors associated with anemia, such as hematocrit, hemoglobin, iron stores, and potential treatment plans for anemia, including administration of erythropoiesis- stimulating agent(s).*
>
> *(5) Evaluation of factors associated with renal bone disease.*
>
> *(6) Evaluation of nutritional status by a dietitian.*
>
> *(7) Evaluation of psychosocial needs by a social worker.*
>
> *(8) Evaluation of dialysis access type and maintenance (for example, arteriovenous fistulas, arteriovenous grafts, and peritoneal catheters).*
>
> *(9) Evaluation of the patient's abilities, interests, preferences, and goals, including the desired level of participation in the dialysis care process; the preferred modality (hemodialysis or peritoneal dialysis), and setting, (for example, home dialysis), and the patient's expectations for care outcomes.*
>
> *(10) Evaluation of suitability for a transplantation referral, based on criteria developed by the prospective transplantation center and its surgeon(s). If the patient is not suitable for transplantation referral, the basis for nonreferral must be documented in the patient's medical record.*
>
> *(11) Evaluation of family and other support systems.*
>
> *(12) Evaluation of current patient physical activity level.*
>
> *(13) Evaluation for referral to vocational and physical rehabilitation services.*

These conditions also mandate:

> (1) *An initial comprehensive assessment must be conducted on all new patients (that is, all admissions to a dialysis facility), within the latter of 30 calendar days or 13 outpatient hemodialysis sessions beginning with the first outpatient dialysis session.*
>
> (2) *A follow up comprehensive reassessment must occur within 3 months after the completion of the initial assessment to provide information to adjust the patient's plan of care specified in § 494.90.*

Regarding patient reassessment, the conditions mandate:

> *In accordance with the standards specified in paragraphs (a)(1) through (a)(13) of this section, a comprehensive reassessment of each patient and a revision of the plan of care must be conducted—*
>
> (1) *At least annually for stable patients; and*
>
> (2) *At least monthly for unstable patients including, but not limited to, patients with the following:*
>
> > (i) *Extended or frequent hospitalizations;*
> >
> > (ii) *Marked deterioration in health status;*
> >
> > (iii) *Significant change in psychosocial needs; or*
> >
> > (iv) *Concurrent poor nutritional status, unmanaged anemia, and inadequate dialysis.*

With the other professional councils of the NKF, and the American Nephrology Nurses' Association (ANNA), CNSW participated in the creation of a sample **Comprehensive Interdisciplinary Patient Assessment** that can be used to fulfill the dialysis assessment regulations (see). Most dialysis units have a standardized assessment format (often electronic) that is used by teams to create patient assessments.

Patient care plans need to be created based on needs identified in the interdisciplinary assessment. CMS regulates that (Federal Register, 2008):

> *The interdisciplinary team…must develop and implement a written, individualized comprehensive plan of care that specifies the services necessary to address the patient's needs, as identified by the comprehensive assessment and changes in the patient's condition, and must include measurable and expected outcomes and estimated timetables to achieve these outcomes. The outcomes specified in the patient plan of care must be consistent with current evidence-based professionally-accepted clinical practice standards.*

As it relates to social workers, CMS regulates (Federal Register, 2008):

> *The interdisciplinary team must develop a plan of care for each patient. The plan of care must address, but not be limited to, the following: (6) Psychosocial status. The interdisciplinary team must provide the necessary monitoring and social work interventions. These include counseling services and referrals for other social services, to assist the patient in achieving and sustaining an appropriate psychosocial status as*

> *measured by a standardized mental and physical assessment tool chosen by the social worker, at regular intervals, or more frequently on an as-needed basis.*

The CNSW recommends that social workers use the Kidney Disease Quality of Life (KDQOL) tool to measure patient mental and physical assessment and fulfill this care plan mandate (social workers in pediatric settings must use an age-appropriate tool, such as PedsQL). **A video training related to KDQOL can be found on the CNSW** website, along with other resources about quality of life measurement. Social workers can **learn more about this tool here**. Some dialysis units use the **KDQOL Complete program** to score, report, and manage KDQOL surveys.

Furthermore, regarding psychosocial aspects of patient care plans, CMS regulates (Federal Register, 2008):

> *The interdisciplinary team must develop a plan of care for each patient. The plan of care must address, but not be limited to, the following:*
>
> *(7) Modality.*
>
> > *(i) Home dialysis. The interdisciplinary team must identify a plan for the patient's home dialysis or explain why the patient is not a candidate for home dialysis.*
> >
> > *(ii) Transplantation status. When the patient is a transplant referral candidate, the interdisciplinary team must develop plans for pursuing transplantation. The patient's plan of care must include documentation of the—*
> >
> > > *(A) Plan for transplantation, if the patient accepts the transplantation referral;*
> > >
> > > *(B) Patient's decision, if the patient is a transplantation referral candidate but declines the transplantation referral; or*
> > >
> > > *(C) Reason(s) for the patient's non-referral as a transplantation candidate as documented in accordance with § 494.80(a)(10). The interdisciplinary team must develop a plan of care for each patient.*
>
> *(8) Rehabilitation status. The interdisciplinary team must assist the patient in achieving and sustaining an appropriate level of productive activity, as desired by the patient, including the educational needs of pediatric patients (patients under the age of 18 years), and make rehabilitation and vocational rehabilitation referrals as appropriate.*

Regarding the implementation of patient care plans, CMS mandates (Federal Register, 2008):

> *(1) The patient's plan of care must—*
>
> > *(i) Be completed by the interdisciplinary team, including the patient if the patient desires; and*
> >
> > *(ii) Be signed by team members, including the patient or the patient's designee; or, if the patient chooses not to sign the plan of care, this choice must be documented on the plan of care, along with the reason the signature was not provided.*
>
> *(2) Implementation of the initial plan of care must begin within the latter of 30 calendar days after admission to the dialysis facility or 13 outpatient hemodialysis sessions*

> *beginning with the first outpatient dialysis session. Implementation of monthly or annual updates of the plan of care must be performed within 15 days of the completion of the additional patient assessments specified in § 494.80(d).*
>
> *(3) If the expected outcome is not achieved, the interdisciplinary team must adjust the patient's plan of care to achieve the specified goals. When a patient is unable to achieve the desired outcomes, the team must—*
>
> > *(i) Adjust the plan of care to reflect the patient's current condition;*
> >
> > *(ii) Document in the record the reasons why the patient was unable to achieve the goals; and*
> >
> > *(iii) Implement plan of care changes to address the issues identified in paragraph (b)(3)(ii) of this section.*
>
> *(4) The dialysis facility must ensure that all dialysis patients are seen by a physician, nurse practitioner, clinical nurse specialist, or physician's assistant providing ESRD care at least monthly, as evidenced by a monthly progress note placed in the medical record, and periodically while the hemodialysis patient is receiving in-facility dialysis.*

CNSW has created a **Care Planning Resource Toolkit** that may be helpful in fulfilling the mandates related to care plans.

There are no federal regulations for social work progress notes (including any mandate about frequency). Social workers are recommended to document patient needs and interventions as needed. Your employer, or state, may have regulations regarding documentation that are more frequent than the federal requirements for social work documentation.

Social workers may be involved in meeting the CMS requirement that all patients be informed of their rights and responsibilities and the grievance mechanism, and the documentation of this is in the medical record (Federal Register, 2008). Social workers should also document a copy of any advance directive or documentation that this issue has been addressed with patients, as applicable.

Some social workers find it helpful to document their efforts on a daily basis to advocate for additional social work support to fulfill all of their patients' needs. CNSW has created a **time tracking tool** that has been used with success.

Documentation requirements can be challenging to achieve but are vital components of patient care delivered by nephrology social workers.

It should be noted that there are no federally mandated requirements related to documentation for kidney transplant social workers. The CNSW listserv often has suggestions and examples related to transplant social worker documentation that may be helpful.

References

Federal Register (2008). ***Conditions for Coverage for End-Stage Renal Disease Facilities***, 42 CFR Part 405, Subpart U, April 2008. Washington, DC: U.S. Government Printing Office.

QUALITY ASSESSMENT PERFORMANCE IMPROVEMENT (QAPI)

Quality improvement has many different names in kidney disease settings, including Continuous Quality Improvement (CQI), Quality Improvement, or Quality Assessment Performance Improvement (QAPI). With the 2008 Conditions for Coverage, all dialysis units are required to have a Quality Assessment Performance Improvement (QAPI) program to improve patient outcomes and reduce medical errors. **V-tag 626** specifies:

> *The dialysis facility must develop, implement, maintain and evaluate an effective, data driven, quality assessment and performance improvement program with participation by the professional members of the interdisciplinary team.*

Medicare mandates that each dialysis unit includes attention to the following components in its QAPI program:

- Adequacy of dialysis: hemodialysis and peritoneal
- Nutritional status
- Mineral metabolism and renal bone disease
- Anemia management
- Vascular access
- Medical injuries and medical errors identification
- HD reuse
- Patient satisfaction and grievances
- Infection control
- Health outcomes: physical and mental functioning, and hospitalization
- Vaccinations
- Patient engagement (not a CMS mandate, but can be reviewed by surveyors)

Social workers can make important contributions to helping patient outcomes related to many of these required components, and QAPI programs are an excellent way to highlight the efficacy of social work intervention. For example, social workers can assess and provide interventions and tracking of patients who miss treatments or end treatments early that is contributing to dialysis inadequacy. Social workers can work with dietitians to help patients with poor nutritional status due to a lack of social support, access to recommended groceries and food, or poor understanding or health literacy that prevents patients from following their recommended diets.

There are many psychosocial barriers to patients taking their phosphorus binders and other medications that improve mineral metabolism and renal bone disease outcomes. These include health literacy, health beliefs, pill burden, social support, patient satisfaction, and financial barriers; see Browne and Merighi (***JNSW*, 2010 Vol. 34**) for a full discussion on this topic.

Social work plays an important role on the interdisciplinary team in helping patients improve outcomes in this area. This is also the case with vascular access outcomes. Patients may not pursue a fistula, or allow their team to use a fistula because of body image or needle fear issue—social workers can help ameliorate these barriers and improve patient outcomes. Social workers can also help teams assess patient satisfaction in a meaningful way, and decrease involuntary patient discharges.

An example of a social work QAPI report, **courtesy of Megan Prescott, MSW, LCSW**, includes:

- **Patient Census**: including recent admissions and discharges, and reasons for activity (i.e., transplant, transfer, etc.)
- **KDQOL**: The number of patients surveyed, and whether these were part of regular assessment or due to status change. I bring the chart that recently circulated on the listserv to follow trends
- **Voc Rehab**: Patient working, in school, referred, working with a VR counselor, disabled or retired, and full-time parent or otherwise meeting their vocational potential.
- **Transplant Status**: I track number of patients listed, listed on medical hold, evaluation in-process, referred but needing follow up, and ineligible (including reason).
- **Missed and Shortened Treatments**: Frequency and trends in the unit and with particular patients who have patterns of missing treatments.
- **Care Plans**: Number completed during the month, and how many were for unstable patients.
- **Complaints and Grievances**
- **Patient Satisfaction**
- **Special Projects and Planning and Implementation**: Currently working on Patient Provider Conflict Training (the ESRD Network Toolkit) a directive with RN and dietitian to reduce missed and shortened treatments, and the NKF program "Living Longer Living Better."

QAPI programs are also a forum to examine clinic staffing issues that impact patient outcomes. **The preamble to the Conditions for Coverage** notes:

> *We are also requiring at § 494.110 that the interdisciplinary team, which includes the RN, social worker, and dietitian, play an active role in the QAPI program. This final rule requires that the interdisciplinary team provide appropriate care to dialysis patients and improve patient care on an ongoing basis. The dialysis facility may need to evaluate staffing levels as part of their action plan for the QAPI program. In order to clarify that the adequate staffing standard applies to all clinical staff, we have added language to the requirement at § 494.180(b)(1), requiring that the RN, social worker and the dietitian be available to meet patient clinical needs.*

CNSW has created **a time tracking tool** to document dialysis social work availability to meet patient clinical needs that social workers may want to bring to QAPI meetings.

Kidney transplant social workers are also important members in their centers' QAPI efforts. Medicare mandates that in kidney transplant programs (**Condition §482.96**) at:

> *The transplant center's QAPI program must use objective measures to evaluate the center's performance with regard to transplantation activities and outcomes…*
>
> *Outcome measures may include, but are not limited to, patient and donor selection criteria, accuracy of the waiting list in accordance with the OPTN waiting list requirements, accuracy of donor and recipient matching, patient and donor management, techniques for organ recovery, consent practices, patient education, patient satisfaction, and patient rights.*

In 1998, the Council of Nephrology Social Workers (with the assistance of Fresenius USA) developed the *Handbook on Continuous Quality Improvement for Nephrology Social Work Practice: Measuring and Improving Psychosocial Interventions and Outcomes Through CQI* to provide recognition of, and a framework for, measurement of psychosocial outcomes.

A comprehensive psychosocial assessment format and problem list is included in this handbook to provide a framework for psychosocial assessment. Additionally, specific psychosocial factors are included for review as they relate to achieving the recommendations of the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (NKF KDOQI™). To complement the psychosocial assessment and provide for the routine and consistent measurement of social work interventions related to Health Related Quality of Life, a list of assessment tools is presented. Case studies are included to demonstrate CQI in process from a social work perspective. A review of further articles on outcome measurement and CQI, provided in the bibliography, is encouraged.

The measurement of social work interventions and psychosocial outcomes provides the conduit to demonstrate the efficacy of a specific intervention or trends, to provide data for research, or to document the need/justification for additional social work staff. To this end, CNSW encourages nephrology social workers to recognize the need to measure interventions and become an active participant or leader in the QAPI process in their facility. **A presentation addressing the social worker's role in QAPI can be found in Appendix B (p. 149)**.

CNSW POSITION STATEMENT ON SOCIAL WORK STAFFING

Background

Chronic kidney disease patients experience multiple losses and psychosocial risks associated with the diagnosis and treatment of kidney disease and require comprehensive psychosocial services at various stages throughout the course of their illness and treatment. Potential barriers such as socioeconomic factors and other biopsychosocial risk factors (i.e., aging, co-morbidity, and rural residence) can negatively impact patient treatment outcome. To ameliorate potential barriers to optimal treatment outcome and to promote maximum rehabilitation and the highest patient-perceived quality of life, kidney failure patients must have appropriate access to master's-prepared nephrology social workers.

Recent Research

Social workers are very involved in providing effective intervention with ESRD patients. However, there are professional challenges that may face nephrology social workers, and they may be assigned inappropriate tasks by their employers. Tasks that are clerical in nature or involve admissions, billing, and determining insurance coverage prevent nephrology social workers from performing the clinical tasks central to their mission (Callahan, Witten, & Johnstone, 1997). Russo (2002) found that all of the nephrology social workers that he surveyed felt that transportation was not an appropriate task for them, yet 53% of respondents were responsible for making transportation arrangements for patients. Russo found that 46% of the nephrology social workers in his survey were responsible for making dialysis transient arrangements (which involved copying and sending patient records to out-of-town units), yet only 20% were able to do patient education. In the Promoting Excellence in End-of-Life Care's 2002 report, End-Stage Renal Disease Workgroup Recommendations to the Field, they recommend that dialysis units discontinue using master's level social workers for clerical tasks to ensure that they will have sufficient time to provide clinical services to their patients and their families.

The 2005 Department of Health and Human Services' proposed Conditions for Coverage for ESRD facilities (Federal Register, 2005, p. 6222) recognize this issue as follows:

> *We recognize that dialysis patients also need other essential services including transportation and information on Medicare benefits, eligibility for Medicaid, housing, and medications, but these tasks should be handled by other facility staff in order for the MSW to participate fully with the patient's interdisciplinary teams so that optimal outcomes of care may be achieved.*

Merighi and Ehlebracht (2004a, 2004b, 2005), in a survey of 809 randomly sampled dialysis social workers in the United States, found that:

- 94% of social workers did clerical tasks, and that 87% of those respondents considered these tasks to be outside the scope of their social work training.
- 61% of social workers were solely responsible for arranging patient transportation.
- 57% of social workers were responsible for making travel arrangements for patients who were transient, taking 9% of their time.
- 26% of social workers were responsible for initial insurance verification.
- 43% of social workers tracked Medicare coordination periods.

- 44% of social workers were primarily responsible for completing admission packets.
- 18% of social workers were involved in collecting fees from patients. Respondents noted that this could significantly diminish therapeutic relationships and decrease trust.
- Respondents spent 38% of their time on insurance, billing, and clerical tasks versus 25% of their time spent counseling and assessing patients.
- Only 34% of the social workers thought that they had enough time to sufficiently address patient psychosocial needs.

The study also noted that as nephrology social workers increased their involvement in insurance and billing, their job satisfaction decreased. This was true particularly for social workers who collected fees from patients. Nephrology social work job satisfaction was correlated positively with the amount of time spent in counseling and patient education and negatively with insurance-related, clerical tasks. Nephrology social workers who spent more time on insurance, billing, and clerical activities reported increased emotional exhaustion. Those who spent more time counseling and educating patients reported less emotional exhaustion. The authors posited that providing education and direct counseling to patients and family members were more congruent with the professional training and education of master's level social workers, and thus more satisfying for them.

Another professional concern for nephrology social workers is high patient caseloads. The Council of Nephrology Social Workers conducted an anonymous online salary and caseload survey of nephrology social workers from March 31 to June 21, 2010 (**Merighi, Browne, & Bruder, 2010**). **To view the poster presentation, visit Appendix A (p. 147).**

This survey (n=1,037) indicates that full time dialysis social workers have caseloads ranging from one to 711 patients (median 125). Transplant social workers can be responsible for hundreds of patients and organ donors. Large nephrology social work caseloads have been linked to decreased patient satisfaction and less successful patient rehabilitation outcomes (Callahan, Moncrief, Wittman, & Maceda, 1998). Social workers report that high caseloads prevent them from providing adequate nephrology clinical services, most notably counseling (Merighi & Ehlebracht, 2002, 2005).

Research suggests that there is a statistically significant correlation between lower social worker caseload size and rehabilitation interventions offered (Callahan et al., 1998). This is also supported by a survey of the Life Options Rehabilitation Advisory Council's (LORAC) exemplary Practices Award Winners. The Exemplary Practices Award Winners are selected after review of facility rehabilitation programming for a designated period of time. This survey shows that 47% of facilities that received this award had an MSW to patient ratio of 75 to 1; and 35% of facilities that received this award had an MSW to patient ratio of 76-90 (Schrag, 1998).

Studies also suggest a positive relationship between patient satisfaction and lower nephrology caseloads (Callahan et al., 1998), as well as patient's perceptions of the importance of access to nephrology social work services (Siegal et al., 1994; Rubin et al., 1997). Siegal's 1994 study of patient expectations related that greater than 84% of patients rely on clinical social workers to assist them with coping strategies, family adjustment, the impact of dialysis on their life, and continuing to be involved with family activities. This same study showed that 91% of the patients believed that access to the nephrology social worker was important. Rubin's 1997 study showed that patients ranked the services provided by the nephrology social worker in the top four of twenty-five important aspects of care.

The Council of Nephrology Social Workers recommends an acuity-based social worker to patient ratio that takes into consideration the psychosocial risks of patients and recommends a maximum of 75 patients per full-time dialysis social worker (see next section for more details). Currently, the state of Texas mandates a load of 75 to 100 patients per full-time social worker. Nevada, likewise, has a mandated ratio of one full-time social worker per 100 dialysis patients. However, in Merighi and Ehlebracht's (2004c) national survey of social workers, they found that only 13% of full-time dialysis social workers had caseloads of 75 or fewer, 40% had caseloads of 76 to 100 patients, and 47% had caseloads of more than 100 patients.

As of 2012, no nephrology social work ratios had been mandated by federal authorities. However, the 2008 Medicare Conditions for Coverage for dialysis units do indicate that every dialysis unit needs to make sure that all professionals have caseloads that allow them to fulfill their duties (Federal Register, 2008). Specifically, condition 494.180 states: "An adequate number of qualified personnel are present whenever patients are undergoing dialysis so that the patient/staff ratio is appropriate to the level of dialysis care given and meets the needs of patients; and the registered nurse, social worker and dietitian members of the interdisciplinary team are available to meet patient clinical needs" (p. 20483).

Nephrology social workers have reported that large caseloads hindered their ability to provide clinical interventions (Bogatz et al., 2005). Social work respondents in this study reported caseloads as high as 170 patients and 72% had a median caseload of 125 patients. The researchers found that 68% of social workers did not have enough time to do casework or counseling, 62% did not have enough time to do patient education, and 36% said that they spent excessive time doing clerical, insurance, and billing tasks. One participant in the study stated: "the combination of a more complex caseload and greater number of patients to cover make it impossible to adhere to the federal guidelines as written. I believe our patients are being denied access to quality social work services" (p. 59).

Social workers may be burdened with clerical tasks that prevent them from providing the CMS-mandated clinical interventions to patients to help improve outcomes. Social workers can advocate in clinics for the transfer of such non-clinical tasks to non-MSWs in order to improve health clinic outcomes. The following are some suggestions for assignments of such tasks, **as provided by Beth Witten, MSW, ACSW, LSCSW**, on the CNSW Membership Listserv.

Tasks that could be done by clerical personnel (in some cases by billing personnel):

- Coping, faxing, scanning, and mailing documents as requested
- Filing items in patient medical records
- Obtaining insurance cards on a monthly basis and alerting billing personnel to any changes
- Verifying insurance, obtaining authorizations for treatment, discussing bills with patients and arranging payment plans (billing personnel)
- Completing Medicare secondary payer questionnaires
- Scheduling and/or troubleshooting transportation arrangements

- Printing and mailing dialysis charges to Medicaid for spenddowns
- Tracking who is due for patient assessments/plan of care meetings and preparing POC invitations to patients
- Printing educational materials and providing them to appropriate staff to explain to patients
- After MSW administers survey, entering KDQOL survey responses into Excel template or KDQOL COMPLETE and printing out results/report for MSW to discuss with patient

Could be done by a college graduate (preferably BSW or other human services related degree) with supervision from an MSW:

- Identifying and referring patients for financial assistance and helping patients negotiate those systems
- Completing forms for medication assistance on recommendation from RN, RD or MSW
- Helping patients review Part D plans annually using their drug lists
- Assisting with non-emergency transient dialysis arrangements
- Identifying and maintaining a list of resources to help the MSW address patients' needs
- Developing and implementing activities designed to keep patients at the clinic for their full treatment
- Other non-clinical activities as assigned by MSW

CNSW Position Statement

The following position statement prepared by the 1998 Executive Committee of the Council of Nephrology Social Workers is based on the "NKF-CNSW Approach to Patient/Social Worker Staffing" which is a research-based staffing guideline. **The 2013 CNSW Executive Committee has reviewed and agrees with the recommendations.** The following statement uses the minimum psychosocial risk factors (PRF) and minimum social work functions for a hemodialysis outpatient setting. Most outpatient dialysis clinics would have a higher patient psychosocial risk profile than that calculated here. The formula can be used for transplant settings as well, but does not include information for peritoneal dialysis patients.

The 2011 United States Renal Data Systems (USRDS) data support the percentages stated in the minimal psychosocial risk factors used to develop this position statement. Additionally, "*The Clinical Indicators for Social Work and Psychosocial Services in Nephrology Settings*" (NASW/NKF, 1994) supports the minimum social work staffing functions listed below. Having reviewed this data, the Council of Nephrology Social Workers supports the validity of the "NKF-CNSW Approach to Patient/Social Worker Staffing" which would indicate **one MSW to every 75 patients** using these minimum calculations.

Please review the entire "Approach" (found in the next section) to develop a staffing ratio that reflects the specificity of a particular unit. Only **minimum** Psychosocial Risk Factors (PRF) were selected from the above-mentioned guideline and used to develop this recommendation. For purposes of minimal social work staffing PRF would include:

BASE VALUE	0.30
>25% of patient population is socially disadvantaged or on Medicaid	+0.10
>25% of patient population is diabetic	+0.10
>25% of patient population is >60	+0.10
Total Facility Psychosocial Risk Factor	**0.60**

(Other psychosocial risk factors usually found in the outpatient hemodialysis setting are excluded in this calculation to define "minimum" staffing needs.)

The Case Function Ratio (CFR) has one of four values based on the number of social work functions performed. Six to nine social work functions routinely performed is the minimum CFR allowed for in the "NKF-CNSW Approach to Patient Social Work Staffing," so the value for CFR is 45.

Minimal Social Work Case Functions, based on CMS's Conditions for Coverage for Medicare Suppliers of ESRD Services (2008) and the National Association of Social Workers/National Kidney Foundation Clinical Indicators for Social Work and Psychosocial Services in Nephrology Settings (1994), used to develop this recommendation for purposes of minimum social work staffing states that the social worker include:

- Psychosocial evaluations
- Casework counseling (patients and families)
- Group work
- Facilitating community agency referral
- Monitoring access and utilization of community agencies and services following referral
- Team care planning and collaboration

(Many functions, which are not included in the above CFR, are generally accepted as routine social work functions in the outpatient hemodialysis setting. These include patient/family education, financial assistance, quality management, and coordination of the renal rehabilitation program.)

Given these minimum values for Patient Risk Factor and Case Function Ratio, the following formula would be used:

$$\frac{\text{PRF x Patient Population During Year}}{\text{Case Function Ratio (CFR)}} = \text{Minimum Recommended Staffing Level}$$

So, if the Total Facility Psychosocial Risk Factor is 0.60 as determined above, and the Case Function Ratio is 45 as determined above, patient population is found to be 75.

$$\frac{0.60 \text{ x } 75}{45} = 1 \text{ MSW}$$

Therefore, we determine the ratio **1 MSW per 75 patients**.

Summary

The National Kidney Foundation's Council of Nephrology Social Workers supports the validity of the "NKF-CNSW Approach to Patient/Social Worker Staffing," which would indicate one full-time MSW to every 75 patients, using minimal calculations. Lower nephrology social worker caseloads increase the probability of positive rehabilitation outcomes and patient satisfaction with care.

(1998)

The 2012-13 CNSW Executive Committee has reviewed and agrees with the recommendations.

(2013)

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APPROACH TO PATIENT/SOCIAL WORKER STAFFING

The Council of Nephrology Social Workers (CNSW) first developed a staffing guideline in 1983; this framework continues to be supported by the CNSW Executive Council in 2013. This research-based guideline takes into consideration the treatment setting, the number of patients seen or anticipated to be seen in a year, the patients' psychosocial risk (acuity), and the number of regularly-performed, mutually agreed-upon social work functions. A calculation of the mathematical equation for any facility will produce the facility-specific recommended social work staffing to assure adequate social work coverage and quality patient care.

A CNSW Ad Hoc Committee was established in April 1983 to develop a method for determining patient/social worker staffing needs for nephrology social work practice. Council members have long identified staffing recommendations as a priority project. The CNSW Executive Committee believes there is a need for such an instrument to promote provision of adequate social work services to renal consumers in a variety of treatment settings. It will assist administrators and social workers to systematically examine the characteristics of the setting, the patient population and nephrology social work functions, and to utilize a uniform and objective method to determine adequate staffing levels.

The committee was chaired by Paula Hanson (VA Medical Center, Seattle, WA); members included Mary Ann Ganofsky (Rainbow Babies and Children's Hospital, Cleveland, OH), Mary Holden (Georgetown University Hospital, Washington, DC), Diane Jones (Douglas Dialysis Facility, Douglasville, GA), Patricia McKevitt (Chromalloy American Kidney Center, St. Louis, MO), and Ann Potts (Northwest Kidney Center, Seattle, WA). Committee composition included experienced nephrology social work practitioners representing pediatric, adult, home, in-center, self-care, teaching, proprietary, and non-profit settings.

Several studies were reviewed prior to the preparation and development of this report. A decision was made to base the committee's recommendation on a study accomplished by the Society for Hospital Social Work Directors of the American Hospital Association. The committee made this decision because the Society's methodology was judged as being sound. It was believed that it would withstand review by the social work profession and health care providers, and it contained elements to safeguard against being self-serving.

Substantial portions of the Society for Hospital Social Work Director's study have been utilized and/or adapted by the committee in the development of the components of the patient-staff ratio formula. Field testing has been undertaken and the preliminary results support the methodology developed. It is expected that this approach will be highly valuable to facility administrators and social workers alike as they examine social work staffing needs in nephrology settings.

While the formula and methods presented address specific patient and setting variables, it is recognized that some facilities may have unique characteristics which influence staffing needs. Consequently, the usefulness of the formula rests not only with an accurate reflection of the patient and setting characteristics, the number of patients routinely provided services, and the identification of mutually agreed upon, routinely performed social work functions, but also with the careful consideration and incorporation of any unique patient and setting variables.

The Formula for Determining Social Work Staffing Needs

The components of the staffing formula include (1) the treatment setting and patient psychosocial risk factors (PRF); (2) the number of existing or anticipated patients; and (3) the social work functions (CFR). The staffing formula is as follows:

$$\frac{\text{PRF x Patient Population During Year}}{\text{Case Function Ratio (CFR)}} = \text{Minimum Recommended Staffing Level}$$

Psychosocial Risk Factor

The psychological, social, and economic problems present in the kidney failure population are well-documented. It is because of these well-recognized problems that professional social work services have been mandated by CMS regulations. This population is at high risk to develop psychosocial and economic problems or to experience an exacerbation of pre-existing problems as a result of their chronic disease and treatment. The psychosocial risk factor (PRF) weighs the existence and quantity of social risks in the patient population being treated in four different settings. Psychosocial risk factor (PRF) incorporates a base value related to the treatment setting with additional increments to reflect specific patient and service characteristics.

The psychosocial risk factor (PRF) has one of four established values, depending on the treatment setting. The base psychosocial risk factor (PRF) should be increased by 0.10 for each complexity present listed under the practice setting.

PSYCHOSOCIAL RISK FACTORS (PRF)	**PRACTICE SETTING**			
Psychosocial risk factors which apply to facility's patients	***OUTPT Chronic Dialysis***	***INPT Acute/ Onset Chronic Dialysis***	***Transplant***	***Pediatric***
BASE PRF	**0.30**	**0.40**	**0.40**	**0.50**
≥ 25% of patient population is socially disadvantaged/ Medicaid	+0.10	+0.10	+0.10	+0.10
Family support/community services generally lacking	+0.10	+0.10	+0.10	+0.10
≥ 10% of patient population is routinely provided social work services when hospitalized	+0.10	+0.10	NA	+0.10
≥ 25% of patient population is diabetic	+0.10	NA	+0.10	NA
If patients are provided social work services in outpatient clinic	+0.10	NA	+0.10	NA
≥ 25% of patient population is > 60	+0.10	NA	NA	NA
≥ 25% of patient population is < 18	+0.10	NA	NA	NA
≥ 25% of patients have living donor	NA	NA	NA	NA
≥ 10% of patient population is transplant	NA	NA	NA	+0.10
OUR FACILITY'S TOTAL PRF				

To calculate total psychosocial risk factor for practice setting, add 0.10 for each risk factor to base PRF.

Number of Patients

TOTAL PATIENTS SERVED BY OUR FACILITY IN PAST 12 MONTHS (or ANTICIPATED IN 12 MONTH PERIOD)

- *Chronic outpatient dialysis programs* = average (or anticipated) number of patients per year in the outpatient dialysis program.
- *Pediatric programs* = average (or anticipated) number of pediatric patients per year in the dialysis program.
- *Transplant programs* = average (or anticipated) number of transplants performed per year.
- *Onset of chronic dialysis treatment in hospital and acute dialysis programs* = average (or anticipated) number of new referrals for evaluation per year.

Case Function Ratio

The case function ratio (CFR) has one of four values, based on the number of social work functions performed.

CFR = Score 45 if 6-9 social work functions are routinely performed
Score 35 if 10-13 social work functions are routinely performed
Score 25 if 14-17 social work functions are routinely performed
Score 15 if 18 or more social work functions are routinely performed

Social Work Functions

The following is a list of social work functions which may be appropriate to the provision of nephrology social work services to patient/family, staff, family, and community. The first six functions are currently required by ESRD Medicare regulations. In addition to these six basic social work activities, other listed functions may be necessary and/or complementary to the overall mission of the facility and its provision of social work service. Beyond the six required services, additional functions used in determining the CFR value must be agreed upon by the hospital/facility administration and must be routinely performed, rather than an occasional or singular activity.

MUTUALLY-AGREEABLE REGULARLY-PERFORMED CFR FOR OUR FACILITY SOCIAL WORKER(S)

1. Psychosocial evaluations: The gathering of information about the patient's social, psychological, cultural, environmental, and financial situation and utilizing this information for a psychosocial assessment and treatment plan for formal report/presentation.
2. Casework counseling (patients and families): Counseling directed toward helping patients and their families adjust to illness/treatment/lifestyle changes and to deal with the adjustment effectively.

3. Group work: Counseling directed toward helping groups of patients and their families deal with specifically identified problems/goals, e.g., role reversal, sexual function.
4. Information and referral: Information provided to the patient and family about the types of community resources available; connection made with the resources so identified.
5. Facilitating community agency referral: Assistance beyond information is provided to ensure patient access to appropriate resources, e.g., applications are completed on behalf of patients and processed; conferences and visits are carried out to agencies on behalf of or with patients; representation of patient and patient interest is directly made to community social agencies; escort, transportation and child care are provided/arranged.
6. Team care planning and collaboration: A structured meeting which provides specialized knowledge to other health care personnel regarding patient psychosocial problems, procedures, or services and participation in development of total care plan.
7. Transfer planning: Collaboration between staff in-patient transfer of treatment modality, and/or preparation and facilitation of patient transfer in/out of treatment facility.
8. Pre-admission planning: Counseling on patient and family problems directly related to planning and arranging for hospital admission.
9. Discharge planning: Counseling on patient problems directly related to planning and arranging for post hospital care in order to provide continuity of care and consolidate gains made during hospitalization.
10. Facilitating use of hospital and/or facility services: Advocacy role is assumed within hospital and/or facility on behalf of patient and family with all facility staff, departments, and hospital personnel.
11. Patient/family education: The enhancement of patient and family knowledge through a structured program geared to provide knowledge to patients and/or families with regard to treatment modalities, psychosocial adjustment to treatment, etc.
12. Financial assistance: Financial or other concrete aid is *provided directly* by the hospital or facility social work department; transportation assistance, medications, prosthetic devices, etc.
13. Case consultation to community agencies: A structured meeting which provides specialized knowledge to health care personnel of an outside agency regarding the psychosocial problems of a patient/family active with the outside agency.
14. Program consultation to hospital staff and/or facility staff: Assesses patient population to determine unmet needs, investigates and channels information about patient care problems to appropriate departments, identifies and makes recommendations for changes in hospital or facility policies and procedures as related to patient/family needs and rights.
15. Program consultation to community agencies: A structured meeting which provides specialized knowledge to community institutions.
16. Hospital/facility planning activities: Significant involvement in the administrative activities and mechanisms of the hospital/facility which relate to short-term and long-term planning and program development; or that relate to community services.
17. Community health planning activities: Working with the community and its agencies to develop necessary programs and uncovering community resources to meet patient and family needs.

18. Community service activities: Responsibility to represent the hospital, facility, or discipline to the community groups in carrying out appropriate programs, e.g., organ banks, Networks, Kidney Foundation Affiliates.
19. Teaching: Routine and systematic teaching of medical, nursing, social work, and other appropriate students.
20. Research: A structured system of study of the psychosocial factors of kidney failure patients, their care, and their needs.
21. Medical review/utilization review audit activities: Participates in the formal concurrent review process of the hospital/facility related to the JCAH, Medical Review Board, and/or Network requirements.
22. Supervisory activities: Responsibility on a regular and ongoing basis for supervision of from two to four full-time professional social work staff involved in direct patient care activities, and/or responsibility for coordinating the renal social work program within the hospital/facility.
23. Other: Additional responsibilities (not included in 1-22 above), performed on a regular and ongoing basis, that are significant to the mission/function of the overall renal care program, e.g., a large home care program, home helper program.

Examples for Determining Staffing Needs

1. Formula for Outpatient Dialysis Program

PRF = 0.60 (0.30 base factor + 0.30 for 3 additional risk factors)
PT# = 80
CRF = 35 (10-13 social work functions)

$$\frac{0.60\ \text{PRF} \times 80\ \text{PTS}}{35\ \text{CRF}} = \mathbf{1.3\ MSWs}$$

2. Formula for Transplant Program

PRF = 0.70 (0.40 base factor + 0.30 for 3 additional risk factors)
PT# = 50
CRF = 35 (10-13 social work functions)

$$\frac{0.70\ \text{PRF} \times 50\ \text{PTS}}{35\ \text{CRF}} = \mathbf{1.0\ MSW}$$

3. Formula for Pediatric Program

PRF = 0.90 (0.50 base factor + 0.40 for 4 additional risk factors)
PT# = 40
CRF = 25 (14-17 social work functions)

$$\frac{0.90\ \text{PRF} \times 40\ \text{PTS}}{25\ \text{CRF}} = \mathbf{1.44\ MSWs}$$

4. **Mixed Service Responsibilities EXAMPLE**

IN HOSPITAL
PRF = 0.60 (0.40 base factor + 0.20 for 2 additional risk factors)
PT# = 24
CRF = 35 (10-13 social work functions)

$$\frac{\text{0.60 PRF x 24 PTS}}{\text{35 CRF}} = \text{0.4 MSW}$$

OUTPATIENT DIALYSIS
PRF = 0.70 (0.30 base factor + 0.40 for 4 additional risk factors)
PT# = 80
CRF = 35 (10-13 social work functions)

$$\frac{\text{0.70 PRF x 80 PTS}}{\text{35 CRF}} = \text{1.6 MSWs}$$

TOTAL = 2.0 MSWs

Our Facility Calculation

$$\frac{\textbf{PRF x Patient Population During Year}}{\textbf{Case Function Ratio (CFR)}} = \textbf{Number of Social Workers Needed}$$

Note: For mixed practice settings (i.e., a social worker who practices in both a dialysis and transplant setting or a social worker who practices in an outpatient dialysis setting and provides social work services to inpatients initiating dialysis), calculate the number of social workers needed for each individual practice setting and add together to obtain the total number of social workers needed.

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NEPHROLOGY SOCIAL WORK JOB DESCRIPTION

General Summary

This position provides psychosocial evaluation, counseling and resource referral services to facility patients; works in collaboration with the multidisciplinary treatment team to incorporate psychosocial needs/concerns in planning care; assists in developing resources to meet patient needs; participates in patient/family and staff orientation, education and in-service activities to promote understanding of the psychosocial impact chronic kidney disease; and documents services in keeping with facility policies to meet Medicare and QAPI requirements.

Essential Functions and Responsibilities

1. Provides on-going comprehensive psychosocial assessment and counseling services to chronic kidney disease patients and their families to promote their quality of life.
2. Provides case management as it focuses on both the patient's biopsychosocial status and the status of the larger social system. Integrates the coordination of the services of others. This method includes needs assessment of the client and family along with arranging, monitoring, evaluating, and advocating for a package of multiple services to meet the client's needs. The goal is to optimize patient functioning.
3. Refers patients/families to a wide range of community services, including providers of health care coverage; income maintenance programs; transportation services; vocational rehabilitation services; exercise programs; volunteer opportunities; local, state and federal agencies; etc., and helps patients/families use these services.
4. Works closely with the interdisciplinary treatment team in planning for patient care and regularly participates in team meetings.
5. Assists in developing and/or improving facility and community resources to meet patient needs.
6. Initiates and/or participates in patient/family and/or staff orientation, education, rehabilitation, and treatment programs, such as developing educational materials and providing group services for patients/families and in-service programs for staff.
7. Advocates on patients' behalf within the renal setting and with appropriate local, state, and federal agencies and programs, and for the development of services.
8. Participates in facility staff meetings.
9. Maintains social work recording and statistics as applicable and participates in QAPI activities.
10. Participates in professional nephrology social work organizations and in other community organizations/activities serving kidney patients.
11. Keeps abreast of research/literature/developments in nephrology social work and attends appropriate continuing education institutes and conferences.

Critical Skills and Abilities

- Capacity to form and maintain therapeutic relationships with patients with chronic/terminal illness and with their families;
- Sensitivity to racial and cultural diversity;
- Advanced assessment and treatment skills, including individual, couple and family therapy;
- Ability to manage a caseload where multiple needs will be presented;
- Ability to set priorities under pressure;
- Capacity to form and maintain effective working relationships with interdisciplinary team members;
- Possess refined collaborative skills;
- Ability to assess needs and develop resource information and programs;
- Ability to develop educational materials;
- Exhibit sound judgment and excellent verbal and written communication skills;
- Commitment to social work values and code of ethics.

Work Conditions

Although interactions with patients/families/staff may occur throughout the facility, including treatment areas, conference rooms, waiting rooms and social work office, this position requires an office, computer, desk, and phone, which allows confidentiality in communicating with patients, families, staff, and community agencies.

Minimum Education and Experience

MSW (Master of Social Work) from a CSWE (Council of Social Work Education) accredited school of social work; current state licensure if applicable; ACSW preferred; minimum of two years of clinical social work experience, preferably in a medical setting.

____

Employee's Signature Date

____

Supervisor's Signature Date

NEPHROLOGY SOCIAL WORK SUPERVISOR JOB DESCRIPTION

General Summary

The person in this position manages the social work department and employees by overseeing staffing, scheduling, job performances, and job evaluations; developing policies and procedures, QAPI programs, and educational programs for staff and patients; and collaborating with the management team and facility's leadership structure.

Essential Functions and Responsibilities

1. Establishes policies, procedures and practices for social work staff in keeping with professional standards and clinic requirements.
2. Assesses staffing needs based on size, nature of patient population, and clinic needs.
3. Recruits, hires, provides orientation, supervises, and evaluates Social Work Department.
4. Creates and maintains climate conducive to department staff's professional requirements and development.
5. Participates in management meetings and interacts with supervisory staff in program planning, problem solving, and educational development.
6. Assists with budget development and management.
7. Develops programs for quality improvement for clinic, staff, and patients.
8. Provides support and counseling to clinical staff in relation to their stressful work environment.
9. Participates in professional organizations on local, state, and national level.
10. Keeps abreast of research/literature/developments in management and nephrology social work. Attends appropriate educational conferences.

Supervisors may also carry a patient caseload and would follow the Job Description requirements for Clinical Nephrology Social Worker.

Critical Skills and Abilities

- Capacity to organize, problem solve and develop ideas and programs.
- Provide leadership skills and encourage department cohesiveness.
- Establish professional presence and network with management team.
- Ability to assess needs and develop resources and programs.
- Requires excellent verbal and written communication skills.
- Ability to define problems, collect data, establish facts, and draw valid conclusions.
- Ability to interpret an extensive variety of information in written or oral form and deal with several abstract and concrete variables.
- Ability to maintain accounting, statistical, and personnel records.
- Possess sound judgment.
- Commitment to social work values and code of ethics.

Work Conditions

Although interactions with patients/families/staff/colleagues may occur throughout the facility, including treatment areas, conference rooms, waiting rooms, and social work office, this position requires an office, with desk, computer, and phone, which allows confidentiality in communicating with patients, families, staff, colleagues and community agencies.

Minimum Education and Experience

MSW from a CSWE-accredited school of social work; current state licensure, if applicable; ACSW preferred; minimum of two years of renal clinical social work experience, and two years of supervisory experience.

Employee's Signature Date

Supervisor's Signature Date

NEPHROLOGY SOCIAL WORK JOB PERFORMANCE APPRAISAL

CNSW acknowledges that job performance evaluations have changed drastically over the past years with the decrease in social work departments and the standardization of corporate evaluation processes. This has led to less direct supervision of nephrology social workers by social worker supervisors. In addition, many evaluations now include multi-disciplinary peer review, and/or patient reviews.

The following description and list of tasks are essential, federally-mandated requirements for clinical nephrology social workers and must be considered during job performance evaluation.

Nephrology social work services support and maximize the psychosocial functioning and adjustment of patients who are experiencing chronic kidney disease and their families. These services are provided to ameliorate social and emotional stresses resulting from the interacting physical, social, and psychological concomitants of chronic kidney disease, including shortened life expectancy; altered lifestyle with changes in social, financial, vocational, and sexual functioning; and the demands of a rigorous, time-consuming, and complex treatment regimen. Social workers function as a part of the health care team in the treatment setting and are responsible for fostering a positive treatment environment policy and routines that are attuned to cultural, religious, and ethnic differences among patients and families and show respect for the individuality, independence, and choice of each patient.

(Adapted from the "NASW/NKF Clinical Indicators for Social Work and Psychosocial Services in Nephrology Settings." 1994. NASW Press: Washington, D.C.)

Essential Functions and Responsibilities

1. Provides comprehensive psychosocial evaluation and counseling services to chronic kidney disease patients and their families to promote their quality of life.
2. Provides case management by focusing on both the patient's biopsychosocial status and the status of the larger social system. Integrates counseling/direct psychotherapeutic practice and coordination of the services of others. This method includes needs assessment of the client and family along with arranging, monitoring, evaluating, and advocating for a package of multiple services to meet the client's conditions. The goal is to optimize patient functioning.
3. Refers patients/families to a wide range of community services, including providers of health care coverage; income maintenance programs; transportation services; vocational rehabilitation services; exercise programs, volunteer opportunities, local, state and federal agencies; etc., and helps patients/families use these services.
4. Works closely with the multidisciplinary treatment team in planning for patient care and regularly participates in team meetings.
5. Assists in developing and/or improving facility and community resources to meet patient needs.
6. Initiates and/or participates in patient/family and/or staff orientation, education, rehabilitation, and treatment programs, such as developing educational materials and providing group services for patients/families and in-service programs for staff.

7. Advocates on patients' behalf within the setting and with appropriate local, state, and federal agencies and programs and for the development of services.
8. Participates in facility staff meetings.
9. Maintains social work recording and statistics as applicable and participates in QAPI activities.
10. Participates in professional nephrology social work organizations and in other community organizations/activities serving kidney patients.
11. Keeps abreast of research/literature/developments in nephrology social work and attends appropriate continuing education institutes and conferences.

NEPHROLOGY SOCIAL WORK CERTIFICATION

Recognizing the need for nephrology social work to be acknowledged as a specialty in the field, the National Kidney Foundation Council of Nephrology Social Workers (CNSW) has developed the Nephrology Social Worker credential (NSW-C) certification program. The certification program will establish an industry standard defining what qualifies a nephrology social worker. This will be the first national credentialed classification for nephrology social work in the industry.

Obtaining a NSW-C will distinguish you as a social worker who meets uniform, high standards of excellence within the field of nephrology social work practice and ethics; authenticate that you have the required advanced skills, knowledge and experience beyond that of a Master of Social Work education; and classify you as a social work professional who is committed to nephrology social work.

Applicants need to have a minimum of two (2) years of experience within a nephrology practice setting to apply for the NSW-C. If approved, the certification will be in effect for three (3) years, at which time the applicant will need to re-apply.

Required Documentation to Apply

To apply for the credential classification the following documentation is required:

- Applicants must be current CNSW members in good standing
- Current resume/CV (in .doc or .pdf format)
- Copy of current license/certification in the state(s) in which you are practicing (in .pdf or .jpg format)
- Three completed Competency Summaries
    - You will need to download from the website, complete and save on your computer. The completed form will need to be uploaded with your application.
    - Two Summaries must be completed by nephrology social workers
    - One Summary can be completed by a non-MSW, however that person must be employed within the field of nephrology (MD, RN, RD)
- Completed CEU Record
    - You will need to download from the website, complete and save on your computer. The completed form will need to be uploaded with your application.
    - Applicants are required to show a total of 20 hours within a two (2) year period. Ten (10) hours must be nephrology related and three hours must be in ethics.
    - The online form provides areas to list Name of Activity and Type, Sponsoring Organization, Description of Content, Dates Attended and CEU Hours Earned

Maintaining Your NSW-C Credential:

- If approved, the Certification will be in effect for three years, at which time the applicant will need to reapply. Membership in CNSW must be maintained throughout the three-year certification period. A CEU Record showing thirty (30) completed hours within the three (3) year period will be required. Competency forms are not required for renewals, however, random audits will occur and these could be requested at that time.

Fees

FIRST TIME Applicant $75.00
RENEWING Applicant $50.00

If you have a question, please contact the NSW-C Board prior to submitting an application at **certification@kidney.org**.

Applicants can apply at: **http://www.kidney.org/cnswcertification**

RECRUITMENT

Recruitment of any staff member can be a difficult task. It can be especially so if the particular professional vacancy is not an area with which you are familiar. Realizing this, CNSW would offer the following suggestions when your facility is faced with hiring a nephrology social worker.

As a national CNSW member, you are welcome to post a job opportunity on the CNSW membership listserv. This is an easy way to reach the majority of our members, who already have nephrology experience. In addition, there are many CNSW Chapters throughout the United States. The **NKF Local Chapter Resources** website can help you determine the one which is closest to your facility. Through networking you may be able to immediately obtain a social worker with previous renal experience.

Other social work organizations, such as the National Association of Social Workers (NASW), may also be of assistance. This is the largest organization of social workers in the country and its membership consists of social workers employed in all fields of social work. The NASW JOBLINK is a nationwide Social Work Employment Line to assist with recruitment and placement. To find out more about NASW JOBLINK, visit the **NASW web site**. NASW also publishes a monthly newsletter, *NASW News*, which includes The Classifieds, a job listing for each state. Each state also has a NASW Chapter and could most likely print information about your facility's need for a social worker in their statewide publication. The national office can provide further information on how to contact the Chapter in your state.

Another group which may be of assistance is your **local Chapter of the Society for Social Work Leadership in Healthcare**. If there is a school of social work with a master's-level program in your area, contact them to publicize the vacancy. They may be aware of recent or former graduates who can meet your needs. Advertising in renal journals may also be a method to reach those who are interested in a social work position, such as *Nephrology News and Issues* and *Dialysis and Transplantation*.

Especially in rural areas or smaller units where a full-time social worker might not be needed, it could be helpful to contact local mental health or health agencies when recruiting. These types of organizations often employ persons with a master's degree in social work and such an individual might be interested in additional hours at your facility.

The Council on Social Work Education (CSWE) surveys graduate programs annually, and provides statistical findings on their website. According to the 2012 Annual Report, in which 98.2% of programs participated, there were 53,835 (34,484 full-time and 19,351 part-time) students enrolled in MSW programs, compared to 43,399 in 2008. There was almost a 34% increase in MSW candidates reportedly preparing for employment in healthcare settings. Thus, it would seem that there is an available pool of qualified professionals.

If your facility is experiencing difficulty in hiring qualified MSW level of staff, perhaps other factors, such as salary and benefits, social work responsibilities, recruitment methods, and administrative support for continuing education and professional growth should be examined. The NASW has analyzed current social work salaries on a national level, and on that basis in **1991**, their Board of Directors recommended that an entry level MSW should be paid at least $25,000 and an MSW with 2 years of experience should receive a minimum of $30,000. The Board also recommended that these minimums must be adjusted "for the economic conditions of specific geographic areas." Finally, CNSW suggests that an inflation factor be considered, as these recommendations were made several years ago. The **NASW's 2009 Compensation**

and Benefits Study reports the median base pay for social work practitioners with an MSW degree is $55,000. In 2010, CNSW conducted a national caseload and salary survey of nephrology social workers and **the results** can be accessed on the NKF website.

When examining whether social work responsibilities may be a factor in recruitment, it might prove beneficial to review several tools developed by CNSW. Both the Standards for Social Work in End-Stage Renal Disease Treatment Settings and the Guidelines for Clinical Practice delineate specific roles and duties which are appropriate for the MSW professional to assume. Furthermore, the Approach to Patient/Social Work Staffing (discussed earlier, on p. 36) provides a formula to assist in determining adequate staffing levels. All of these documents can be obtained from the NKF National office.

The 2008 Federal Regulations require that all dialysis and transplant facilities have an individual with a master's degree of social work available to provide mandated social work services to their patients. These Regulations were written based on both comments received from social workers and other professionals and on the wide array of psychological and social needs of kidney failure patients at that time. CNSW believes that the needs of patients with kidney failure have not lessened, but indeed have become even more complex in our ever-changing society. It is hoped that the above suggestions will assist facilities in hiring social workers who are qualified to provide the services that our patients deserve.

RETENTION

The profession of nephrology social work is one with both high levels of stress and great rewards. Those entering the field do so to help others, but like all caregivers, each individual needs personal recognition. This section presents some causes of burnout for nephrology social workers and facilitates the shared responsibility of the administrator and the social worker in preventing burnout.

Burnout has been identified in all occupations from housewife to air traffic controller to nephrology social worker. Burnout steals productivity through fatigue, apathy, poor self-concept, and negativism about one's job, facility, and co-workers. It robs kidney failure patients of the nephrology social worker's caring and concern. Burnout is a shared responsibility between the individual and the organization for which the individual works.

Causes of burnout are many and varied. What leads to burnout in one individual is found stimulating by another. However, some generally-accepted causes of burnout for nephrology social workers include:

- Unclear role definition, including the lack of uniform acceptance of the role of the social worker. This includes difficulty in determining when a task (such as provision of patient/family emotional support) is completed and how well the task has been performed. Task completion and assessment are essential in promoting positive self-esteem.
- The assignment of too many tasks to be performed in the time provided. This leads to high levels of stress.
- Role strain or lack of guilt-free time off. Many nephrology social workers are solo practitioners whose work remains when they return.
- Stressful working conditions that demand multiple clinical and facilitative techniques but do not allow privacy and confidentiality of communication. This stress can be intensified if solo practitioners feel isolated from other social work professionals and have limited or no peer supervision and support.
- High turnover of patients due to sudden death, transfer, or transplant without closure and high turnover of other renal staff due to job burnout. This can lead to feelings of loss and anger.
- Little chance for advancement, which can lead to a sense of hopelessness and helplessness.

Given the highly stressful nature of the social work profession, the following are means of providing essential employee recognition and enhancing social work retention:

- Encourage two-way communication about the social work role and task responsibilities from the perspectives of both the social worker and the administrator to enhance mutual understanding.
- Encourage nephrology social work self-assessment of the ability to perform expected tasks and establish a mutually agreed upon written task assignment which can be revised by the social worker's ongoing assessment of tasks and time available.
- Provide a positive work atmosphere that allows for confidentiality of communication and privacy to enhance productivity.

- Encourage ongoing professional development and continuing education through administrative and financial support for professional meeting attendance, subscription to professional journals and periodicals, and membership in professional organizations.
- Encourage membership and attendance at meetings of professional organizations through providing time off and financial support to attend such meetings as local and national CNSW and NKF meetings where peer support and supervision can be obtained.
- Purchase facility copies of nephrology social work publications.
- Encourage literary pursuits and research including scheduling presentations at facility in-services, encouraging professional presentations and publications, outcome assessments and an opportunity to perform literature searches.
- Provide regular evaluation of the salary and performance of the nephrology social worker. If the nephrology social worker is performing his/her responsibilities well, let him/her know. Provide criticism constructively and provide an opportunity for the social worker to present his/her self-assessment and organizational assessment.

Sometimes it is a challenge to find a master's-trained clinical social worker who is interested in working in a nephrology setting. The reasons may be as varied as the individuals and the facilities themselves. However, as with other renal professionals, nephrology social workers appreciate an administrator and a facility which provides employee recognition and will reward that administrator and facility with a commitment to remain on the job. Therefore, employee recognition leads to nephrology social work retention which means less stress for the facility administrator.

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3. PSYCHOSOCIAL ASPECTS OF CHRONIC KIDNEY DISEASE

PSYCHOSOCIAL ASSESSMENT FORMS

Adult

Most dialysis facilities now use electronic medical records for their psychosocial assessments, which can generate an interdisciplinary comprehensive plan of care, and progress notes. Generated templates should include these basic assessment criteria:

- Patient Demographic Information
- Status of Advance Directive or Guardian
- Developmental History
- Educational History
- Financial Status
- Living Situation and Social Support
- Medical History and Adjustment to Illness
- Cognitive Level
- Mental Health Concerns
- Treatment Modalities Options
- Rehabilitation Status and Goals
- Clinical Assessment or Impression
- Recommendations
- Plan of Action

Previous sections have addressed the Centers for Medicare and Medicaid Services (CMS) 2008 Conditions for Coverage for ESRD Facilities (CfCs), which mandated emphasis on the importance of attending to psychosocial barriers to kidney disease. CNSW offers a tool to assist with a **Comprehensive Interdisciplinary Patient Assessment (CIPA)** and the appropriate time frame for completion.

In addition, CNSW **compiled a chart that outlines all aspects of the 2008 CfCs for the dialysis setting** that attend to psychosocial aspects of ESRD. This chart includes the actual language in the CfC document, as well as the language from the document's preamble.

Pediatric

Pediatric Nephrology Social Work is a specialty area within the field of Nephrology. Children who are diagnosed with renal failure face a lifelong challenge. The parents and families of these children are intimately involved in daily care and planning for these children. For parents, this can be an overwhelming task. The pediatric nephrology social worker has a significant role in providing services for the child and the family

The bio-psychosocial-emotional assessment is the foundation for care planning for these patients and families. Environmental and financial issues are often complicated and require careful ongoing monitoring. Issues of dual family structures, custody and, on occasion, the need for state child protective services are complicated by medication and dialysis schedules. Family communications are essential to successful medical management of the pediatric patient. Family counseling is an important responsibility of the pediatric nephrology social worker as parents and siblings are often challenged in dealing with the overwhelming needs of the CKD child. Grief and loss issues are important to discuss.

The pediatric nephrology social worker is charged by the interdisciplinary team with addressing the multiple issues faced by these children and families. Counseling, advocacy, resource management, and education are foundation services to which the pediatric social worker adds community and school interfacing and mediation services. State and federal guidelines for children's education must be integrated into the overall care plan. Early childhood development resources within the community often are unaware of the specific demands on the child and family dealing with chronic renal disease. Educating these providers is the role of the pediatric nephrology social worker, as well as referral, advocacy and follow-up on the delivery of available services.

For comprehensive psychosocial assessments of pediatric kidney patients, there are several issues to consider as part of the social work evaluation:

- Growth and Development
- Parenting
- Family History
- School and Rehabilitation Needs
- Financial Concerns
- Mental Health Concerns
- Child Abuse and Neglect
- Quality of Life Survey (Peds QL)
- Treatment Modality Options
- Managing Care Across Multiple Homes
- Transition to Adult Care

CNSW has developed an online **Pediatric Toolkit** for members. The modules currently available in the Toolkit are:

- Assessment
- Grief and Loss
- Insurance
- School Issues
- Child Abuse/Neglect
- Transitions
- Pediatric Patients Speak Out

CNSW members can also participate in a **CNSW Listserv dedicated to pediatric issues**.

KIDNEY TRANSPLANTATION

Introduction

The Transplant Section in this practice guide only briefly addresses the key psychosocial topics related to transplant social work practice and services provided to kidney transplant recipients, their donors and their family members. Extensive data and publications related to psychosocial issues specific to the transplant population are available, but are beyond the scope of this section. The intent is instead to provide general information that will be helpful when performing day-to-day transplant social work functions. Refer to the following CNSW publication for more information about kidney transplantation:

> Harder, J., Klein, S. K., Peace, L., Browne, T., & Sparks, J. (2006). *Kidney transplantation: A primer for nephrology social workers*. NY, NY: National Kidney Foundation.
>
> Available through the **NKF Store**; item *#12-80-0947*

Material presented in this section is basic, and also includes reference to articles related to significant topics that social workers will likely encounter with transplant recipients, donors and their families. In addition, patient resources and organizations are provided which are helpful for both social workers and transplant recipients. (*Please note that these may have changed since the publication of this guide*.)

Reading the reference list (found on p. 62) is highly encouraged and recommended as there are over four decades of excellent literature pertaining to the psychological, familial, and social issues related to transplantation. The articles do not represent the multifaceted transplant topic by any means, but were selected for their general applicability and relevance to transplant social work practice.

Kidney transplant is thought to be an optimal treatment choice for those with chronic kidney disease (CKD). Over the years, studies in this population indicate that a successful kidney transplant allows an individual to return to many activities and the lifestyle experienced prior to the need of some form of CKD treatment. Some of the reported benefits of a successful transplantation include freedom from dialysis, fewer diet restrictions, enhanced stamina and physical performance, rehabilitation (i.e., employment, family role), psychological well-being, less morbidity and mortality, and overall improved quality of life. Most patients learn from staff and other recipients that undergoing transplant is the ultimate form of therapy to treat their disease. However, transplant offers its own unique set of issues that may involve complex medical and psychosocial factors over the patient's lifetime.

Transplant is another form of *treatment* for CKD, not a *cure* for the illness. Many patients (and transplant staff) believe that transplant will assist the patient in returning to a "normal" lifestyle, as it was before the disease was diagnosed. Studies reveal that transplant recipients do have an improved quality of life, are more likely to re-enter the work force, experience enhanced physical energy, and enjoy the freedom from restrictions imposed by dialysis. However, individuals must also adjust to the lifetime demands of managing a transplanted organ and the potential side effects that may accompany this form of treatment.

Recipients are at risk for: organ rejection; possible side effects caused by immunosuppressive medications, such as opportunistic infections, body changes, and other illnesses (e.g., cancers, bone disease); re-hospitalizations; financial stress related to paying for expensive medications; and related potential psychosocial stressors. Disappointment of not returning to "normal" as expected can produce very stressful and challenging circumstances. Even in successful graft (kidney) function, adjustment to being "well" after being ill for so long may take time and appropriate counseling.

The psychological changes that individuals experience throughout the transplant process vary by pre-existing medical and psychological conditions, age, comprehension and perception of illness, motivation, and support systems available. The clinical transplant social worker is in the privileged position to learn and understand the unique needs of a specific patient and family who is either entering or already managing life with a transplant. Whether performing pre-transplant evaluations, in-patient or post-transplant interventions, or educational and support group efforts, it is essential that the social worker have a comprehensive knowledge base about organ transplant.

Dialysis social workers familiar with CKD bring their own unique knowledge to understanding this patient population (for instance, why recipients are so focused on creatinine levels). It is recommended that new transplant social workers also read the materials given to recipients, in order to familiarize themselves with the terminology and patient expectations. Those individuals who are being considered for preemptive transplant (transplant before requiring dialysis) will be very new to their illness and are likely to require more education during the initial meeting(s) with the transplant social worker. Patients who have been dialyzed or who are returning for another transplant (re-transplant) are likely to be more knowledgeable or realistic about the transplant process and post-surgical life. However, much may have changed since their last transplant (i.e., newer protocols, shortened length of stay, patient maturity, etc.). The patient may only be reconsidered for transplant after adequate time has passed, if their previous graft was lost to non-adherence.

In addition to addressing the needs of the transplant population, the social worker has a significant role within the transplant team. The unique clinical skills offered by performing sophisticated psychosocial assessments are used by the team, not only in determining transplant candidacy, but also in how the team may coordinate specific interventions to enhance the transplant process. Staff generally looks to the social worker's expertise in determining how the patient and family might best be served, particularly whether any factors exist that place the recipient at increased risk, which may warrant additional attention. Graft function is tied to many complex psychosocial factors in a patient's daily life and social workers are in a position to intervene therapeutically and provide the appropriate resources necessary so an individual can achieve an improved quality of life with a successful transplant.

Psychosocial Considerations and Evaluation

Transplant programs vary in how or whether they use psychosocial assessments in determining an individual's eligibility for transplantation. Some programs may identify particular factors as a risk to successful transplant outcome, while others may not. Larger programs may conduct less formal interviews (i.e., over the phone or questionnaires), while others may perform them on-site and perhaps include a multi-disciplinary aspect. It is important to note that the recommended CMS guidelines suggest that each transplant candidate undergo a complete psychosocial evaluation by a qualified social worker.

The psychosocial evaluation is not only used in helping the team determine eligibility, but also in developing interventions for any potential identified psychosocial risks that are revealed during the evaluation process. The ultimate goal is for an individual to achieve a successful transplant. It is only under exceptional circumstances that an individual is denied an opportunity for transplantation, since it is difficult to predict which behavioral and psychological factors negatively influence transplant outcome.

A comprehensive psychosocial assessment is conducted in order to maximize the transplant process. Discovery of any psychosocial limitations should not automatically rule out an individual, but direct the social worker and team to appropriate interventions. It is important to recognize that some active mental illnesses (i.e., schizophrenia), current drug use, and behaviors interfering with adherence are viewed as contraindications to successful transplant outcomes. The social worker might direct the team to the best approach and plan when determining what is necessary for the recipient prior to becoming a suitable transplant candidate.

The evaluation allows the social worker to identify strengths and vulnerabilities of prospective candidates and then make appropriate recommendations to enhance the transplant process. With any "high risk" concerns, social workers may be in a position to intervene in a therapeutic manner, or refer individuals to appropriate resources (while discussing recommendations with the patient's dialysis social worker or nephrologist).

Most social workers only see an individual at the time of the evaluation, not having any further interaction with him or her until the time of transplant. In the case of transplant from a non-living donor (vs. living donor transplant), the time lapse could be years. Psychosocial changes may have occurred since the time of the initial assessment and a re-evaluation of present circumstances is necessary in order to adequately predict and address the patient's current situation and possible concerns for future outcome.

Social workers are also frequently called upon to evaluate potential living donors. The Consensus Statement on the Live Organ Donor (The Authors for the Live Organ Donor Consensus Group, 2000) recommends how potential organ donors should be evaluated when pursuing donation. The Psychosocial Process Workgroup (one of seven groups at the Consensus Conference) consisted of a variety of mental health professionals who worked with donors and identified key areas that should be examined in potential volunteer donors. Another recommendation made in the Report is that the donor's evaluator be separate from the recipient's evaluator so there is no potential for conflict of interest between the donor's and the recipient's best interests. The 2007 CMS Transplant Conditions of Participation require than an independent donor advocate assess living donors.

The following two articles address some of the key psychosocial aspects and important components of the psychosocial evaluation:

Dew, M. A., Switzer, G., DiMartini, A. F., Matukaitis, J., Fitzgerald, M. G., & Kormos, R. (2000). Psychosocial assessments and outcomes in organ transplantation. *Progress in Transplantation*, *10*(4), 239–259.

Engle, D. (2001). Psychosocial aspects of the organ transplant experience: What has been established and what we need for the future. *Journal of Clinical Psychology*, *57*(4), 521–549.

Although it usually occurs between patients and donors who have a relationship with one another, altruistic donations from donors who do not know transplant recipients are becoming more common. These altruistic kidney donations include "paired donors," which is a growing phenomenon in kidney transplantation. In its simplest form, paired donation matches strangers who need kidney transplants and have kidney donors in their social support networks who are not good matches for their own specific transplantation needs. These donors are “paired” with other patients, who receive their kidneys for transplantation.

Paired donations are becoming increasingly complicated. Rees and colleagues (2009) report on a paired donor chain that resulted in ten different kidney transplants at six different transplant centers in five different states. In November of 2010, Georgetown University Hospital set the record for the size of a paired donation kidney swap, transplanting sixteen different CKD patients with organs from donors who included spouses, aunts, parents, children, cousins and strangers to these 16 patients. The donors were not biologically compatible with their family members with CKD (or were strangers with benevolent motives for donating a kidney), and were matched in this “kidney swap” with one of the 16 patients by Georgetown University’s kidney transplant center. Because of the scarcity of deceased organ donors in the United States, transplant centers and the United Network of Organ Sharing (UNOS), want to increase future rates of paired kidney donation (Georgetown University Hospital, 2010).

Financial Considerations

A major concern for most transplant patients is the high cost of maintaining an organ transplant. They must take life-long, expensive medications in order to keep their grafts functioning. Frequently, recipients may change their employment status due to physical limitations caused by their illness. Their insurance coverage options may change as a result. Finances are a serious consideration for recipients since they need adequate medication coverage. Without these medications, transplant patients would reject their grafts. Recipients will sometimes elect to “stretch” their medications out, or stop them altogether if they have no coverage. As a result, they may lose their transplanted organs and put their organs or lives in jeopardy. The social worker is then called upon to assist the recipients in developing an appropriate plan for some form of coverage. Some transplant centers have designated financial counselors for this purpose, and the patients may be referred to the appropriate resource. Whatever system is in place, the transplant social worker must be aware of the financial resources available for transplant recipients.

The following article is an excellent source of information detailing Medicare coverage for transplantation and immunosuppressive medications.

> Thomas, C. (2001). The expanded Medicare coverage of immunosuppressive medications. *Transplant News and Issues*, May, 15-17.

Financial Resources for Transplant Recipients

1. **State Kidney Programs**
2. **National Foundation for Transplants**
3. **Pharmaceutical Research and Manufacturers of America**
4. **Patient Assistance Programs** for common pharmaceutical drugs frequently used by transplant patients
5. **HealthWell Foundation** assists with immunosuppressive medications and insurance premiums

Rehabilitation, Vocational Rehabilitation and Transplant Recipients

Transplant recipients are in a unique position. First, many transplant recipients are able to continue working once they have their transplant. Perhaps they were able to have a living donor transplant before they became disabled, making it easier for them to remain active in their roles and responsibilities. Additionally, some patients become disabled before receiving their transplant and need Vocational Rehabilitation services in order to re-enter the workforce. Finally, many transplant recipients are interested in vocational rehabilitation and employment. Once their Medicare or Medicaid is discontinued, they can now seek health insurance coverage through the Affordable Care Act. Information can be found at **www.healthcare.gov** or 1-800-318.2596.

Transplant social workers are in a key position to encourage transplant recipients to consider rehabilitation and employment. This is particularly true for kidney transplant recipients who are not disabled or retired and will have their Medicare terminated three years post-transplant. These patients need to begin thinking about vocational rehabilitation and employment well before the transplant so that they can be enrolled in employer group health insurance by the time they lose Medicare. Transplant recipients who receive disability income (SSI or SSDI) need to plan for the time when they will be determined as "not disabled" and lose their income and their Medicare or Medicaid.

The following article shows how social workers and transplant programs can encourage transplant recipients to successfully seek vocational rehabilitation services and meaningful employment:

> Carter, J. A., Winsett, R. P., Rager, D., Hathaway, D. K. (2001). A center-based approach to a transplant employment program. *Transplant News and Issues*, S18-S22.

CNSW members can also participate in a **CNSW Listserv dedicated to transplant issues**.

Recommended Reading for Transplant Social Workers

Books

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Transplant Related Journals/Publications:

Dialysis and Transplantation

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Journal of Nephrology Social Work (JNSW): Council of Nephrology Social Workers, National Kidney Foundation

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Progress in Transplantation*:* Publications for Society for Transplant Social Workers, North American Transplant Coordinators Organization, et al.

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Living Kidney Donor Evaluation and Resources

Health Resources and Services Administration's (HRSN) Organ Procurement and Transplantation Network (OPTN) have made policy changes for living donation, which are effective February 1, 2013. These changes will create national standards for evaluation and informed consent of all living kidney donors. (**Policy 12.0**)

Psychosocial Evaluation of the Living Kidney Donor (Policy 12.3.3)

This psychosocial evaluation must be performed by a psychiatrist, psychologist, and or clinical social worker. Documentation of the psychosocial evaluation must be maintained in the donor record. The psychosocial evaluation must include the following components:

- Assess for any psychosocial (including mental health) issues that might complicate the living donor's recovery and identify potential risks for poor psychosocial outcome;
- Assess for the presence of high-risk behaviors as defined by the US Public Health Service (PHS) that have the potential to increase the risk of disease transmission to the recipient;
- Assess history of smoking, alcohol, and drug use/abuse and dependency;
- Identify factors that warrant educational or therapeutic intervention prior to final donation decision;
- Determine that the potential donor understands the short and long-term medical and psychosocial risks associated with living donation, for both donor and recipient;
- Assess whether the decision to donate is free of inducement, coercion, and other undue pressure by exploring the reason(s) for volunteering to donate and the nature of the relationship (if any) to the transplant candidate;
- Assess the potential donor's ability to make an informed decision and the ability to cope with the major surgery and related stress. This includes the potential donor having a realistic plan for donation and recovery, with social, emotional and financial support available as recommended; and,
- Review the occupation, employment status, health insurance status, living arrangements, and social support of the potential donor and determine if the potential donor understands the potential financial implications of living donation.

Required psychosocial exclusions for Living Donors:

- Less than 18 years old AND mentally incapable of making an informed decision
- High suspicion of donor coercion
- High suspicion of illegal financial exchange between donor and recipient
- Diagnosable psychiatric conditions requiring treatment before donation, including any evidence of suicide.

Independent Living Donor Advocates (Policy 12.4.1)

The living kidney donor recovery hospital must provide an independent donor advocate (IDA) who is not involved with the potential recipient evaluation and is independent of the decision to transplant the potential recipient. A social worker can act as the IDA.

The IDA must assist the potential living kidney donor with the evaluation process and focus on their needs and questions. The IDA must be knowledgeable about risks and benefits associated with all phases of the donation process. IDA responsibilities include, but are not limited to the following:

- Promote the best interests of the potential living donor
- Advocate for the rights of the potential donor
- Assist the potential donor in obtaining and understanding information regarding the:
  - Consent process
  - Evaluation process
  - Surgical procedure
  - Medical and psychosocial risks
  - Benefit and need for follow-up

Donor Resources:

National Living Donor Assistance Center (NLDAC) provides financial assistance to those who want to donate an organ. Priority is given to individuals not otherwise able to afford the travel and subsistence expenses associated with living organ donation.

National Kidney Foundation

United Network for Organ Sharing (UNOS)

Department of Health and Human Services

Donate Life America

Waterman, A, and Dehig, S, "The Living Gift, Education about Living Kidney Donation" (2002)
Available through the Missouri Kidney Program: 1-800-733-7345

REHABILITATION AND KIDNEY DISEASE & KIDNEY FAILURE

Beth Witten, MSW, ACSW, LSCSW (2014)

Background

Kidney disease and kidney failure have the potential to impact physical and mental functioning, leading to physical debilitation and depression. Recognizing this in 1976, the Centers for Medicare & Medicaid Services(CMS) included a requirement for dialysis and transplant programs to have master's prepared social workers to provide social services to patients and their families "directed at supporting and maximizing the social functioning and adjustment of the patient."

The 2008 ESRD Conditions for Coverage (CfCs) included **requirements for the social worker and other members of the interdisciplinary team (IDT)** to direct care related to patient functioning including:

- **Patient assessment** at §494.80(a)(7) which requires an "evaluation of psychosocial needs by a social worker" (V510); §494.80(a)(9), which requires the entire IDT to assess the dialysis patient's "abilities, interests, preferences, and goals" (V512); §494.80(a)(12) and (13), which require the IDT to evaluate current physical activity level and need for referral to vocational and physical rehabilitation services (V515);
- **Patient plan of care** at §494.90(a)(8), which requires the IDT to "provide the necessary monitoring and social work interventions" including "counseling services and referrals for other social services, to assist the patient in achieving and sustaining an appropriate psychosocial status as measured by a standardized mental and physical assessment tool;" and
- **Quality assessment and performance improvement** at §494.110(a), which requires the IDT to track and trend facility-level "health outcomes," which CMS interprets as including patient functioning.

Social workers are uniquely qualified to take the lead in helping the IDT address functioning not just of the kidneys but of the "whole person" by assessing, educating, counseling, and referring the patient as needed to community resources. Social work interventions can enhance the likelihood that patients will achieve and sustain *their* goals, including rehabilitation. What follows is not an all-inclusive list of psychosocial interventions, but is intended to help social workers consider ways they can help patients review their skills and strengths, set rehabilitation goals. and work with the IDT to toward optimal rehabilitation outcomes.

Encouragement

Social workers working toward restoration of the whole person can:

- Model for patients and colleagues the positive attitude that is necessary to motivate others;
- Establish "buddy programs" or patient "mentors" to encourage new patients to talk with trained, well-adjusted, motivated peer helpers (for example, see **NKF Peers Program**);
- Encourage students to stay in school as long as possible to enhance their chances of earning a living wage;
- Encourage working patients to continue to work to maintain their financial security, socialization, self-esteem, and health insurance coverage;

- Encourage those who are retired or too disabled to work to improve their physical fitness so they can do as many previously enjoyed activities as possible;
- Encourage those with special needs, such as those who are blind, hearing impaired, or unable to walk to learn from others who have adapted and continue to live high-quality lives; and
- Encourage patients to seek help from community resources and advocacy groups to remain as independent as possible.

Education

Social workers can help patients become empowered and take charge in managing their disease and treatment by:

- Educating all patients about treatment options and how each would fit with their lifestyle, personality, values, and goals, understanding that treatment change is possible, even likely, as situations and needs change;
- Sharing materials written in a language and at a reading level the patient can use to become an active healthcare consumer;
- Teaching patients how to safely take control of those things they can control and allowing others to manage those things they can't control;
- Helping patients understand that successful rehabilitation efforts not only depend on what others do for them, but on choices they make in following their treatment plan;
- Informing the healthcare team that research shows that empowered, activated patients do better and take less staff time so the IDT is motivated to give patients more control over their health and treatment.

Informed hemodialysis (HD) patients can learn to do as much self-care as possible, including but not limited to cleaning their access site, weighing themselves before and after dialysis, taking their temperature, setting up their HD machine, cannulating their vascular access, recording their dialysis treatment, and holding their needle sites after dialysis. Most peritoneal dialysis (PD) patients can learn to monitor their vital signs, choose the correct PD solution, set up their PD cycler (if applicable), do PD connections/disconnections, document their PD treatments, and order their own supplies. Most kidney or kidney-pancreas transplant patients can learn to manage their treatment prescription, report symptoms, and keep follow-up appointments.

Because kidney failure is life altering, patients need to understand that it's not uncommon to feel angry, anxious or depressed. Social workers can help patients understand, accept, and work through these feelings.

Exercise

It would be unrealistic to expect anyone who has a chronic progressive disease and who may have become deconditioned due to kidney disease and kidney failure to participate as fully in physical activities as they did when healthy. However, social workers can help debilitated patients begin to resume previously enjoyed activities by:

- Assessing what, if any, regular activity each patient did in the past, what he or she does currently, and what he or she would like to be able to do to set goals;
- Encouraging sedentary patients to start being more active by starting slowly to build up strength, endurance and flexibility and increasing their physical activity level as they can with their physician's approval;
- Assessing patients' ability to do activities of daily living and identifying problems for physician referral to physical rehab specialists;
- Linking patients with amputations with other amputees and encouraging use of prostheses when possible and therapy to be as independent as possible;
- Encouraging patients who need it to obtain rehabilitation therapy; and
- Reminding staff members to encourage each patient to do what he or she can to maintain or improve physical functioning.

Employment

A goal of any renal rehabilitation program should be to help youth get as much education as possible and to help adults with kidney disease and kidney failure to keep their jobs or find new ones. Physicians, families and the IDT need to set expectations for patients who were working or attending school before kidney failure to keep their jobs or stay in school; to accommodate patients' work or school schedule for treatments, home training, and appointments; and to ask about and help the patient manage work-limiting symptoms. Working offers an outlet for socialization, improved self-esteem, more financial security, and the possibility of a comprehensive employer group health plan (EGHP). A social worker can promote vocational rehabilitation by:

- Helping patients understand the benefits of staying in school or working;
- Advocating for facility policies that prioritize shift assignment to accommodate patients who work, attend school, or otherwise participate in productive activity;
- Encouraging patients who want to work to consider transplant and home dialysis options—at other facilities if necessary—and to encourage staff to accommodate their work or school hours when setting a training schedule;
- Educating patients about legal protections for those with disabilities and offer to advocate with employers as needed;
- Educating teachers about any special needs a child with kidney disease has and work with the school to develop an individualized education plan if one is needed;
- Educating vocational rehabilitation (VR) counselors about the unique needs of those on dialysis and with functioning transplants; refer suitable patients to VR counselors for evaluation, job training, job placement, and job retention services and collaborating with them to educate counselors, allow access to the facility for patient recruitment, assure paperwork is completed timely; and encourage patients to keep scheduled appointments;
- Collaborating with Social Security Administration (SSA) work incentive liaisons to dispel myths patients may have about working while receiving Social Security disability benefits;
- Educating patients about federal, state and local programs and services that can help them maintain or obtain employment or schooling;

- Helping retirees or those unable to work to make full use of their knowledge, experience and interests through volunteering in the community or the facility, which could include maintaining a patient bulletin board, running a support group, contributing to a facility newsletter, running a fundraising campaign, or providing mentoring for new patients or their families;
- Making referrals to community agencies for those who need help with independent living and act as the coordinator of information between those agencies and the dialysis facility or transplant program, making sure that the patient fully understands all options and plans.

Evaluation

Success of psychosocial interventions has been difficult for nephrology social workers to quantify. However, research has repeatedly shown that poor physical and mental functioning increase the relative risk of hospitalization and death. The 2008 Conditions for Coverage at §494.90(a)(6) requires dialysis social workers to offer a standardized survey—the KDQOL-36 (or age appropriate)—to all eligible dialysis patients. Eligible patients include those who have been on dialysis at least three (3) months and are not cognitively impaired, psychotic, or speaking a language for which there is no interpreter or translation. The regulation requires the survey to be offered at regular intervals, or more often if needed. The first survey should be offered during the fourth month of dialysis during the first reassessment and prior to the plan of care. It should be offered annually or more frequently as needed thereafter. Offering the survey to patients who are unstable may allow identification and action to help the patient become stable faster. In evaluating patients' psychosocial needs and outcomes of psychosocial interventions, social workers can:

- Assess patients' baseline emotional and physical status, including activities of daily living, as well as their interests, skills, past and current activities, and goals;
- Document rehabilitation interventions provided using a system that allows analysis of the effects of those interventions;
- Look for trends in physical, emotional and behavioral changes, and health-related quality of life (HRQOL) scores that may be related to rehabilitation interventions;
- Report the results of the HRQOL survey and discussions with the patient to help the IDT prioritize areas the patient identified for improvement;
- Report to the patient and the IDT which social work interventions appear to produce measurable improvement in outcomes;
- Help the dialysis or transplant program's quality assessment and performance improvement (QAPI) team examine the relationship between psychosocial and rehabilitation initiatives and rates of hospitalization, employment, and continuation of employer group health plans, all of which have the potential to prove the value of money spent to provide adequate social work staffing and rehabilitation efforts.

Select Laws that Protect Workers with Disabilities

Section 504 of the Rehabilitation Act protects people with disabilities from discrimination based on their disability. This Section prohibits discrimination in service availability, accessibility, delivery, employment, and the administrative activities and responsibilities of organizations that receive Federal financial assistance, including Medicare and Medicaid. This law is enforced by the Department of Health & Human Service's Office of Civil Rights.

The **Americans with Disabilities Act (ADA)** protects those with a condition that significantly affects a major life activity and who work for employers with 15 or more employees. In 2004, a federal district court ruled in the case of *Fiscus v Wal-Mart* that those who require dialysis for kidney failure are protected by the ADA. Judge Michael Chertoff wrote: "A physical impairment that limits an individual's ability to cleanse and eliminate body waste does impair a major life activity."

The ADA requires employers to offer reasonable accommodation for workers who can perform the essential functions of their job if the employee requests accommodation. Employees don't have to tell the employer the nature of their disabling condition. Accommodation can include but is not limited to flexible scheduling, time off and a clean place to do a PD exchange, or the ability to sit rather than standing too long or take more breaks, as long as the essential functions of the job are done. Accommodations must be reasonable. Most job accommodations that dialysis patients need are not costly and there may be tax credits or deductions for businesses that accommodate workers with disabilities. The Job Accommodation Network is a good resource. The **Equal Employment Opportunity Commission** enforces employment provisions of the ADA.

The **Family and Medical Leave Act (FMLA)** applies to all public (federal, state, local) and education agency (school) employees as well as private employers that have 50 or more employees for at least 20 work weeks within 75 miles of the eligible worker's location. Employers must provide up to 12 weeks of unpaid job protected leave annually for an eligible worker to care for their own serious medical needs or those of a spouse, parent, or child. If the leave is to care for a service member's serious medical need and the eligible worker is a spouse, parent, or child, the employer must provide up to 26 weeks in a single 12 month period. To be eligible, a worker must have worked for the employer at least 12 months (not necessarily consecutive) and have worked at least 1,250 hours during the last 12 months. Time off can be taken in increments as small as the company tracks time. Companies must continue health coverage under the same terms and conditions as if the worker hadn't taken leave. The Wage and Hour Division of the Department of Labor's Employment Standards Administration enforces the FMLA.

The **Individuals with Disabilities Education Act (IDEA)** requires states to provide funds for schools' early intervention and special education services for youth with disabilities from birth to age 21. The requirement for schools to work with parents to develop and implement an Individual Educational Program (IEP) is part of this law. This law is enforced by the Department of Education.

Social Security Disability Programs

To educate patients, dialysis and transplant social workers need to be informed about Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs and eligibility requirements. Both disability programs require the person to have a significant impairment that is expected to result in death or prevent work at a substantial level for at least a year. SSDI requires a recent work history and payment of Social Security taxes. SSI does not require a work history but is only available to those with limited income and assets. There is a 5-month waiting period for SSDI, except when someone is expected to die sooner. The Social Security Administration (SSA) pays SSDI checks for the prior month so the recipient will receive the first check 7 months after being determined disabled. SSI can start sooner than SSDI. Benefits can sometimes be backdated.

SSA considers dialysis and transplant potentially disabling. The **SSA "blue book"** describes what "impairments" are considered potentially disabling and when to expect a continuing disability review. For example, SSA could review a transplant recipient's health status as soon as one year post-transplant. However, SSA may not review the status of someone on dialysis for years.

Social Security Work Incentive Programs

Nephrology social workers should understand Social Security work incentive programs in order to dispel myths patients may have about working with a disability. Several brochures are available that explain these programs. SSA also has work incentive liaisons in local offices in order to provide information about work incentives, and area work incentives coordinators (AWICs), who conduct public outreach on work incentives. Social workers could ask local work incentive liaisons or AWICs to speak at CNSW Local Chapter or patient meetings. SSA also offers webinars for those who receive disability. The **Social Security "Red Book"** has a wealth of information about work incentive programs for SSDI and SSI recipients. What follows are some, but not all, work incentive programs described in that book that may help people with kidney disease and kidney failure.

Substantial Gainful Activity (SGA) (SSI and SSDI)

SSA compares the SSDI or SSI recipient's work earnings with the "substantial gainful activity" (SGA) level to determine if benefits can continue to be paid or must be discontinued. In 2014, the current SGA is $1,070 a month—those who are legally blind can earn up to $1,800 a month. These amounts change every year and can be found by calling Social Security at (800) 772-1213 or visiting **www.socialsecurity.gov**.

Impairment-Related Work Expenses (SSI and SSDI)

SSA will review and may approve out-of-pocket expenses that allow someone to stay healthy enough to work. To be approved, "impairment-related work expenses" (IRWE) cannot be reimbursed by any other source. If SSA approves them, the IRWE amount is deducted from "countable" work earnings before SSA determines if earnings are above the SGA. If the SSI or SSDI recipient has any approved IRWE deductions, he or she can earn that much more than the SGA and their disability check. Having more income because of IRWE deductions may allow patients without full coverage to pay for medical and medication costs, treatment-related transportation and even a home dialysis helper. Those who are legally blind may report other expenses under the Blind IRWE described in the **"Red Book."**

Trial Work Period (SSDI only)

SSA provides SSDI recipients with a 9-month "trial work period" (TWP) to attempt to work or run a business. During the TWP the SSDI recipient can earn as much as they can and keep all their SSDI cash benefits. If countable earnings after SSA-approved deductions are more than $770 (in 2014, changes yearly), SSA counts that as one trial work month. Self-employment over 80 hours in a month uses one trial work month. Once all 9 trial work months are used during a rolling 60-month period, SSDI payments will stop after a 3-month grace period. Once all 9 trial work months are used, they cannot be replenished, but it is possible to return to disability if a health setback occurs.

Extended Period of Eligibility (SSDI)

Someone who uses all 9 trial work months and continues to work at the SGA level will lose SSDI. However, if that person is unable to work any month during the next 36 months because of disability, he or she can receive an SSDI check that month.

Continuation of Medicare Coverage (SSDI)

Dialysis patients keep Medicare coverage as long as they're on dialysis even if they work. Most people on dialysis get Medicare Part A free and have Part B after paying a premium.

Transplant patients who have Medicare only because of ESRD lose Medicare 36 months after their transplant. Someone (including transplant recipients) who gets Medicare because of another disability in addition to ESRD can keep Medicare beyond 36 months. Even if that person works and exhausts the trial work period, he/she can keep free Medicare Part A and premium Part B and Part D for another 7 years and 9 months.

Medicare for People with Disabilities Who Work (SSDI)

Someone under age 65 who works with a disability and is about to lose free Medicare Part A after 7 years and 9 months of work earnings can elect to pay premiums for Part A. This makes it possible to for them to pay the usual premium and keep Part B and Part D. Enrollment options include: (1) the month free Medicare Part A ends and the following 7 months, (2) during the general enrollment period from January 1 through March 31, (3) whenever covered by an employer group health plan (EGHP) or (4) for 8 months after EGHP coverage ends. Under this work incentive, EGHP coverage, if any, pays after Medicare.

State Payment of Medicare Premiums (SSDI)

Anyone with limited income and assets who has Medicare may apply to their state for help paying their Medicare Part B premium under a Medicare Savings Program called Qualified Medicare Beneficiary (QMB) or Specified Low-Income Medicare Beneficiary (SLMB). QMB also pays Medicare deductibles, coinsurance and copays. For those with limited income and assets whose free Medicare Part A has ended due to work (see above), the state can pay the Part A premium under a Medicare Savings Program called Qualified Disabled and Working Individuals (QDWI).

Earned Income Exclusion (SSI)

SSA counts less than half of what an SSI recipient makes from work to decide how much SSI cash to pay. SSA first subtracts $20 from income, then subtracts $65 and divides what's left in half to determine "countable earnings." If the countable earnings are less than $721–the federal benefit rate for SSI in 2014, SSA will pay the difference between the countable earnings and $721 in SSI. The SSI federal benefit rate may change each year. There are examples in the **"Red Book."**

Section 1619 Benefits for SSI Recipients Who Work (SSI)

Under **Section 1619(a)**, if someone who was receiving SSI the month before returning to work is still disabled and still has limited resources, he or she will get SSI cash benefits as long as gross wages (or net earnings, if self-employed) are below the SGA level after SSA deducts impairment-related work expenses (IRWE).

Under **Section 1619(b)**, if someone who is disabled with limited resources was receiving SSI the month before returning to work, he or she can keep Medicaid benefits as long as work earnings don't exceed the state "threshold." This amount is far above eligibility guidelines for those with limited income and resources who don't work. Anyone who receives SSI should report their work status and earnings to SSA.

The 1619 program is administered by SSA, and State Medicaid caseworkers may tell people who have SSI and Medicaid they can't work and keep Medicaid.

Student-Earned Income Exclusion (SSI)

In 2014, disabled students under 22 years of age can earn up to $1,750 per month or $7,060 per year if they regularly attend school. These amounts may change annually based on the cost of living. College students must attend 8 hours of classes a week. Students in grades 7-12 must attend at least 12 hours of classes per week. Students in vocational training must attend 12 hours weekly or 15 hours weekly if coursework includes shop practice. Home-taught students with disabilities can use this benefit if they have a tutor or home visitor who directs the courses given by a school (grades 7-12), college, university, or government agency.

Plan for Achieving Self-Support (PASS) (SSI and SSDI)

An SSI recipient who wants to go to school, start a business, buy a car or has another goal which would allow him or her to become self-sufficient, can develop a plan and a budget with the help of a Vocational Rehabilitation counselor, an SSA representative, a friend, relative, or the nephrology social worker. Once approved by SSA for a PASS, the SSI recipient can "set aside" money from his or her SSI check to pay bills related to the plan. The recipient may pay bills directly or save money in a designated account to fund the plan when they have enough money. This money does not count against the SSI or Medicaid resource limit and SSA will supplement the SSI check to the SSI federal benefit payment, in essence paying for education, the business, car, etc. SSDI recipients may be able to take advantage of the PASS program if the money they set aside for the plan reduces their income below the SSI maximum. This may make them eligible for state Medicaid too. The work incentive liaison at SSA can provide more information about the **Plan to Achieve Self-Support (PASS) Program** or you can call 1 800-772-1213.

Ticket to Work (SSI and SSDI)

Almost anyone receiving SSI or SSDI is eligible for but not required to participate in the Ticket to Work program. State vocational rehabilitation agencies and other approved providers called "employment networks" help people with disabilities find and keep jobs. Find out more about the **Ticket to Work** program by calling 1-866-YOURTICKET.

Continued Payment Under Vocational Rehabilitation or Similar Program (Section 301) (SSI and SSDI)

If an SSI or SSDI recipient is working on a program with his or her state vocational rehabilitation agency or a similar employment program when he or she recovers medically, SSI or SSDI cash benefits can continue until the program ends—as long as the program is expected to improve the chances that the SSI or SSDI recipient will be able to permanently leave the disability rolls after the program is completed. Program examples include but are not limited to Ticket to Work, vocational rehabilitation agencies, PASS, and an Individualized Education Program (IEP) for those ages 18-21.

Expedited Reinstatement (SSI and SSDI)

Many people worry about going back to work at a level that would cause them to lose SSI or SSDI then and having a health setback that could keep them from working. They worry that they wouldn't have SSI or SSDI to fall back on. If this happens within 5 years of losing SSI or SSDI due to work earnings, they can apply for expedited reinstatement of SSI or SSDI. Expedited reinstatement allows SSA to pay SSI or SSDI benefits for 6 months while conducting a medical review to see if benefits should continue. SSA does not expect the person to pay back the 6 months of benefits if the medical review finds the person is not disabled.

Other work incentives can be found at **www.socialsecurity.gov/work**.

Conclusion

Social workers can make a significant impact in the lives of ESRD patients by broadening their understanding of rehabilitation issues, rehabilitation resources, and collaborating with the IDT and others to empower patients. In helping ESRD patients achieve their potential, we can take heed from this quote from the philosopher, Goethe:

> *I have come to the frightening conclusion that I am the decisive element. It is my personal approach that creates the climate. It is my daily mood that makes the weather. I possess tremendous power to make a life miserable or joyous. I can be a tool of torture or an instrument of inspiration. I can humiliate or humor, hurt or heal. In all situations, it is my response that decides whether a crisis is escalated or de-escalated, and a person humanized or de-humanized.*
>
> *If we treat people as they are, we make them worse. If we treat people as they ought to be, we help them become what they are capable of being.*

Kidney-Specific Health-Related Quality of Life (HRQOL) Surveys

Kidney Disease Quality of Life (KDQOL-36)

Survey for adults ages 18 and older

Two generic scales (12 questions)
- physical functioning - PCS
- mental functioning - MCS

Three kidney-specific scales (24 questions)
- burden of kidney disease (4 questions)
- symptoms/problems (12 questions)
- effects of kidney disease on daily life (8 questions)

Free survey, Excel scoring template, multiple translations, FAQs, references:
www.rand.org/health/surveys_tools/kdqol.html

Free description of the survey and its use under "About Us," subscription to access scoring service, patient and clinic reports, action plans, educational resources:
www.kdqol-complete.org

PedsQL 3.0 ESRD Module

Patient report survey for children ages 5-18 and parent report survey for children ages 2-18

Scales: (34 kidney-specific questions):

- General Fatigue (4 questions)
- About My Kidney Disease (5 questions)
- Treatment Problems (4 questions)
- Family and Peer Interaction (3 questions)
- Worry (10 questions)
- Perceived Physical Appearance (3 questions)
- Communication (5 questions)

Information on licensing, administration, scoring, and review copy of survey:
www.pedsql.org

Rehabilitation Resources

Job Accommodation Network
(800)526-7234 (Voice) (877)781-9403 (TTY)

Life Options Rehabilitation Program
414 D'Onofrio Drive, Suite 200
Madison, WI 53719
(800) 468-7777

National Kidney Foundation
30 E. 33rd Street
New York, NY 10016
(800) 622-9010

Rehabilitation Services Administration
U.S. Department of Education

Renal Support Network
1311 N. Maryland Avenue
Glendale, CA 91207
(866) 903-1728

Social Security Administration (SSA)
(800) 772-1213
(800) 325-0778 (TTY)
Free interpreter services for multiple languages

U.S. Department of Labor
Office of Disability Employment Policy
200 Constitution Avenue
Washington, DC 20210
(800) 633-7365

Financial Aid

The Smart Guide to Financial Aid

U.S. Department of Education

Free Application for Federal Student Aid

www.floridastudentfinancialaid.org
(800) 366-3475 or (888) 827-2004

www.collegeanswer.com
through Sallie Mae
(888) 272-5543

www.collegeboard.com
(866) 392-4088

"**Financial Aid for Disabled Persons and their Families 2012-2014**" from Resource Service Press

National Center for Parents with Disabilities – scholarships specifically for high school seniors or college students who have parents with disabilities:

Job Sharing

www.mission.jobshare.com

Work Options
(541) 359-3677

U.S. Office of Personnel Management
(202) 606-1800

PALLIATIVE CARE

Issues related to palliative care are critically important in the chronic kidney disease (CKD) population, and are considered a clinical priority (Davison, 2001). Kidney disease patients may have the same symptom burden, quality of life, and psychological distress as patients with terminal cancer (Saini et al., 2006). According to Jablonski and other experts (2008, p. 206), "there is an urgent need to incorporate palliative care into the treatment of patients with end-stage renal disease (ESRD)." CKD patients are faced with many different palliative care issues, including enhancing quality of life, advance care planning, pain issues, decision making, end-of-life concerns, a high mortality rate, and hospice needs. At any point during treatment, it is a kidney disease patient's right to refuse to start or to discontinue dialysis.

Many kidney disease patients can live long and successful lives; however, those with ESRD have far lower life expectancy than the general population. At least 21% of deaths in dialysis patients are preceded by a patient decision to withdraw dialysis (United States Renal Data System (USRDS), 2002); attention to the palliative care needs in this population is critical. Also important is the demographic composition of the ESRD population. The rates of elderly patients (age 75 and older) have doubled since 1997 (USRDS, 2009), and older patients are more likely to have other co-morbid illnesses and conditions that also diminish their life expectancy and quality of life.

Despite the high death rate, quality-of-life concerns, pain issues, and advance care planning needs of this population, kidney disease patients underutilize palliative care services, and many kidney disease teams are ill-equipped to address patients' palliative needs. To better prepare them, the kidney disease community has made strides in addressing these critical patient needs, starting with the publication of the *Clinical Practice Guideline on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis* (Renal Physicians Association, 1999). In 2002, the Kidney End-of-Life Coalition was created, with the mission of promoting "effective interchange between patients, families, caregivers, payers, and providers in support of integrated patient-centered end-of-life care of chronic kidney disease (CKD) patients" (Kidney End-of-Life Coalition, 2010).

In addition, the most recent CMS Conditions for Coverage (CfCs), which dictate the scope of care and required services provided to every dialysis patient in the United States, now require that every dialysis patient receive information on refusal of treatment as a patient right, and that every patient must be informed about advance directives. An important part of these conditions mandates that every dialysis and kidney transplant program must have an interdisciplinary team, that includes a Master's level social worker, nephrologists, surgeons, nurses, dietitians and patient care technicians. Therefore, social workers in CKD facilities need to be knowledgeable about the domains of palliative care relevant to their patients and families, and, likewise, social workers in palliative care programs, hospices and other health settings need to be knowledgable about the unique palliative care needs of CKD patients.

The components of an ideal renal palliative care program include attention to pain and symptom management, advance care planning, psychosocial and spiritual support to patients and families, and ethical issues in dialysis decision making (Moss et al., 2004). As the goal of any palliative care program is to enhance patient quality of life, this is congruent with ESRD care provision where all patients must have their quality of life measured every year, and relates directly to the finding that patient quality of life can independently predict morbidity and mortality (DeOreo, 1997; Knight, Ofsthun, Teng, Lazarus, & Curhan, 2003).

Treating pain in kidney disease patients is a challenge. Because of their kidney failure, patients cannot metabolize medications like other individuals, and prescribers must be cautious not to prescribe pain medications which are toxic to patients, or those which dialyze out of their system during treatments. This is particularly the case for dialysis patients; transplant patients have better kidney function in order to process the medications. The Mid-Atlantic Renal Coalition (2009) published the booklet *Clinical Algorithm & Preferred Medications to Treat Pain in Dialysis Patients* to assist medical teams in assessing pain and treating it appropriately. For dialysis patients, this guideline recommends that the following medications *not ever* be used in dialysis patients for pain, as they can become toxic: morphine, codeine, meperidine, and propoxyphene. Because of the complexities of pain management in kidney disease patients, it is recommended that dialysis teams consult with palliative care experts in this area to determine the proper strategy for pain management for individual patients.

Episodic, acute, and chronic pain are very common among CKD patients and can negatively impact patient quality of life and increase depression (Devins et al. 1990; Weisbord et al., 2005). Iacono (2003, 2004) found that 60% of dialysis patients have chronic pain, and that 66% of these patients were using prescription medication for pain. Germain, Cohen, and Davison (2007) found that 50% of CKD patients had chronic pain. Many ESRD patients also have significant pain prior to their death (Cohen et al. 2005). In spite of these facts, only 48% of more than 1,000 dialysis professionals reported having discussions with patients about pain (Weiner, 2008). Patients may have pain related to kidney disease and treatment-related issues, in addition to pain caused by co-morbid conditions.

When a patient is first diagnosed with kidney failure, they have the choice to refuse any renal replacement therapy. After patients start dialysis, they have the right to stop dialysis at any time. If patients do not receive dialysis and they have ESRD, they will die. Without dialysis, the median number of days that patients will survive is eight days; however, patients routinely live even longer (Germain et al., 2007). A research study of 115,239 deceased dialysis patients found that 96% of patients who stopped dialysis died within one month (Murray, Arko, Chen, Gilbertson, & Moss, 2006). Death from ESRD is not usually painful (National Kidney Foundation, 2007).

It is the shared work of nephrology social workers and their interdisciplinary teams to engage patients in informed consent discussions about starting or stopping dialysis (Brown, 2007). Moss et al (2004) suggest that when talking to patients about not starting dialysis, teams should take the following factors into account and attend to them in their discussions: realistic patient prognosis, patient survival with and without dialysis, the details of what dialysis treatment would require (surgery for an access, diet and fluid restrictions, time required every week), explanation of palliative and hospice resources available in the community, assurance that the nephrologist will not "abandon" the patient if the patient decides not to start dialysis, and inclusion of the patient's support network in such discussions.

Nephrology social workers are the experts in the area of advance care planning in their dialysis units. In research conducted by Rabetoy and Blair (2007), only 25% of nurses discussed advance care planning with patients, compared to 82% of social workers. In 2008, CMS mandated that all dialysis patients have discussions with their teams about advance directives. These regulations likewise mandate that if dialysis facilities are legally unable to honor a patient's advance directives (for example, a Do Not Resuscitate (DNR) request), they must have a protocol in place to transfer the patient to a unit that will honor the patient's wishes. With regard to DNR orders, dialysis teams need to be sure that they are in compliance with state laws, as some require a dialysis-only DNR order while others can be guided by the order on file at a hospital or nursing home. Educating dialysis staff includes increasing awareness of who has a DNR order, and what will occur in case of a patient adverse event such as cardiac arrest. Dialysis teams who work collaboratively to create a plan to intervene with patients who die with a DNR order need to consider how they will respond to the needs of other patients in the unit and how they will create a bereavement ritual for themselves and other patients. Staff should also have contact information for the patient's funeral home, be knowledgeable of local laws and regulations related to patients who die at the center with a DNR order, have up-to-date emergency contact information for all patients, and have a practiced routine of what will happen to the patient's body after death.

Nephrology social workers can collaborate with their hospice peers to advocate for patients and educate payers about patient eligibility. In addition to such skills as family assessment and interventions, psychological assessment, and resource finding, social workers on kidney disease interdisciplinary teams have been found to be the most knowledgeable about patient eligibility for Medicare hospice benefits (Thompson, Bhargava, Bachelder, Bova-Collis, & Moss, 2008).

Nephrology social workers can guide patients and families with various palliative care decisions, such as advance directives, withdrawal issues, and hospice resources. Each state has its own laws regarding durable health care plans and living wills. Contact your local Bar Association or Choice in Dying organization for your state's forms and regulations. The NKF has created an **Advance Directives patient brochure** for dialysis units to educate their patients in advance care planning. Related brochures address topics such as **Dialysis Patients' Bill of Rights**, **Dialysis: Deciding to Stop** and **If You Choose Not to Start Dialysis Treatment**. The brochures explain the concept of planning for future medical care at a point when patients may not be able to communicate. It covers the legal, psychosocial, and medical issues associated with advance directives.

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Caring Connections provides state-specific Advance Directives.

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Partnership for Caring, Inc. provides state-specific Advance Directives
475 Riverside Drive, Suite 1835
New York, NY 10115
212-870-2003

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The Renal Physicians Association (RPA) wrote the position paper, *Quality Care at End of Life*, which led to the RPA and the American Society of Nephrology (ASN) publishing an evidence-based clinical practice guideline; *Shared Decision Making*, which addresses withholding and withdrawal of dialysis.

Society for the Right to Die
250 W. 57th Street
New York, NY 10107
212-246-6953

PREGNANCY AND KIDNEY DISEASE

The combination of pregnancy and kidney disease results in a high-risk pregnancy, and requires frequent dialysis treatments, good nutritional intake, along with emotional support. Any interest in pregnancy should be discussed with the nephrology team in advance, along with the patient's high risk OB/GYN physician. Transplant patients may have an easier time getting pregnant, but their immunosuppressive medication regime may negatively affect the health of the infant. Birth control is recommended for any kidney patient who is sexuality active.

- **Kidney School** offers a Sexuality and Fertility learning module (Module 11)
- NKF provides information on **Pregnancy and Kidney Disease**
- **Life Options Rehabilitation Program** fact sheet
- **Gift of Life Institute's National Transplantation Pregnancy Registry**
- **Seattle Institute for Sex Therapy, Education and Research: Sexuality and the Renal Patient** fact sheet
- National Kidney Federation's (UK) article: **Sex problems with renal failure**

Related Articles

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SUPPORT GROUPS

Group work is an important aspect of nephrology social work. CNSW encourages social workers to facilitate and coordinate groups, whether they are considered support or educational meetings, or have a short-term or on-going existence. Dialysis and transplant patients and their families tend to enjoy the networking and fellowship that can thrive in a group setting.

It is common for a support group to need the intervention of a professional social worker when first starting or when trying to "save" a struggling group. The goal of the professional is to intervene so that the group is preserved and the leadership is returned to the patient and family member leaders. If the professional remains involved with the group, his or her role should be minimal unless the dynamics of the support group require increased intervention. The process of the support group is self-determined.

NKF offers several opportunities for patient support involvement, such as their **Peers Lending Support Program** along with several constituent groups such as the Patient & Family Council (PFC), TransAction Council, the Living Donor Council, and the National Donor Family Council. To learn more about NKF constituent membership, visit the **NKF-PFC website**.

The American Association of Kidney Patients (AAKP) offers a **Support Group Guide Book** for individuals interested in forming an independent support group. The local ESRD Network is another resource for information on support groups.

A new, dynamic version of support groups exist in online chats, blogs, and message boards that focus on kidney issues. Some of these resources are professionally monitored, but others are not:

- **AKF's Pair Up** for women with kidney disease
- **AAKP's support group listing**
- **Dialysis Patient Citizen's blog**
- **Renal Support Network**
- **MEI's Life Options helpline and message board**
- **DaVita's Discussion Forum**
- Bill Peckham's **Dialysis from the Sharp End of the Needle** blog and discussion board
- **I Hate Dialysis** site

SYMPTOM-TARGETED INTERVENTION (STI)

Developed by Melissa McCool, LCSW, in 2010, Symptom-Targeted Intervention (STI) is a method designed for nephrology social workers to help patients manage depression. It can be used in brief intervals with patients while they are receiving dialysis treatments in order to help reduce depressive symptoms and improve quality of life.

Using STI, the clinician identifies depression in the patient, asks the patient to identify the most problematic symptom, then addresses that symptom using an evidence-based selection of brief cognitive, behavioral and mindfulness techniques.

STI enhances existing nephrology social work skills in identifying, treating, and tracking outcomes of patient issues requiring clinical intervention. A rather short period of intervention has led to a reported improvement in PCS (Physical Component Summary) and MCS (Mental Comment Summary) scores in patients, as well as improvement in CES-D (The Center for Epidemiologic Studies Depression Scale) scores. The brief time invested in training holds promise for impacting nephrology social work and improving patient and dialysis clinics' outcomes.

For more information, visit: **http://stiinnovations.com**

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4. CHRONIC KIDNEY DISEASE MEDICAL INFORMATION

GLOSSARY OF MEDICAL TERMINOLOGY

Abdominal Cavity: The area in the lower part of the trunk of the body that contains the urinary and digestive systems and is covered by the peritoneal membrane.

Acute: Short duration or onset. Acute kidney failure requires short term treatment but is often reversible.

Acute Dialysis: Emergency or temporary dialysis provided to patients suffering from acute (temporary) kidney failure or to patients with chronic kidney failure who have been admitted to the hospital.

Acute Kidney Failure: A sudden onset of kidney failure resulting from disease, injury, or other insult to the kidney.

Acute Tubular Necrosis (ATN): Sudden failure of one's own kidney(s) or a transplant to function due to impaired blood supply or chemical injury.

Adequacy: Enough dialysis to avoid symptoms of uremia. (See Kt/V and URR).

Anemia: A condition caused by a very low number of red blood cells in the body. Anemia causes paleness, weakness, and fatigue.

Anticoagulants: Medicines used to help prevent blood clotting.

Antiseptic: Chemical that stops the growth of bacteria or germs; however, it does not necessarily destroy them.

Arterial line: Tubing connected to a needle inserted into the hemodialysis patient’s vascular access. During dialysis, the arterial line carries blood away from the body and into the dialyzer (artificial kidney) on the dialysis machine.

Artery: Blood vessel carrying blood under pressure away from the heart to the various parts of the body. Part of the circulatory system.

Artificial Kidney Machine: Hemodialysis machine. A machine that circulates a patient's blood through a cleansing fluid in order to maintain the chemical and fluid balance of the body.

Aseptic: Free of bacterial or infectious organisms. Sterile.

Bacteria: Small one-celled organisms found everywhere. Many kinds are harmless or beneficial; certain ones cause infections and may be dangerous.

Bilateral nephrectomy: Removal of both kidneys.

Bladder: The sac in which urine produced by the kidneys is collected and stored until the urine is released from the body.

Blood Cells: The single cells of blood. Red blood cells are vital for moving oxygen from the lungs to the body; white blood cells act to fight infection and destroy bacteria.

Blood Pressure: Pressure of the blood flowing against the blood vessels.

Blood Urea Nitrogen (BUN): Urea is a waste product of protein breakdown. BUN is a chemical measurement of the amount of nitrogen, which comes from urea, which is present in the blood. The level of your BUN will help determine whether you are eating too much or too little protein.

CAPD: Continuous Ambulatory Peritoneal Dialysis (see Peritoneal Dialysis) CAPD is a cleansing process that is repeated four or five times a day.

Calcium (Ca): A mineral found in the blood that is important to the body's functioning and for healthy bones.

Catheter: A plastic or rubber tube through which fluids enter or leave the body. A Foley catheter is used to withdraw urine from the bladder.

CCPD: Continuous Cycling Peritoneal Dialysis. Like CAPD, dialysate fluid is drained into the abdomen through a catheter. Instead of changing the fluid several times each day as in CAPD, a machine changes the fluid several times each night while the patient sleeps.

Chronic: A disease showing little change or slow progress and long duration. Chronic kidney disease is not reversible and requires lifelong treatment.

Chronic Kidney Disease (CKD): The slow destruction of normal kidney tissue that occurs over months or years.

Coagulation: Formation of a blood clot.

Conductivity: Measurement of the electrical activity of the dialysate concentration.

Continuous Ambulatory Peritoneal Dialysis (CAPD): A type of peritoneal dialysis performed by the patient on a continuous basis without major equipment.

Continuous Cyclic Peritoneal Dialysis (CCPD): A kind of peritoneal dialysis performed by the patient using a machine for eight to twelve hours every night.

Contaminate: Make dirty, impure, or no longer sterile.

Creatinine: One of the waste products of the body used as a measurement for kidney function. It is produced at a fairly constant rate in the body and is not influenced by diet. The level of creatinine corresponds to the degree of kidney disease.

Dialysate: A chemical solution, very similar in content to the blood plasma, used in hemodialysis and peritoneal dialysis treatments.

Dialysate Delivery System: That part of the hemodialysis machine that provides a steady flow of dialysate to the artificial kidney during hemodialysis.

Dialysis: The process of keeping the chemical balance of the blood when the kidneys have failed. Waste products and excess fluids are removed from the blood by allowing them to pass out of the blood through a special membrane in the artificial kidney.

Dialysis Center/Facility: A place supplying different types of dialysis services. It must meet the Federal requirements of certification as a kidney dialysis center.

Dialysis Shift: The average time required to dialyze a group of patients. This time includes both the setup and cleanup of the equipment. The dialysis shift may also be referred to as a patient shift.

Dialysis Station: The equipment and space required to perform a single dialysis treatment.

Dialyzer: The filter on the dialysis machine that removes waste products and fluid from the blood. Also called the artificial kidney.

Disequilibrium: Headaches and dizziness during dialysis. It can occur if dialysis removes a lot of fluid very quickly, or if blood pressure drops.

Dry weight: A patient's weight without excess fluid.

Edema: Collection of fluid in the body tissue resulting in swelling.

Electrolytes: Substances found in the bloodstream that are kept in balance by diet, medicines and dialysis. Examples include sodium (Na^+) and potassium (K^+).

End Stage Renal Disease (ESRD): Terminology used by CMS for that stage of chronic kidney disease when dialysis or transplant becomes necessary for survival.

Erythropoietin (EPO): A substance produced by the kidneys that stimulates the bone marrow to produce red blood cells.

Extracorporeal: Pertaining to circulation outside the body.

Exchange: The process of draining used peritoneal dialysate from the abdomen and putting in fresh dialysate. An exchange may be done by the patient or by a cycling machine.

Fibrin: Protein product sometimes seen in blood or in peritoneal fluid.

Fistula: A connection made between an artery and a vein in an arm or leg. A fistula that is made through surgery causes the vein to become larger so that needles can be easily inserted to connect the patient to the hemodialysis machine.

Glomerulonephritis: A disease involving inflammation of the tissues of the kidneys.

Glomerulus: Special tissue that serves as a filter in the formation of urine.

Gore-Tex/Impra: A synthetic vessel surgically grafted to allow access to the blood circulation.

Graft: A transplanted organ or vessel. An access that is made by connecting one end of a piece of artificial vein to the patient's vein and the other end to the patient's artery. The graft is a larger vessel with the rapid blood flow needed for efficient hemodialysis.

Hematocrit (Hct): Percentage of red blood cells to the total blood volume.

Hematoma: Accumulation of blood that has escaped from a blood vessel into surrounding tissue. Bruise.

Hemodialysis: The process by which the blood is taken outside the body to an artificial kidney where waste products and extra fluids are removed. The filtered blood is then returned to the body.

Hemoglobin (Hgb): The part of the red blood cell that carries oxygen.

Heparin: Medication that slows the natural clotting process.

Hepatitis: Inflammation of the liver, usually due to a viral infection.

Home Dialysis: The patient and a helper are trained to operate the dialysis equipment and perform the dialysis treatments in the home.

Hyper-: Prefix meaning higher than normal.

Hyperkalemia: A high level of potassium in the blood that can cause irregular heartbeat and ultimately cardiac arrest. It is a potential problem for people on dialysis.

Hypertension: High blood pressure. Some cases of hypertension can result in kidney damage.

Hypo-: Prefix meaning lower than normal.

Hypotension: Low blood pressure due to any cause.

Immunosuppressive Medications: Drugs taken to help prevent rejection of a transplanted kidney. Also cause weakening of the body's system of defense against infection.

In-center Dialysis: Facility-based treatments providing full care.

Inflammation: A reaction by a part of the body to injury, infection or irritation. Symptoms include redness, pain, heat, swelling or loss of function to the area.

Infuse: Introduce a liquid into something.

In-patient Dialysis: Dialysis treatments administered to those patients who have been admitted to the hospital. Also called acute dialysis.

Intermittent Peritoneal Dialysis (IPD): A type of peritoneal dialysis performed three to four times weekly for a total of 36 to 42 hours per week. This treatment requires the use of a machine and is usually done by health professionals.

Kidney: One of the two organs located at the upper back of the abdominal cavity, one on each side of the spinal column. One of their functions is to maintain the chemical balance of the body. Another is to remove excess fluid from the body.

Kidney Transplant: The surgical removal of a kidney from the body of one person to the abdomen of another person to replace kidney function.

Kt/V: A formula for prescribing adequate dialysis and measuring if the patient is receiving enough dialysis.

Leukocyte: White blood cell.

Lymphocyte: A special kind of white blood cell.

Metabolic End Products: Chemicals produced by normal body functions that are not needed by the body.

Metabolism: The way the body breaks down food into simpler materials or waste matter.

Modality: A type or mode of treatment. The modalities of treatment for individuals with end-stage kidney disease include hemodialysis, peritoneal dialysis, and transplant.

Monitor: A mechanical or electrical device for checking and recording conditions of patient and/or equipment.

Nephrologist: Doctor (physician) who specializes in kidney diseases and their treatment.

Nephron: The part of the kidney that acts to maintain the body's chemical balance. There are about one million nephrons in each kidney.

Neuropathy: Refers to any disease of the nerves. Sensitivity of the nerves is usually decreased as a result.

Occlude: To clamp off, to kink, or to stop the flow.

Osmosis: The movement of a fluid of low concentration through a semipermeable membrane to a fluid or area with a higher concentration.

Osteodystrophy: Defective bone formation.

Out-Patient Dialysis: Dialysis done on an out-patient basis at a renal dialysis center or facility.

Patent: Unobstructed, open.

Parathyroid Gland: One of several small endocrine glands located in or around the thyroid gland in the neck. These glands secrete a hormone that regulates calcium-phosphorus balance.

Peritoneal Dialysis: A method of cleansing the blood by putting a special fluid solution called dialysate in the peritoneum; wastes and fluid from the blood pass through the membrane into the dialysate.

Peritoneum: The membrane lining the abdominal cavity. It surrounds the digestive organs in the body.

Phlebitis: Inflammation involving the walls of a vein.

Plasma: The liquid part of blood.

Polycystic Kidney Disease: A hereditary disease involving cysts that destroy functioning kidney tissue over a period of twenty to forty years.

Potassium (K^+): A mineral necessary to the body but harmful when out of balance.

Pulmonary Edema: A condition in which the body holds extra fluid in the lungs. It causes shortness of breath.

Quality Improvement Performance Assessment (QAPI): The systematic way the dialysis interdisciplinary team plans to improve patient outcomes and reduce medical errors based on clinical data.

Rehabilitation: A return to stable health, a positive outlook, and enjoyable activities that make people feel better physically and mentally.

Renal: Having to do with the kidneys.

Kidney Transplantation Center: A hospital approved to furnish transplantation and other medical and surgical specialty services required for the care of the transplant patient.

Renin: A substance produced by the kidney which acts to raise the blood pressure.

Semipermeable Membrane: A membrane such as cellophane that permits the passage of only certain size particles through it.

Septicemia: Presence of harmful microorganisms in the bloodstream or other tissues.

Serum: The clear liquid that separates from the blood when it is allowed to clot.

Shunt (Scribner Shunt) (External AV Shunt): An artery and a vein connected by external tubing to allow repeated access to the bloodstream.

Sodium (Na^+): A mineral that helps control fluid content in the body.

Sterile: Completely free of any living microorganisms; aseptic.

Subcutaneous (Sub-q): Underneath the skin.

Systemic: Affecting the entire body.

Tissue Typing: A blood test used to determine the compatibility between an organ donor and the recipient for a transplant.

Trauma: Injury or wound.

Toxins: Chemical waste products produced by the metabolic processes of the body, such as digesting food, breathing, and mental and physical activity.

Ultrafiltration: The method used to remove excess fluids from the blood during dialysis.

Urea: A waste product formed by the breakdown of protein in the body.

Uremia: Toxic condition associated with loss of kidney function and the retention of metabolic waste products in the blood. The symptoms are weakness, nausea, itching, sleep disturbances, headaches, impaired memory and confusion.

Ureter: One of two tubes within the body that carries urine from the kidneys to the bladder.

Urethra: The tube through which urine is discharged from the bladder.

Urologist: A doctor (physician) who diagnoses and treats disorders of the urinary system.

URR: Urea Reduction Ratio. A formula to measure the adequacy of dialysis.

Vein: Blood vessel carrying blood to the heart form the various parts of the body. Part of the circulatory system.

Venous: Anything related to a vein.

Venous line: In hemodialysis, the tubing that returns the clean blood from the dialyzer back to the patient through the access.

Kt/V AND UREA REDUCTION RATIO (URR) DEFINITION

What Does Kt/V Mean?

Literal Definition:

K = fractional clearance of the dialyzer (efficiency in removing urea from the body water)
t = actual time in a dialysis session
V = volume of body water from which urea is removed.
It is a dimensionless figure.

Functional Definition: Kt/V is a precise way of expressing the dose of dialysis given. Under the prescriber's control are the size of the dialyzer chosen, the blood flow and the dialysate flow, all of which affect clearance (K), and the time on dialysis (t).

At present, expert opinion is that Kt/V should be equal to, or greater than, 1.2. In peritoneal dialysis the expert opinion is a Kt/V of 2.0. It is necessary to understand that the larger the "V," the greater the clearance and/or the longer the time necessary.

The prescribed Kt/V may not equal the delivered Kt/V because neither the clearance nor the "t" may be as prescribed. Delivered Kt/V is derived from the age, sex, race, height, weight of the patient (to initially calculate "V"), residual kidney function, pre- and post-dialysis BUN (blood urea nitrogen value), ultrafiltration loss during dialysis and urea generation. While this appears complicated, many user-friendly computer programs are available. It should be noted that these programs provide information on protein catabolic rate, which in stable patients, is equivalent to dietary protein intake.

What is a Urea Reduction Ratio (URR)?

URR (urea reduction ratio) is a measure of BUN reduction during dialysis:

$$\textbf{URR} = \frac{\textbf{Pre BUN} - \textbf{Post BUN}}{\textbf{Pre BUN}} \times \textbf{100\%}$$

At present, expert opinion is that the URR should be, at a minimum, 65%.

URR provides information useful to epidemiological studies but may be less valuable in individual patients. URR can be corrected for ultrafiltration to provide a more accurate estimate of Kt/V.

TREATMENT OPTIONS

Several types of dialysis and a variety of settings are available to meet the individual needs of each patient and his/her family. It is important for social workers to know something about each type and its setting. Patients will want to work with the health care team in choosing the modality that will best meet their needs. As mandated by the CMS Conditions for Coverage for ESRD Facilities, **all patients must be informed of all treatment options available to them, even if the center does not provide all forms of treatment**.

A patient may choose one type of dialysis or setting and later find that another type might better meets his or her needs. In helping patients make any decision about treatment type and setting, social workers should facilitate a review of the pros and cons of each choice and how each choice could affect the patient. A number of studies conclude that the more responsibility a person takes for his or her care, the happier and healthier he or she will be.

This section has been divided into two parts**: (1) the types of dialysis treatments** and **(2) the treatment settings.**

(1) Types of Treatment

There are two basic types of dialysis: **hemodialysis** and **peritoneal dialysis**.

HEMODIALYSIS

The word "hemo" refers to blood. During a treatment, all the blood in the body travels several times through a filter, called a "dialyzer." Hemodialysis is performed by circulating the blood out of the body through the artificial kidney filter where waste products are removed. To have a hemodialysis treatment, the patient sits in a recliner chair next to a hemodialysis machine. The skin may be numbed and two needles are inserted into a vein in the forearm. The needles are connected to tubing. The tubing takes the blood through the filter (artificial kidney) for cleansing and returns it to the body. Only about 2 cups of blood are outside the body at any one time so the patient does not feel weak. At the end of the treatment, all blood is returned to the body and the needles are removed. Less than an ounce of blood is lost during a hemodialysis treatment. Each person has his/her own needles, tubing, and filter which are attached to the dialysis machine and utilized for that particular treatment only. The blood never touches any surface where another person's blood has been. The patient is not at risk of getting a blood-borne disease while on hemodialysis.

Many people worry that dialysis is painful. Numbing the skin or placing the needles into the vein can cause brief discomfort, but cleaning the blood is not painful. During treatments the patient can read, watch TV, do crafts, write, talk with others or rest.

Treatments for chronic hemodialysis can be in a clinic that may be in a hospital or an outpatient setting. This type of treatment usually takes three to four hours, three times per week. The team will work with the patient to determine the right schedule, diet and type of dialysis.

The hemodialysis regime can vary: daily, overnight, and home hemodialysis are also available patient treatment options. Research suggests that hemodialysis received more frequently than three times a week provides patients with better outcomes, including improved mortality, morbidity, and quality of life. In the Frequent Hemodialysis Network (FHN) Trial Group's 2010 investigation, reported in the *New England Journal of Medicine*, 125 patients were randomly assigned to a clinical trial and received hemodialysis six times per week, while 120 patients were randomly assigned to a group receiving the standard three-times-per-week hemodialysis. After a year of this randomized clinical trial, patients who received more frequent dialysis were found to have lower mortality rates and better cardiac status.

In his meta-analysis of the research related to the benefits of home hemodialysis, Rosner (2010) concludes that patients who receive hemodialysis at home rather than in a dialysis center have significantly better outcomes, including improved mortality, morbidity, nutritional status, and quality of life. This and other research that evaluates the benefits of home hemodialysis suggests that the improved outcomes related to this treatment modality can be attributed to the longer dialysis treatment times that home hemodialysis patients usually receive, compared to patients who dialyze in outpatient centers only three times per week.

Home hemodialysis is a treatment option that allows patients to perform their own dialysis at home. Patients and one social support network member receive comprehensive training to master their own hemodialysis. Dialysis centers arrange for equipment and supplies needed for home hemodialysis to be delivered and set up, using the small hemodialysis machines that the technology related to this modality now supports. Patients are trained to insert their own hemodialysis needles, set up and run hemodialysis machines, and troubleshoot any concerns. Patients can dialyze in the comfort of their homes, or perform hemodialysis when travelling. Patients who receive home hemodialysis see the members of their dialysis teams when they return to the dialysis clinic for routine laboratory testing and follow up visits.

In order to have chronic hemodialysis, a minor operation is done either to enlarge and strengthen the patient's vein or to place a soft synthetic vein inside the arm or thigh. This is called an "access" because it provides a way to get the blood outside the body to cleanse it. A vascular surgeon who specializes in blood vessel surgery performs the operation. The procedure is done several weeks before dialysis is necessary, in order to give the vessel time to develop and heal.

Types of Access Used in Hemodialysis

Permanent:

A **fistula** is an artery and vein that are joined under the skin. This allows a large amount of blood flow into the vein, making the vein grow large enough to place the needles required for hemodialysis.

A **graft** is a vessel made from soft synthetic tubing. One end is joined to an artery and the other is joined to a vein under the skin. Again, this makes a larger vessel for placement of hemodialysis needles.

Both types of accesses are inside the body. There are no tubes on the outside of the arm or leg. There are two main problems that may occur with accesses: clotting and infection. Although some patients never have clotting problems, others have a constant battle with clots that grow within the fistula or graft. These clots are not life threatening because they do not move to the heart or lungs. However, they have to be found and surgically removed quickly after they form or they will permanently block the vessel. To make sure blood is flowing through the vein, the patient checks the area daily by either lightly touching the area (to feel for a pulse, called a bruit) or by listening to the bloodflow through a stethoscope.

Infection can be another problem. To avoid this, the skin over the access will be cleaned thoroughly before needles are inserted. Any redness, drainage, or signs of infection should be reported quickly.

The patient should save the access arm just for dialysis and avoid anything that puts pressure on the access since extended pressure could cause clotting. The patient should not let anyone draw blood from his or her access arm nor utilize it for taking blood pressure.

Permanent catheters are like subclavian catheters (see below). Surgery is necessary to place the catheter into the patient's body as well as to remove it. Usually this type of catheter is limited to those patients who cannot get either a fistula or a graft to work successfully.

Temporary:

Subclavian catheters are plastic tubing placed in a large vein near the collarbone. This is also used in emergency dialysis or when no other access is available. This may provide temporary access for several months. The tubing is inserted with local anesthetic in surgery or in an outpatient department.

Femoral catheters are soft plastic tubing placed in a large vein in the groin. This is used in emergency dialysis or when no other access is available. This is seldom used for more than one or two dialysis treatments. The catheter is placed into the vein in surgery or in an outpatient department.

PERITONEAL DIALYSIS

As in hemodialysis, peritoneal dialysis uses a filter to remove the extra fluids and wastes thereby cleaning the blood. Research suggests that patients who receive peritoneal dialysis instead of in-center hemodialysis have better outcomes, including improved mortality and morbidity rates. A study of 9,277 dialysis patients from across the United States demonstrated that peritoneal patients have a 40% decrease in risk of mortality compared to patients who received hemodialysis three times per week (Charnow, 2010). Interestingly, a recent anonymous survey of nephrologists suggests that the overwhelming majority of nephrologists would choose peritoneal or home hemodialysis if they themselves needed renal replacement treatment (Schatell, Bragg-Gresham, Mehrotra, & Merighi, 2010). When asked what treatment modality they would choose for themselves if they had kidney failure and a five year wait for a kidney transplant, only 6.4% of the 660 nephrologists surveyed indicated that they would choose standard three-times-per-week in-center hemodialysis. Forty-five percent of the doctors responded that they would choose peritoneal dialysis for themselves, and 45% responded that they would choose home hemodialysis.

With peritoneal dialysis, no blood is taken from the body. The blood is cleansed inside the body by using the body's own peritoneal membrane as the filter. The peritoneum is a thin membrane that lines the wall of the abdomen and the digestive organs (including the liver, stomach and intestines). The inside of this membrane is called the peritoneal cavity. The peritoneal membrane is a lining with tiny openings like the hollow tubes inside a dialyzer. When a special dextrose dialysis fluid is placed inside the peritoneal cavity, the membrane acts as a filter. Waste products and extra fluid from the blood pass through tiny holes in the filter (the peritoneum) into the dialysis fluid. The wastes and fluid are removed from the body through a catheter and then thrown away.

The catheter is a small, soft tube, about 1/4 inch in diameter. It is placed into the peritoneal cavity during a minor surgical operation. The catheter leaves the body in the lower abdomen, about 1 inch below and to the side of the navel. A few inches of the catheter extend outside the body. This area around the catheter is called an "exit site" and provides the pathway through which dialysis fluid can be placed. The patient and the surgeon plan the exact “exit site” so the tubing can be worn comfortably and can be hidden easily under clothing.

Bandages are not needed to cover the catheter. However, once the catheter area heals, it must be kept clean. The nurse will give the patient safe, simple instructions for cleaning the exit site. Once the area is dry, many people fasten the catheter with a small piece of tape to the abdomen. The catheter is not removed between treatments and, if cared for, can last for many years. It does not prevent a patient from continuing his or her normal lifestyle or activities.

There are three basic methods of peritoneal dialysis: Continuous Ambulatory Peritoneal Dialysis (CAPD), Continuous Cycling Peritoneal Dialysis (CCPD) and Intermittent Peritoneal Dialysis (IPD).

Continuous Ambulatory Peritoneal Dialysis (CAPD)

A peritoneal dialysis procedure is called an "exchange" because used fluid is removed and replaced with fresh fluid. A CAPD "exchange" involves using the peritoneal cavity, a catheter, tubing and two bags (one full and one empty). The empty bag is for draining the used dialysis solution from the peritoneal cavity. When the abdomen is empty, it is filled with the fresh dialysis solution from the full bag. The exact "exchange" method differs with the kind of tubing used.

In between each "exchange," the fluid surrounds the internal organs. It does not go into the stomach or any other organs. Waste products pass from the blood through the peritoneal membrane and into the dialysis fluid.

The dialysis solution is left in the peritoneal cavity for four to six hours to collect wastes from the blood. Each time the patient changes the fluid and repeats the steps of draining out the old solution and replacing with the new solution, an "exchange" has been completed. The process of draining the dialysate and replacing fresh solution takes 30 to 40 minutes. Most people change the solution four times a day.

Advantages of CAPD:

- The treatment can be performed alone—a clean, draft-free area is all that is needed.
- The treatment can be done at the times the patient chooses—most often in the morning, at lunch, near dinner and before going to sleep
- The treatment can be done in many locations—at home, in town or while traveling
- A machine is not needed—supplies are easily packed in a small tote bag

Disadvantages of CAPD:

- Treatments can break up the patient's daily schedule
- The treatment must be done daily, usually 4 times a day
- CAPD requires a storage space for PD supplies

Continuous Cyclic Peritoneal Dialysis (CCPD)

CCPD is similar to CAPD, except that a machine automatically fills and drains the fluid (dialysate) from the peritoneum. Treatments last from 8 to 12 hours every night.

Advantage of CCPD:

- It is performed every night while the patient sleeps.

Disadvantages of CCPD:

- It requires a machine
- The patient may need help from a partner
- The machine may alarm during the night which may interrupt sleep
- The patient needs a storage room for supplies

Intermittent Peritoneal Dialysis (IPD)

IPD uses the same type of machine as CCPD to add and drain the dialysate. IPD can be done at home, but it is usually done in the hospital or the dialysis unit. IPD treatments take longer than CCPD. Treatments are done several times a week, for a total of 36 to 42 hours per week. Sessions may last up to 24 hours.

Advantage of IPD:

- Health professionals usually perform treatments.

Disadvantages of IPD:

- The patient may need to go to a hospital or dialysis unit
- It takes a lot of time
- To do IPD at home, the patient needs a machine

Diet

The diet for peritoneal dialysis patients is slightly different than that for hemodialysis patients. For example, the PD patient may:

- Be able to have more salt and fluids
- Need to eat more protein
- Have different potassium limits
- Need to cut back on the number of calories eaten because the sugar in the dialysate may cause the patient to gain weight

Peritonitis

A possible complication to any of the types of PD is peritonitis, or infection of the peritoneum. This can happen if infection enters the body through the catheter site where connection and disconnection take place. Peritonitis can cause a fever and stomach pain in patients.

To avoid this infection, the patient must be careful to follow the instructions for connecting and disconnecting the catheter correctly and know the early signs of peritonitis. These include redness or swelling around the catheter and cloudy dialysate. It is important to report any of these signs to the doctor so the peritonitis can be treated quickly in order to avoid serious problems.

(2) Treatment Setting

Dialysis can take place in many settings. The patient and the health care team will need to work together in deciding which setting is best. The patient may even choose one location and change it later if necessary.

There are four types of treatment settings: home, in-center, partial care, and acute care. Acute care is the only setting that always takes place in the hospital. The other three treatment settings can all be outside the hospital.

Home Dialysis

The patient does this type of dialysis at home. If the patient chooses home hemodialysis or CCPD, a helper is needed. For CAPD, the patient can usually perform the whole treatment by himself or herself. The treatment fits into the patient’s own schedule rather than having to fit into a unit's schedule. Time can be saved by not traveling to a unit. Home dialysis puts the patient in greater control of the prescribed treatment, diet and medicine. Members of the health care team will teach the patient how to recognize symptoms that should be reported to them. Someone is always available by phone to help the patient with any phase of the care. Also, the dialysis unit can help with backup treatments if needed. The patient visits the clinic monthly for lab tests and an examination by the health care team.

In-Center

In-center dialysis includes hemodialysis and IPD. These are done in outpatient units: the patient comes to the center for treatment and goes home after the treatment is finished. The patient may be asked to perform some parts of the treatment, if he/she is physically able. The patient will be educated about the treatment, diet and medicine, and how these work together. The health care team will work with each patient to find a treatment time that meets the patient’s needs.

Partial Care

Another name for this type of dialysis is self-care hemodialysis. Like in-center, partial care is done in outpatient units where the patient will perform all or parts of the treatment. Again, the health care team can help with the treatments.

Acute Care

The patient will be dialyzed in an acute or in-patient unit whenever he/she is hospitalized.

KIDNEY TRANSPLANTATION

Dialysis is just one form of treatment for kidney failure. Another way of treating kidney failure is with a kidney transplant. A kidney transplant is the surgical placement of a kidney that has been donated by one person (donor) into a person whose own kidneys no longer function (recipient). Normal kidneys come in pairs; however only one kidney is needed to maintain life.

There are two types of kidney transplants. One is done using a kidney from a living donor. The living donor must be evaluated as acceptable based on psychosocial, medical and surgical criteria in order to donate a kidney. The second type of transplant is a kidney from someone who has just died, either from a fatal illness or an accident in which the kidneys are not harmed. This type of donor is a "deceased donor," or non-living donor, and the transplant is called a deceased donor transplant. Deceased donor (or “cadaver”) kidneys are given by the donors themselves by pledging this gift before death or by the donor's family after death. Deceased donor kidneys make transplants possible for those people who do not have a living donor.

Kidney transplantation is the most cost-effective treatment for ESRD and provides patients with enhanced physical and mental health, especially when compared to dialysis (Becker et al., 2000). An objective of Healthy People 2010 and a proposed objective of Healthy People 2020 is to increase the number of dialysis patients who get kidney transplants (U.S. Department of Health and Human Services, 2000). Transplants may not always be possible. There are situations where patients are not medically or psychosocially suited for transplant, or in which the patient prefers another form of treatment.

Not every patient on dialysis can have a kidney transplant. Many times, this depends on a patient's overall health and psychosocial status. The decision to have a kidney transplant comes only after careful evaluation by the entire multidisciplinary transplant team, including surgeons, nephrologists, social worker and transplant nurse coordinator. The patient's feelings about transplantation are also a factor. The patient needs to feel comfortable with this choice.

Transplantation is not a random process. First, blood types must be compatible. Then proteins called "antigens" are found through a blood test called tissue typing. Antigens play a major role in how the body’s immune system functions and identifies cells that determine "likenesses" between the patient’s tissues and the donor's, whether the donor is living or cadaveric. A good match occurs when the donor and recipient share antigens that are alike. However, newer immunosuppressive (anti-rejection) medications have made this antigen matching less important in preventing rejection.

Rejection is the body’s natural immune response to a foreign object, such as a virus, bacteria, or a transplant organ. The body’s immune defense system sees these invaders as foreign and tries to destroy them. It cannot tell the difference between a “good” foreign object, such as a new kidney, or something that could harm the body, such as a virus.

Pre-transplant blood typing and antigen testing finds likenesses between the tissue of the recipient and donor to try to fool the body and keep it from seeing the kidney as something that isn't "original equipment." Every transplant recipient is at risk for rejection, even in living donor transplants. All transplant recipients must take immunosuppressive medications for the life of the transplanted organ. Success depends on the ability of the medications to prevent rejection while keeping the recipient free of complications. Rejection can occur even if the patient is taking the prescribed medications exactly as prescribed. However, rejection does not necessarily mean the patient is going to lose the kidney. Treatment is available that can often stop the rejection before it harms the kidney transplant. If the treatment is a success, rejection is reversed and the kidney works normally.

At this time there is no way to tell how long a transplanted kidney will last. Some patients have not kept the new kidney for more than a few hours or days. Others have had a working kidney for over twenty years. Chances of a successful transplant depend on the type of transplant, the age of the recipient and the cause of the original kidney disease. Adherence in taking the immunosuppressive medications as prescribed also plays a large role in the success of a kidney transplant. Generally, a living donor transplant has an 80 to 95 percent chance of being successful for one or more years.

With the use of the newer immunosuppressive medications, the kidney transplant from a deceased donor has a great chance of working the first year and longer, although this varies from individual to individual. About 70 percent of the transplants done today are from deceased donors.

Living Donor Transplants

An individual who wishes to donate a kidney should first talk with a doctor or transplant coordinator. Once the decision to donate the kidney is made, there is much testing. The potential donor will need to have blood and urine tests, x-rays and special kidney tests. If all the tests are favorable, surgery is scheduled. It is important to know that any unusual or abnormal findings will prevent the donor from giving a kidney. The health care team will not risk a potential donor's current or future health.

One concern the patient may have about getting a transplant from a living donor is the cost. If the patient is covered by Medicare, the medical costs of the donor will also be covered by Medicare. Private insurance also covers the cost, in most cases.

If testing eliminates a potential living donor, the patient can still get a kidney from a cadaveric source.

All kidney transplant programs are required by CMS regulations to have a “Living Donor Advocate,“ whose job is to look out for the welfare and well-being of the potential living donor to the exclusion of all other considerations. This role is often filled by a nephrology social worker, who also conducts a comprehensive psychosocial assessment of all the prospective living donors.

Deceased (Non-Living Donor) Transplantation

One never knows when a deceased donor kidney may become available. The tissue typing of a person awaiting a kidney transplant is put into a computer, so it is always ready. When a kidney becomes available, the tissue typing of the donor is also put into the computer. The computer then indicates who the kidney matches best. When the potential recipient arrives at the hospital at least one more test will need to be done. This test is called a "cross match" and takes several hours to complete. This test measures if the recipient has antibodies in their blood that would react strongly against the donor kidney. A “positive” cross match means there is a strong antibody reaction. In this case, the surgery will not take place as there is a very high likelihood that the recipient’s immune system would reject the new kidney right away. A “negative” cross match means there is no such antibody reaction and the surgery can then proceed. This does not mean the patient will never get a kidney. It means this kidney was not right for that patient. Sometimes we learn about special tissue typing from a positive cross match, so that the patient's chances for a deceased donor kidney match may even be improved.

The option of refusing a kidney is available to patients. There are times in a patient's life when a 4 to 7 day stay in the hospital is not possible. A refusal does not change the possibility of being called again at another time. Repeated refusals, however, might indicate serious doubt on the patient's part. The patient may want to rethink his or her decision to have a transplant.

The patient's physical condition at the time a kidney becomes available is very important. Any infection or illness may keep the patient from getting a kidney. In order to stay "in shape," the patient must stay as healthy as possible. This means being well dialyzed, watching fluids, taking medicines as prescribed, and letting the health care team know about any problems.

Transplant Surgery

Whether the kidney comes from a living or a deceased donor, the operation is basically the same. The kidney is placed in the lower abdomen, rather than in the usual kidney location in the back, because blood vessels are easier to reach. The artery that carries blood to the kidney and the vein that removes blood from the kidney are surgically connected into two blood vessels in the abdomen. The ureter, the tube that carries urine from the kidney to the bladder, is also transplanted.

As with any surgery, there are risks involved with anesthesia, infection, and other complications. After transplantation, the danger of infection is real because of the large doses of anti-rejection or immunosuppressive drugs given. These drugs lower the body's immune system and thus the ability to fight infection. Doctors who work with transplant patients are aware of these possibilities and watch for any possible problems.

Dialysis after transplantation is not unusual. Often the transplanted kidney goes through a period of adjustment and does not work immediately. If this happens, dialysis is used to increase kidney function until the new kidney takes over.

It is important for patients to think seriously about the financial considerations involved in kidney transplantation, especially the costs of anti-rejection medicines. These medications will be required as long as the kidney transplant works, and can easily cost more than $1,000 per month. A patient should consider the continued payment obligations for these medications if Medicare entitlement ends. Medicare currently pays only 80% for the medications for three years after transplant for patients whose only entitlement to Medicare is end-stage kidney disease. For those patients whose Medicare entitlement is based on age or disability and who were enrolled in Medicare at the time of their transplant, coverage of these medications will last for as long as they are on Medicare. Patients should talk to their transplant facility staff about what the anticipated costs will be.

Advantages of transplantation:

- The patient no longer experiences routine dialysis, with its own side effects and dietary restrictions.
- The patient is no longer anemic.

- The patient's lifestyle becomes more normal. Many transplant patients have returned to school, to work and to other pre-dialysis activities.
- Health is improved. Statistics indicate people live longer with a kidney transplant than if they stayed on dialysis.

Disadvantages of transplantation:

- The medicines that the patient must take as long as the transplant lasts may have side effects.
- The patient faces potential rejection and decreased kidney function after transplantation.
- Anti-rejection medications are expensive.
- The patient will initially have to make frequent trips to the transplant center, but these will eventually decrease.

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Additional Resources

- **American Association of Kidney Patients**
- **American Society of Nephrology**
- **American Society of Pediatric Nephrology**
- **American Society of Transplant Surgeons**
- **Centers for Medicare and Medicaid Services:**
- **Dialysis from the Sharp End of the needle** (Patient-created website about kidney disease)
- **Healthy People 2020**

- **Home Dialysis Central**
- **iKidney.com**
- **Institute on Rehabilitation Issues**
- **Kidney and Urology Foundation of America, Inc.**
- **Kidney Directions: For Research in Polycystic Kidney Disease**
- **Kidney Disease Quality of Life (KDQOL) Working Group**
- **KDQOL Complete** (resource to help administer and score KDQOL assessments)
- **Kidney School**
- **Life Options**
- **National Institute of Diabetes and Digestive and Kidney Diseases**
- **National Kidney Disease Education Program**
- **National Kidney Foundation**
- **The Nephron Information Center**
- **NephrOnline**
- **NephroWorld: The Whole World of Nephrology**
- **PKD Foundation: For Research in Polycystic Kidney Disease**
- **Promoting Excellence in End of Life Care**
- **Renalnet: Kidney Information Clearinghouse**
- **RenalWeb: Vortex Web Site of the Dialysis World**
- **United Network of Organ Sharing**
- **United States Renal Data System**

NUTRITION

From the time a patient is diagnosed with decreased kidney function up to and including a modality choice, there will be changes in his or her dietary requirements. The NKF has brochures available addressing the changing nutritional needs at each juncture. This information is valuable both for practicing social workers and patients. The NKF website also provides cookbooks, recipes, and cooking tips, as well as an "Ask the Dietitian" blog. The following brochures/fact sheets can be obtained through the NKF website or online store": NKF Online Store: **http://www.kidney.org/store**

Diet for Early Stages of Chronic Kidney Disease (Stages 1-4)

- Nutrition and Early Kidney Disease: Are You Getting What You Need? (Stages 1 – 4)
- Nutrition for Children with Chronic Kidney Disease
- Enjoy Your Own Recipes Using Less Protein
- Sodium and Your CKD Diet: How to Spice Up Your Cooking
- Potassium and Your CKD Diet
- Phosphorus and Your CKD Diet
- Carbohydrate Counting with Chronic Kidney Disease
- How to Increase Calories in Your CKD Diet
- Iron and Chronic Kidney Disease: What You Need to Know
- Cholesterol and Chronic Kidney Disease

Diet for those on Dialysis (Stage 5)

- Dietary Guidelines for Adults Starting on Hemodialysis
- Nutrition and Kidney Failure (Stage 5): Are You Getting What You Need?
- Nutrition and Hemodialysis
- Nutrition and Peritoneal Dialysis
- Sodium and Your CKD Diet: How to Spice Up Your Cooking
- Phosphorus and Your CKD Diet
- Potassium and Your CKD Diet

General Kidney Disease Diet Info

- Dining Out With Confidence
- Use of Herbal Supplements in Chronic Kidney Disease
- Vitamins and Minerals in Kidney Disease
- What You Should Know About Good Nutrition
- Your Guide to the New Food Label
- Spice Up Your Diet
- Emergency Meal Planning
- Emergency Meal Planning For Diabetics
- Food Safety is a Must!

Diet and Kidney Stones

- Diet and Kidney Stones

For further information, contact:

National Kidney Foundation, Inc.
30 East 33rd Street
New York, NY 10016
800-622-9010
212-889-2210

5. NKF COUNCIL OF NEPHROLOGY SOCIAL WORKERS

HISTORY

When chronic maintenance dialysis became a reality in the 1960s, medical social workers rapidly became involved in this new treatment modality. The unique nature of the treatment, with its stresses and restrictions, served to mobilize renal social workers to reach out to each other to pool their knowledge and resources, increase their skills and provide mutual support. Local and regional groups of nephrology social workers began meeting on a regular basis, often as an adjunct to conferences sponsored by established organizations. In April of 1973, 75 social workers, chaired by Meg Jamison, met at a Veterans Administration interdisciplinary meeting in Boston, in conjunction with the American Society of Artificial and Internal Organs. This group was approached by the National Kidney Foundation regarding the formation of a national organization of nephrology social workers that would eventually serve as an advisory council to NKF. After much discussion and full recognition that those present were not truly regionally representative of social workers active in nephrology, the group voted to become a national organization. They took the name, the "Association of Nephrology Social Workers (ANSW)" and appointed officers. Dr. Norman Deane of the New York Nephrology Association contributed $250 toward getting the new organization started.

During the summer of 1973, the Renal Amendment took effect. The amendment removed the financial disincentives to providing chronic hemodialysis and thereby greatly improved patient access to treatment. As new facilities opened across the country, nephrology social workers not present at the Boston meeting were identified and invited to participate in ANSW.

In November of the same year, at the Annual Meeting of the National Kidney Foundation, the decision was made to adopt the professional council structure and invite ANSW to become the social work advisory council to NKF. The Council of Nephrology Social Workers (CNSW) was established with Judith Kari succeeding Meg Jamison as the first official CNSW President. Over the past 40 years, 17 social workers have chaired the Council. Their names are listed in Table 1.

Early efforts of the Council focused on the formulation of regulations by which the ESRD program would be guided and implemented. The organization prepared a series of position papers outlining social work concerns and recommendations for the upcoming Federal regulations. Ultimately, the organization had considerable input into the final regulations which, when released in 1976, mandated that social workers in ESRD programs hold master's-level degrees.

CNSW Professional Standards and Education

One of the first undertakings of CNSW was to develop a program that would orient new workers to the field. A "New Worker Workshop" was developed and offered each year at the NKF Annual Meeting. This program was so successful that the Council decided to put together a comprehensive resource manual utilizing its contents. The "Practice Guide for Nephrology Social Work" was published in 1988, and a second edition was released in 1990. Editions published after 1996 have been renamed "**Standards of Practice for Nephrology Social Work**."

Developing and promoting professional standards has been a major goal of CNSW. Collaborating with the National Association of Social Workers (NASW) in 1978, CNSW established more specific standards for nephrology social workers in the document "Standards for Social Work in End Stage Renal Disease Treatment Settings." In 1992, the "Quality Assurance Manual" was published as a tool to assist social workers in implementing quality assurance programs in their facilities. Collaborating again with NASW in 1995, CNSW released "NASW/CNSW Clinical Indicators for Social Work and Psychosocial Services in Nephrology Settings." This publication provided a framework for measuring social work outcomes. The "Quality Assurance Manual" was updated and renamed "Continuous Quality Improvement for Nephrology Social Workers" in 1998. In 2002, CNSW released the first edition of its publication entitled "Professional Advocacy for the Nephrology Social Worker." Since that time CNSW has created numerous publications for social workers, see **www.kidney.org/cnsw** for more details.

CNSW Membership

CNSW currently has over 700 members and active local chapters across the country. These Chapters form an integral part of the organizational structure. The chapters are divided into five geographical regions and a representative who oversees each region serves on the Executive Committee of the Council.

A large, active membership is essential for the growth and strength of CNSW. In order to represent and act on behalf of the nephrology social work community and to have the resources necessary to develop and maintain appropriate programs, projects, and publications, it is of the utmost importance that nephrology social workers identify with and belong to CNSW.

Membership in national CNSW is a shared professional responsibility. The profession and the clients we serve benefit from the activities and accomplishments of CNSW. In turn, individual nephrology social workers are vital sources of support and input.

It is strongly recommended that all CNSW Local Chapter participants hold current membership in national CNSW. To accomplish this goal, it is suggested that each Chapter Chair (or the designated Chapter Membership Chairperson) assume the responsibility for encouraging and promoting national CNSW membership. All social workers new to nephrology should be provided with information about and an application for membership in CNSW; all current Chapter members should be routinely encouraged to join and/or renew their memberships.

Many CNSW Chapters serve as providers of educational activities and resources for professionals in their local NKF Division or Affiliate territory. In order to maximize consistency and quality assurance of all NKF-supported programs, all accredited educational programming by CNSW Chapters must now be approved through the NKF National Office. Chapter activities are reviewed by a CEU Review Board that consists of fellow CNSW members. The Board assures that all NKF continuing education activities awarded CEU approval are of high quality and in compliance with accreditation standards set by the Association of Social Work Boards (ASWB). For more information on how to receive CEU approval for your chapter's program, visit the **Local Chapter Resources website**.

Membership Benefits

CNSW provides the individual worker with a voice in professional issues and legislative matters as well as peer support and an organizational identity. CNSW membership is open to all nephrology social workers. Associate membership is available to anyone interested in the goals of the organization.

Membership in CNSW entitles you to:

- Join and/or establish a Local Chapter

- Run for local or national office
- Receive CNSW National Awards
- Contribute to and receive *RenaLink* and the *Journal of Nephrology Social Work*
- Apply for a CNSW research grant (when available)
- Make a presentation at the annual NKF Spring Clinical Meetings
- Attend the annual NKF Spring Clinical Meetings at a reduced rate
- Volunteer for a standing and/or ad hoc committee
- Obtain CNSW Publications
- Participate in the four CNSW LISTSERVS: General Membership, Transplant, Pediatrics, and Chapter Chair

Membership in CNSW may be obtained by contacting the National Kidney Foundation at (800) 622-9010 and requesting a Professional Member Brochure or by joining on-line at **www.kidney.org** and selecting "Join NKF."

CNSW Email LISTSERVS

The Council has four very active e-mail LISTSERVS, one each for general membership, regional chapter chairpersons, kidney transplant social workers, and pediatric social workers. These Internet resources allow members quick access to their colleagues, support, and clinical suggestions for problems and concerns.

Visit the **CNSW LISTSERV page** to sign up, log off, or search the LISTSERV archives.

CNSW Publications

Serving as a forum to encourage discussion, the first issue of the *CNSW Newsletter* appeared in 1975, edited by Paul Dieke. The newsletter was produced four times per year and changed its name to the *CNSW Quarterly* in 1998. *Perspectives*, the journal of CNSW, was first published in 1976 to provide a broader and more complete discussion of the complex issues facing nephrology social workers. Research funded by the CNSW Research Grant Program is published in this annual journal, which was developed into the *Journal of Nephrology Social Work* in 1996. Although it began as a collection of reprinted articles, the current *Journal of Nephrology Social Work* contains original material and is now published twice per year.

CNSW Awards

Acknowledging the contributions made to the profession by its membership is another major goal of the Council of Nephrology Social Workers. A number of awards are distributed each year at the annual luncheon at the NKF Spring Clinical Meetings. The CNSW Merit Award is given to a member who has demonstrated dedication to the profession through leadership, community involvement, research, or publication. To honor the contributions of a social worker new to the field, the New Worker Award was instituted in 1989. The achievements of an entire chapter are recognized with the CNSW Chapter Award, which was established in 1991.

The Robert W. Whitlock Lifetime Achievement Award was established in 2009, and is named in honor of Robert W. Whitlock, MSSW, MHA, LCSW, Director of the Missouri Kidney Program (MoKP), a leader in the kidney community, who passed away in 2008. Bob was a dedicated nephrology social worker and an outstanding contributor to research, teaching and clinical practice in nephrology social work. CNSW also provides regional awards, and awards in pediatric and transplant settings. For more information on nominations and awards, visit the **CNSW Awards webpage**.

CNSW Robert W. Whitlock Lifetime Achievement Award Winners

2009: Patricia McKevitt
2010: Judith Kari
2011: Beth Witten
2012: Sandra Coorough
2013: Michael Cervantes
2014: Stephanie Johnstone

Legislative Advocacy

From its early involvement in the establishment of the Federal regulations, CNSW has been involved in legislative advocacy. It has collaborated with organizations like NASW, the Society for Social Work Leadership in Health Care and the American Network of Home Health Care Social Workers to advocate for strong social work standards in health care. It has lobbied to protect patient rights in welfare and immigration reform. Together with NKF's Office of Scientific Activities and Public Policy, CNSW has also advocated for improvement in health insurance coverage for people with kidney disease. The organization worked with NKF in the establishment of the Legislative Advocacy Network and has been a strong advocate for extending Medicare coverage of immunosuppressive medications for transplant recipients.

Professional Advocacy

Since its inception, CNSW has addressed many challenges to the profession of nephrology social work. One of these issues has been the size of social work caseloads. Although the Federal regulations mandate that social workers in ESRD clinics hold a master's degree, they do not specify a patient to social worker ratio. As caseload size increased in the 1980s, social workers became concerned about their ability to provide quality care. In an effort to establish a staffing guideline, in 1983 CNSW recommended a formula for determining appropriate social work staffing. The formula utilized the number of social work functions performed and the psychosocial risk factors of the patient population to determine an adequate level of staffing. The staffing formula was revised and updated in 1998, recommending a minimum social worker to patient ratio of 1 to 75.

Another challenge to the profession is the hiring of unqualified individuals to serve as social workers in dialysis clinics. CNSW has adopted a strong stance supporting the Federal regulations, which define a dialysis social worker as a master's-prepared professional. Personnel with undergraduate training can certainly perform concrete tasks (such as arranging transportation or making referrals to community resources). However, only those social workers who hold the master's degree are qualified to do counseling, which enhances overall quality of life for patients with CKD. A number of papers written by CNSW substantiate this position. "Definition of Qualified ESRD Social Work Staff" (1981), "Quality and Accessibility of Social Work Services to Dialysis Patients" (1989), "ESRD Regulations: Definition of Social Services and Qualified Social Workers" (1990), "Maintaining the Qualified Social Worker in End-Stage Renal Disease Settings" (1994), and "The Role of the Nephrology Social Worker in Optimizing Treatment Outcomes for End-Stage Renal Disease Patients" (1998) all emphasize the importance of having an advanced-level professional in the dialysis facility.

In October of 2008, Medicare enacted the first update to the Conditions for Coverage (CfCs) for transplant and dialysis facilities in 30 years. These regulations specify the care provided in all ESRD facilities in the United States and its territories, and are used by state and federal surveyors to determine if facilities are performing adequately. The CNSW organized its members to provide a response to these conditions, advocating for attention to ESRD psychosocial issues and appropriate utilization of MSWs on renal teams. Indeed, because of CNSW's efforts to organize social workers in response to the CfCs, social work was the profession who wrote the most comments to CMS related to the proposed regulations.

Research Grants

The purpose of the CNSW Research Grants Program is to further knowledge of psychosocial factors in chronic kidney disease and to enhance clinical social work intervention with dialysis and transplant patients/families.

CNSW recognized that social workers in clinical practice often lack the time and funding to conduct empirical research, so the organization requested that NKF fund a psychosocial research grant program in 1981. This request was approved, and the first three CNSW research grants were awarded in 1982. To date, the CNSW Research Grants Program has funded over 40 proposals. Unfortunately, since 2011, NKF has temporarily suspended funding for professional council research grants. CNSW continues to stress the importance of these research funds and will seek restoration of these funds from NKF. CNSW also encourages members to seek research funding opportunities through other sources.

Leadership

Over the past 40 years, CNSW has grown in size, sophistication, and stature. The organization has struggled to cope with the changing healthcare industry in a way that upholds social work standards and ultimately strengthens the profession. Much of the organization's success has been attained through the support of the National Kidney Foundation. The Council of Nephrology Social Workers looks forward to continued collaboration with the National Kidney Foundation in the next millennium.

Chairpersons of the Council of Nephrology Social Workers, 1975-2015

Term	Chairperson
1975-1978	Judith Kari
1978-1982	Paula Hanson
1982-1984	Patricia McKevitt
1984-1986	Dianne Barth
1986-1988	Jean Carosella
1988-1990	Karren King
1990-1992	Beth Witten
1992-1994	Rosa Rivera-Mizzoni
1994-1996	Charlie Thomas

Term	Chairperson
1996-1998	Mary Beth Callahan
1998-2000	Maureen McKinley
2000-2002	Wendy Funk Schrag
2002-2004	Sally Rice
2005-2009	Teri Browne
2009-2011	Jeff Harder
2011-2013	Stephanie Stewart
2013-2015	Leanne Peace

Additional References:

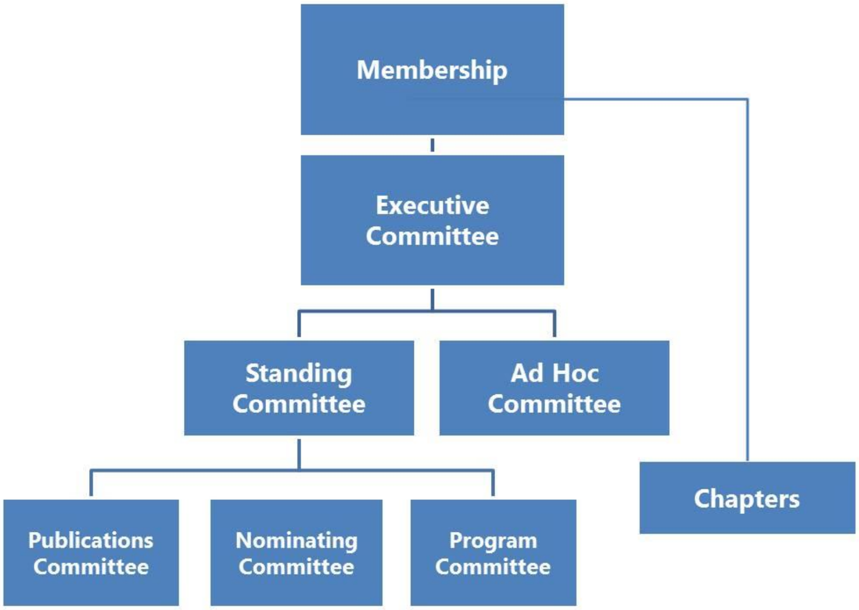
Gammarino, M., Kammerer J., & King, K.: Councils of the National Kidney Foundation, 40th Anniversary Issue. In S.G. Massry (Ed.) *The National Kidney Foundation: The First Forty Years*. Philadelphia, PA, WB Saunders Co, 1990, pp 143-144

ORGANIZATIONAL CHART

CNSW operates with four basic bodies:

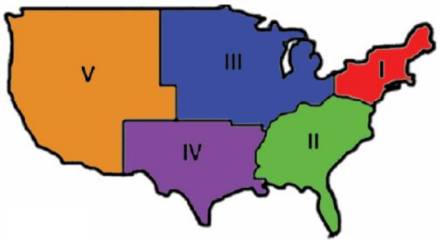
1. **Executive Committee**
2. **Standing Committees**
3. **Ad Hoc Committees**
4. **Chapters**

The structure of CNSW is as follows:



How are the NKF Regions Defined?

The Council is divided into five regions: I, II, III, IV and V.
The regions are as follows:



Region I: Connecticut, Delaware, Maine, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont, *Africa, Canada (New Brunswick, Newfoundland, Nova Scotia, Ontario, Prince Edward Is., Quebec)*

Region II: Alabama, District of Columbia, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee, Virginia, West Virginia, *Bahamas, Caribbean, Europe, Puerto Rico*

Region III: Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, Wisconsin, *Canada (Manitoba, Saskatchewan)*

Region IV: Arkansas, Louisiana, New Mexico, Oklahoma, Texas, *Mexico, Central America, South America*

Region V: Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, Oregon, Utah, Washington, Wyoming, *Asia, Australia, Canada (Alberta, British Columbia, Yukon Territory), Middle East*

How Does One Actively Participate in CNSW?

Since any organization, including CNSW, is only as good as the active participation of its membership, involvement in the following areas should be seriously considered: volunteering for Standing and Ad Hoc Committees; nominating colleagues and Chapters for annual awards; running and voting in Council elections; contributing to *RenaLink* and the *Journal of Nephrology Social Work*; participating in the CNSW LISTSERVS; submitting abstracts and attending local and national meetings; developing local initiatives in chapter planning and programming; and brainstorming new ways to participate.

Which Elected Offices Are Open Each Year?

Holding office entitles one to membership on the Executive Committee. Each officer serves a two-year term (Chair Elect serves for 2 years as Chair-Elect, then 2 years as Chair, then 2 years as Immediate Past Chair).

In even-numbered years, the following offices are elected:

- Chair-Elect
- Region II & IV Representative

In odd numbered years, the following offices are elected:

- Region I & V Representative
- Region III Representative
- Membership Chairperson

The Immediate Past Chairperson continues as a member of the Executive Committee and serves as Chairperson of the CNSW Nominating Committee.

The Publications Chairperson, Professional Education Chairperson and Program Chairperson are appointed by the Chairperson and are also members of the Executive Committee.

For further information concerning job responsibilities for any Executive Committee position, or guidelines for CNSW Chapter affiliations contact your CNSW Region Representative. **Executive Committee contacts are kept current for viewing online**.

National Kidney Foundation™ | Council of Nephrology Social Workers

NKF-CNSW RULES AND REGULATIONS

Bylaws

(As Amended April 2008, reviewed 2013)

ARTICLE I: NAME

The name of this organization shall be the Council of Nephrology Social Workers of the National Kidney Foundation (hereinafter referred to as the Council).

ARTICLE II: PURPOSES

The purpose and functions of the Council shall be:

A. To act as an advisory body to the National Kidney Foundation,

B. To promote identity and solidarity as a professional specialty, and to advocate for the nephrology social worker.

C. To disseminate information concerning the psychosocial aspects of dialysis and transplantation, while promoting quality services and care to those affected by kidney disease.

D. To formulate and recommend to the National Kidney Foundation local and Federal legislation related to kidney disease.

E. To promote community and professional education programs related to the psychosocial aspects of kidney disease.

F. To promote research related to kidney disease.

ARTICLE III: MEMBERSHIP

Section 1. The Council shall consist of regular members, associate members, honorary members, student members and retired members.

Section 2. Regular Members. Any social worker who fulfills the federally mandated standard for working in the field of end stage renal disease, and who provides direct or indirect service in this field shall be eligible for regular membership. Retired members can choose to remain as a Regular Member or can choose to pay a lesser membership fee as a Retired Member.

Section 3. Associate Members. Any social worker living or working outside the United States or any allied health professional interested in the field of end stage renal disease shall be eligible for associate membership. In addition, those persons supporting the purposes of the Council and those rendering special services to the Council shall be eligible for associate membership.

Associate members may vote, but shall not hold office or act as Chairperson of a Committee.

Section 4. Student Any student is eligible for membership but is not eligible to vote or hold office.

Section 5. Honorary Members. Anyone may be awarded honorary membership upon recognition of special services to the Council for unusual work in the field of interest of the Council. They shall not have the privilege of voting, holding office or serving as a Chairperson of a Committee unless they also qualify for Regular Membership. They shall not be required to pay annual dues.

Section 6. Retired Members – Any social worker who previously fulfilled the federally mandated standard for working in the field of end stage renal disease providing direct or indirect service, and is now retired, is eligible for membership. The retired social worker is not eligible to vote or hold office. The dues for the Retired Member shall be the same as for a Student member.

ARTICLE IV: CHAPTERS

Section 1. Chapters of the Council may be formed according to criteria determined by the Executive Committee of the Council.

ARTICLE V: EXECUTIVE COMMITTEE

Section 1. Purpose. Between the annual meetings, the purposes of the Council shall be carried out by an Executive Committee.

Section 2. Composition. The Executive Committee shall consist of the Chairperson, Chairperson-Elect, Immediate Past Chairperson, Membership Chairperson, Publications Chairperson, Clinical Nephrology Program Chairperson and Co-Chairperson, Professional Education Chairperson and Regional Representatives of the five National Kidney Foundation Regions.

Section 3. Officers. The officers of the Council shall be a Chairperson, Chairperson-Elect, and Immediate Past Chairperson. The Chairperson and Chairperson-Elect shall be elected in odd numbered years for a two-year term. The Chairperson must have at least two (2) years of experience on the Executive Committee. Previous CNSW Executive Committee experience is preferred for the Chairperson-Elect position. Alternatively, prior experience or knowledge working with CNSW or National Kidney Foundation boards and programs, along with a letter of support from the candidate's CNSW Regional Representative, will suffice. At the end of the Chairperson's two-year term of office, the Chairperson-Elect will automatically assume the Chairperson position for a two-year term. The previous Chairperson will become Immediate Past Chairperson. The Immediate Past Chairperson's term on the Committee shall be for two (2) years following his/her term as Chairperson of the Council.

Section 4. Chairpersons/Regional Representatives. Membership Chairperson and Regional Representatives of I&V and III will be elected in even numbered years for a two- year term. Regional Representative of II&V will be elected in odd numbered years for a two-year term. The Clinical Nephrology Program, Publications and Professional Education Chairpersons and Co-Chairpersons will be appointed by the Chair with the approval of the Executive Committee. The term of office of such appointee shall continue for two years, with a possible reappointment to additional terms at the discretion of the Chairperson. Region Representatives must live in the NKF/CNSW region from which they are elected.

Section 5. Election of Executive Committee. The Executive Committee shall be nominated by the Nominating Committee of the Council. The Nominating Committee shall seek suggestions from all categories of membership. The Immediate Past Chairperson of the Council shall serve as the Chairperson of the Nominating Committee. If possible, at least two nominees shall be presented for each office.

The ballots bearing the names of the nominees and offices for which they have been nominated shall be available for electronic voting. Members will be notified by postcard and/or the CNSW listserv, as well as through *RenaLink*, on instructions for online voting. CNSW members in good standing may vote only for the Region Representative for the region in which they reside.

Elections shall be by majority vote of those members who vote in the election. In the event of a tie vote for any Executive Committee position, no less than five members of the CNSW Executive Committee will vote by secret ballot. To maintain an odd number of votes, as needed, the Nominations Chair will either vote or abstain from voting. The Nominations Chair will tally the votes and announce the winner. Any Executive Committee member who is a candidate in the tie vote will abstain from voting to break the tie.

Announcement of results shall be at the clinical meeting, in CNSW publications and on the CNSW general membership listserv.

Section 6. Term of Office. Each member of the Executive Committee shall serve for a two-year term. The term shall commence upon such officer's installation at such annual business meeting. Each officer shall be eligible for reelection for not more than one additional term of office in the same position consecutively. If the officer is first appointed to fill a vacant position, she/he is eligible for re-election twice to that same position consecutively. The Chairperson and Chair-Elect cannot run for re-election to the same position for consecutive terms.

Section 7. Vacancy in Office. In the event of a vacancy in any elected office, except Chairperson, the

Executive Committee shall elect a successor from nominees selected for such office by the Nominating Committee. The appointee to fill such a vacancy shall serve until the next election. In the event the Past Chairperson cannot fulfill their duties, the Executive Committee will appoint an individual to complete the term and fulfill the duties of the office of Past Chairperson,

If the office of the Chairperson should become vacant before completion of a two-year term, the Chairperson's duties shall be passed on to the Chairperson-Elect for the remainder of that term.

Section 8. Eligibility for Office. Regular members shall be able to seek and hold elected office only as long as he/she meets the requirements for regular membership. If the regular membership requirement cannot be met, the officer may remain in the office for no more than a four-month transition period. Regular members who have previously provided direct services (that meet the federally mandated standard) for at least two of the past ten years are eligible to seek and hold office if presently providing indirect service or recently retired. Indirect services will be interpreted as MSWs who work in the ESRD arena providing patient education to ESRD patients, MSWs who are renal administrators, MSW supervisors of nephrology social workers who meet the federally mandated standard, MSWs who are ESRD Network social workers, MSWs pursuing advanced degrees, etc. All candidates must demonstrate, to the nominating committee, knowledge of the current issues in nephrology social work practice.

Section 9. Removal From Office. An officer may be removed from office for nonperformance of duties as outlined in the Position Objectives or actions contrary to the interests of the Council. A 2/3 vote of the Executive Committee and official notification by the Chairperson of the Council is required.

ARTICLE VI: AD HOC COMMITTEES

The Chairperson of the Council may appoint Ad Hoc Committees as it may be deemed necessary. The Chairperson and members of such Committees shall serve from the date of their appointment until the next annual meeting of the Council at which time such Committee may again be appointed by the Chairperson. All Regular Members in good standing are eligible to serve on an Ad Hoc Committee.

ARTICLE VII: DUES

The Council is a nonprofit organization and any dues collected shall be utilized only for operational and educational purposes. Council membership (which includes membership in the National Kidney Foundation) is dependent upon paying the assessed annual dues of professional members.

ARTICLE VIII: GENERAL

Section 1. Ru1es and Regulations. The Rules and Regulations may be amended by vote conducted by mail prior to the annual meeting and the results announced at the annual meeting.

Voting may also occur electronically. Changes in the Rules and Regulations may be proposed by recommendation of the Executive Committee or the Rules and Regulations Committee. Members may propose changes to the Rules and Regulations through their Region Representative.

Section 2. Policy. Policy is a definite course or method of action selected to guide and determine present and future major decisions within the framework of the Rules and Regulations. All policy must be proposed through the Executive Committee and ratified by the majority of the return vote of the membership. Operational guides can be decided upon by the Executive Committee without membership approval to handle the day-to-day workings of the Council.

Section 3. Conduct of Business In the event that the operation of the Council has procedural questions, Robert's Rules of Order shall govern to the extent compatible herewith.

Section 4. Minutes and Communication. The minutes of the Executive and all Committees shall be open to inspection by the membership. Committees may freely communicate with the membership at large via any CNSW Newsletter.

Section 5. Research Grants. The Chairperson-Elect shall have the responsibility of chairing the Research Grants Committees While in office; the Chairperson-Elect shall not be eligible for a research grant.

Section 6. Quorum. Six (6) members of the Executive Committee present at any Executive Committee meeting or Executive Committee conference call shall constitute a quorum for all purposes, and the action of the majority of the members present shall be the actions of the CNSW. For future reference a Quorum is defined as one-half the number of members of the Executive Committee plus one more member.

April 2014 Reviewed and Accepted
NKF-CNSW Executive Committee
SCM14 in Las Vegas, NV

NKF, CNSW, and CHAPTER RELATIONSHIPS

The Council of Nephrology Social Workers, whose membership and chapters are represented by the CNSW Executive Committee, is a professional council of the National Kidney Foundation and serves in an advisory capacity to the Foundation. As a result of this affiliation with NKF, CNSW benefits from a wide range of rights and privileges while also assuming certain responsibilities to work within defined organizational policies and constraints.

Working within the structure of the NKF, CNSW assumes responsibility for:

1. Acknowledging and participating in furthering the goals of the Foundation;
2. Designating the CNSW Chair (and other Executive Committee members as appointed by the Chair) to serve on appropriate NKF Committees;
3. Submitting all CNSW position papers, comments on legislation, proposed standards, etc., to appropriate NKF committees for consideration, after the review and approval of the CNSW Chairperson and Executive Committee; and
4. Submitting all CNSW publications; i.e., *RenaLink, Journal of Nephrology Social Work,* pamphlets, etc. to the Council Chair and other appropriate NKF representatives for review.

In the same manner that national CNSW must work within the structure of the NKF, it is important that CNSW Chapters are aware of and responsive to the implications of being a part of a larger organization. It is through a mutuality of goals and ongoing collaborative efforts that CNSW and its Chapters enhance their strength, accomplish their objectives, and develop relevant, effective programs and projects. Thus, while it is appropriate for Chapters to address professional, practice, and community resource issues of local concern (in keeping with the overall goals of CNSW and in conjunction with local NKF Division and Affiliate offices), issues, positions, or standards that have potentially broader implications must be reviewed and approved by national NKF-CNSW. If Chapter Chairs have questions or concerns, the Region Representative or Membership Chair on the NKF-CNSW Executive Committee should be contacted.

For example, while an individual nephrology social worker may and should respond to legislative concerns, national CNSW and CNSW chapters cannot officially write in support of/or against legislative or regulatory proposals unless the response is in keeping with the NKF position.

The review and/or approval process ensure appropriate and consistent positions between NKF Committees and Councils, and maintains consistency between national and chapter CNSW positions. In addition, these review processes afford CNSW and/or its chapters an opportunity to secure consultation, additional credibility, and the broad-based support of NKF. By maintaining close cooperative and collaborative relationships, NKF, the national CNSW organization, and local CNSW Chapters are all strengthened in our efforts to effectively address issues of mutual concern.

National
Kidney
Foundation™

NKF ORGANIZATION

The National Kidney Foundation is the leading organization in the U.S. dedicated to the awareness, prevention and treatment of kidney disease for hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of Americans at risk.

In addition to its headquarters office in New York City, the NKF has several locally-based Division and Affiliate offices. A listing of all local offices is available through the National office:

National Kidney Foundation, Inc.
30 East 33rd St.
New York, NY 10016
800-622-9010
212-889-2210
www.kidney.org

Volunteers serve in very important roles in all levels of the organization. Please take the time to become familiar with your local office, and the many services and programs provided through it.

The CNSW is one of the specialty professional councils operating under the aegis of the NKF, along with the Council of Nephrology Nurses and Technicians (NKF-CNNT), the Council on Renal Nutrition (NKF-CRN), and the Council of Advanced Practitioners (NKF-CAP). As NKF is a unique organization which offers professional representation and membership across all disciplines involved in kidney healthcare, Councils have the opportunity for interdisciplinary meetings and planning, for administrative and fiscal management and for a broad-based legitimacy.

6. CHRONIC KIDNEY DISEASE INFORMATION

Beginning July 1, 1973, the Federal government extended Medicare benefits to nearly all patients with chronic kidney failure. Benefits may also be available through insurance policies, state aid programs, state renal programs, or certain other agencies. However, because Medicare will probably pay most of the medical bills, a brief discussion of the Medicare program is included.

To access the booklet ***Medicare Coverage of Kidney Dialysis & Kidney Transplant Services***, revised April 2012, call 1-800-633-4227 and ask for CMS Product #.10128.

How to Enroll in Medicare

To obtain Medicare, one must apply and the patient or certain family members must meet specific work requirements. The local Social Security office can supply applications and more detailed information about the work requirements.

What Medicare Does Not Pay

Although Medicare will pay for a large portion of the medical bills (including services not related to treatment of kidney disease), many services are NOT covered by Medicare. These include take-home drugs, private duty nursing, eyeglasses, hearing aids, most cosmetic surgery, most dental work, and various other services. Therefore, one will often hear Medicare payment discussed in terms of "covered" services, and it is important to remember that not all services are covered by Medicare.

With Medicare, the patient shares in the cost of medical treatment by paying "deductible" and "coinsurance" amounts. These are discussed in more detail later in this section.

When Medicare Begins

There is a 3-month waiting period before Medicare begins for in-center hemodialysis patients. However if a patient starts training for home dialysis (peritoneal or hemodialysis) or receives a transplant during this time, the waiting period is cancelled. Medicare will begin the first month the patient starts treatment.

It is important to note that if a patient is covered by an employer group health plan (EGHP), Medicare will be the secondary payer during an initial period of up to 30 months from the date of Medicare eligibility. At the end of this 30-month period, Medicare becomes the primary payer.

At times a patient may choose to defer enrollment in Medicare during the coordination of benefits period (the 30 month period from the date of Medicare eligibility). This typically occurs when the EGHP provides 100% coverage during this period. When a patient is considering deferring Medicare, the EGHP benefits specialist should be contacted by the patient or the social worker to verify coverage.

When Medicare Ends

If a patient regains kidney function and no longer needs dialysis, benefits will stop 12 months after dialysis ends. If a successful transplant is received, benefits will end 36 months after the date of the transplant.

Kinds of Benefits

There are three primary types of Medicare benefits: Part A (Hospital insurance), which pays inpatient hospital bills, Part B (Medical insurance), which pays many other expenses, such as outpatient hospital services, physicians' fees, etc., and Part D which covers prescription medications. Dialysis treatments are covered under Part B.

If a person qualifies for Medicare, he or she will automatically receive Part A. Part A benefits are free, but one must apply for and pay a monthly premium for Part B.

The amount of the Part B premium may increase on January 1 of each year. Social Security will either deduct this premium from the patient's monthly benefit check or send him a separate bill, generally on a quarterly basis. The local Social Security office can provide more information about payment of the premium.

Part A Benefits

Because Part A pays for inpatient services, the benefits are stated in terms of the "number of days available." These days are figured for a period of time called a "benefit period" or "spell of illness." A benefit period ends when the patient has been out of a hospital or nursing home for 60 consecutive days. During each benefit period, Medicare will pay for 90 days of care as follows:

1. For the first 60 days, Medicare pays all covered medical expenses except a Part A deductible. The amount of the deductible is determined by the Federal government and may increase each year.
2. For the next 30 days ("coinsurance days"), Medicare pays all covered medical expenses except a daily Part A coinsurance amount.

After a patient has been out of the hospital or nursing home for 60 consecutive days, his benefits are renewed. When he/she begins a new benefit period, he will again have 90 days of Medicare coverage.

In addition to the 90 days available during each benefit period, Medicare allows each patient 60 Life Time Reserve (LTR) days. These days are given only once during a lifetime and, when used, are not renewed. When LTR days are used, Medicare pays all covered medical expenses except a daily Part A coinsurance amount.

If a patient uses all 150 days available during one benefit period (60 regular days, 30 coinsurance days, and 60 LTR days) and needs to return to the hospital, he or she will have exhausted his Part A benefits and Medicare will not cover any expenses under Part A.

Part B Benefits

Because Part B pays for outpatient hospital services and physicians' fees, benefits are stated in terms of "covered charges" and are figured on a yearly basis. During each calendar year, a patient must pay a Part B deductible, after which Medicare will pay 80% of "covered charges" at a rate considered "reasonable and customary." The amount not paid by Medicare is due from the patient or coinsurance.

The Omnibus Budget Reconciliation Act of 1986 (Public Law 99-509) contained provisions for Medicare payment of immunosuppressive drugs following a Medicare-covered organ transplant.

Immunosuppressive Drug Coverage

Transplant recipients whose transplant surgery was covered by Medicare are eligible for immunosuppressive drug coverage. Generally, under this benefit, payment will be made for 80% of the cost of self-administered immunosuppressive drugs that are specifically labeled and approved for marketing as such by the Food and Drug Administration. This benefit is subject to the Part B deductible and coinsurance provision. For those patients whose Medicare entitlement is ESRD **only,** coverage will be limited to 3 years after the date of the transplant procedure. If Medicare entitlement is based on age or disability, coverage for immunosuppressants is extended for the life of the transplant. From surgery until hospital discharge, payment for these drugs are included in Medicare's Part A payment to the hospital.

Part D Benefits

Beginning in 2006, all people with Medicare have access to a prescription drug benefit. The open enrollment period for the Medicare Part D benefit is from October 15 through December 7, each year. In addition to the open enrollment period, all **new** Medicare beneficiaries have a 7-month period to enroll in the benefit, which includes the 3 months prior to their 65th birthday, the month of their birthday, and the 3 months following their birthday. The benefit is offered by private plans that have been approved by Medicare. There are two basic types of plans:

- Medicare Prescription Drug Plan (PDPs) — which is a free-standing drug plan that complements original Medicare, some Medicare Cost Plans, some Medicare Private fee- for-service (FFS) Plans, and Medicare Medical Savings Account (MSA) Plans.
- Medicare Advantage Plan (like an HMO or PPO) — which provides drug coverage as part of a complete healthcare coverage plan and is delivered through a managed care entity (e.g. HMO, PPO). Medicare Advantage Plans with prescription drug coverage are sometimes called MA-PDs. Patients must have Part A and Part B to join a Medicare Advantage Plan.
- Beneficiaries are able to choose among a large number of drug plan options offered by a variety of different sponsors in most local areas. The drug plan options differ in many ways including monthly premium, deductible, co-payments/coinsurances, coverage gaps, formulary, pharmacies employed and whether it is a PDP or MA-PDP. As of 2014, the standard option has a benefit structure consisting of a $310 deductible, a 25 percent copayment for the next $2850 of covered prescription drug costs, then a coverage gap until out-of pocket drug expenses reach $4500, at which point the patient begins to pay no more than a 5 percent copayment and the program pays at least 95% for all remaining prescription drug costs for the year.
- Beneficiaries with incomes below $17,505 (single) and $23,595 (couple) in 2014, with limited assets, will qualify for help to pay for the Part D benefit. These values represent 150% of Federal Poverty Guidelines. These individuals should contact Social Security at 1-800- 772-1213 or online to apply for this extra help. Dual eligibles — beneficiaries who qualify for both Medicare and Medicaid — will pay no monthly premium, have no deductible or coverage gap and pay only a very low co-payment.
- It is important for Medicare beneficiaries to consider enrolling in a Medicare drug plan when they become eligible if they do not already have "creditable" drug coverage from another source or they will have to pay a penalty if they later decide to enroll in a Medicare drug plan. The late enrollment penalty is calculated by multiplying 1% of the "national base beneficiary premium" ($31.08 in 2012) times the number of months the beneficiary delayed joining a Part D program and is applied to the monthly premium. The penalty will stay in effect as long as the beneficiary

remains in a Part D plan.

For more information, visit

- **Your Guide to Medicare Prescription Drug Coverage**
- **Closing the Coverage Gap**
- Medicare's booklet on **Who Pays First**
- Medicare and EGHP **Coordination of Benefits calculator**

ESRD NETWORKS

Federal legislation relating to ESRD established Networks to serve as liaisons between the federal government and the providers of ESRD services. The Networks' functions include monitoring quality of care indicators and maintaining timely, complete data on the ESRD program. At present there are 18 Networks in the U.S. (refer to Directory of ESRD Networks below).

The Networks' responsibilities include but are not limited to the following:

1. Encourage the use of treatment settings most compatible with the successful rehabilitation of patients.
2. Encourage self-dialysis or transplantation of the maximum practical number of patients who are medically, socially, and psychologically suitable for such treatment.
3. Encourage patient and staff participation in vocational rehabilitation programs.
4. Provide a patient grievance mechanism.
5. Collect, validate, and analyze data concerning patients and their treatment.
6. Provide accurate, timely data to local, state, and federal government agencies and to the public.
7. Develop criteria and standards relating to quality and appropriateness of patient care.

ESRD Network activities are aligned with the Department of Health and Human Services (HHS) National Quality Strategy (NQS), the Centers for Medicare & Medicaid Services (CMS) Three Aims, and other CMS priorities designed to result in improvements in the care of individuals with ESRD. The ESRD Networks promote positive change relative to the Three Aims:

- Better care for the individual through beneficiary and family centered care
- Better health for the ESRD population
- Reduced costs of ESRD care by improving care

Directory of ESRD Networks

Network 1
IPRO: Network of New England
(Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont)
(203) 387-9332
www.networkofnewengland.org

Network 2
IPRO
(New York)
(516) 209-5578
http://www.ipro.org/index/esrdny

Network 3
Quality Insights Renal Network 3
(New Jersey, Puerto Rico, Virgin Islands)
(609) 490-0310
www.qirn3.org

Network 4
Quality Insights Renal Network 4
(Delaware, Pennsylvania)
(610) 254-2418
www.qirn4.org

Network 5
Mid-Atlantic Renal Coalition [MARC]
(Virginia, West Virginia, Maryland, District of Columbia)
(804) 320-0004
www.esrdnet5.org

Network 6
Southeastern Kidney Council
(Georgia, North Carolina, South Carolina)
(919) 855-0882
http://www.esrdnetwork6.org

Network 7
FMQAI: The Florida End Stage Renal Disease (ESRD) Network
(Florida)
(813) 383-1530
www.fmqai.com/esrd.aspx

Network 8
Network 8
(Alabama, Mississippi, Tennessee)
(601) 936-9260
http://www.esrdnetwork8.org

Network 9/10
The Renal Network, Inc.
(Delaware, Illinois, Indiana, Kentucky, Ohio, Pennsylvania)
(317) 257-8265
www.therenalnetwork.org

Network 11
Renal Network of the Upper Midwest, Inc
(Minnesota, Michigan, North Dakota, South Dakota, Wisconsin)
(651) 644-9877
www.esrdnet11.org

Network 12
Heartland Kidney Network
(Iowa, Kansas, Missouri, Nebraska)
(816) 880-9990
www.heartlandkidney.org

Network 13
FMQAI: End Stage Renal Disease Network 13
(Arkansas, Louisiana, Oklahoma)
(405) 942-6000
www.network13.org

Network 14
ESRD Network of Texas.
(Texas)
972-503-3215
www.esrdnetwork14.org

Network 15
Intermountain ESRD Network, Inc.
(Arizona, Colorado, Nevada, New Mexico, Utah, Wyoming)
303-831-8818
www.esrdnet15.org

Network 16
Northwest Renal Network
(Alaska, Idaho, Montana, Oregon, Washington)
206-923-0714
www.nwrenalnetwork.org

Network 17
Western Pacific Renal Network
(American Samoa, Guam, Mariana Islands, Hawaii, Northern California)
415- 897-2400
www.esrdnet17.org

Network 18
FMQAI: ESRD Network 18 of Southern California
(Southern California)
323-962-2020
www.esrdnetwork18.org

NATIONAL KIDNEY FOUNDATION

Who We Are

The National Kidney Foundation is the leading organization in the U.S. dedicated to the awareness, prevention and treatment of kidney disease for hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of Americans at risk.

What We Do

- **Educating** Americans through public awareness initiatives about kidney disease and ways to reduce their risk.
- **Empowering** those at risk to take action at free, local kidney health screenings.
- **Supporting** kidney patients, organ donors, and their families—online, on the phone toll-free, and through personal peer-mentoring.
- **Advocating** as the voice of the kidney patient in Washington DC to address the organ donor shortage, fund more kidney research, and defend Medicare coverage for kidney disease.
- **Sharing** the latest treatment information and practices with healthcare providers so all patients get the best possible care.

Did You Know?

- 1 in 3 American adults is at high risk for developing kidney disease today. The risk increases to 1 in 2 over the course of a lifetime.
- 1 in 9 American adults has kidney disease—and most don't know it.
- High blood pressure and diabetes are the two leading causes of kidney disease.
- Major risk factors for kidney disease include diabetes, high blood pressure, family history of kidney failure and being age 60 or older.
- Kidney disease kills over 90,000 Americans every year—more than breast and prostate cancer combined.
- African Americans are 3 times more likely to experience kidney failure.
- Every day 13 people die waiting for a kidney.

The National Kidney Foundation Dollar

The NKF is a tax-exempt, not-for-profit, 501(c)(3) organization. All contributions to the Foundation are tax deductible to the fullest extent of the law. Approximately 80 cents of every dollar donated directly supports programs and services. NKF meets the comprehensive standards of America's most experienced charity evaluator, the Better Business Bureau Wise Giving Alliance. For more information, review the **2013-2018 Strategic Plan** and the **Annual Reports and Financials**, found on the **kidney.org** website.

PROGRAM HIGHLIGHTS (from the *2013 Annual Report*)

AWARENESS

Your Kidneys and You

In this new community-based initiative launched in 2013,trained volunteers deliver presentations to members of the general public, highlighting the role of the kidneys in the body, educating about healthy lifestyle and risk reduction, and encouraging individuals to take action by talking to their doctor about testing for kidney disease.

Public Education

The National Kidney Foundation remains the leader in educating the public about kidney disease and its risk factors. In 2013, kidney.org was the highest-ranked website in searches for "kidney disease," accessed by more than four million constituents. In addition, research published in the NKF's journal, American Journal of Kidney Diseases, found that 59% of Americans will develop kidney disease in their lifetime. The NKF used this study to drive awareness and issue recommendations for annual screening with a simple urine test for those over 60 as well as others at risk. The release of this study generated over 100 million media impressions.

Kidney Walk

Kidney Walk, the signature event of the NKF, is the nation's largest walk to fight kidney disease. Held in 81 communities around the country, the event raises awareness and funds lifesaving programs that educate and support patients and their families. Last year, Kidney Walks attracted 80,000 walkers, 5,000 teams, and over 200,000 donors who got the word out about kidney disease and risk factors while raising $8 million

PREVENTION

NKF Cares

NKF Cares offers support to more than 10,000 people affected by kidney disease, organ donation, and transplantation each year. Through a toll-free hotline and dedicated email, NKF Cares directly addresses questions from kidney patients and family members from around the United States on a wide variety of topics, including risk reduction, financial impact of kidney disease, nutrition, and treatment options.

KEEP Healthy

A new, community-based initiative, KEEP Healthy offers free kidney health checkups to help people assess their own kidney disease risk. After taking a brief health survey and having blood pressure and Body Mass Index (BMI) measured, participants are offered educational information and consultation with a medical professional. Follow-up recommendations are offered, including healthy lifestyle tips and specific tests to take at the doctor's office.

Chronic Kidney Disease Primary Care Outreach

NKF launched a national initiative to reach primary care practitioners with important information about screening at-risk patients to achieve early detection and prevention of kidney disease. On the local level, our outreach initiatives included a conference for primary care professionals in the Midwest that ultimately benefitted 5,000 patients. In the Greater New York area, an annual conference highlighting the Cardiac-Kidney-Diabetes connection and additional programs on obesity and diabetes drew over 300 doctors, ultimately impacting the health of thousands of patients.

TREATMENT

Advocacy

The NKF continues to be a powerful voice for kidney patients, representing the interests of the kidney community in Washington D.C. every day. This year, NKF met with key members of the federal government to ensure that the Affordable Care Act meets the needs of people with kidney disease, continued to advocate for expanded immunosuppressive drug coverage for transplant recipients, and stood firm against proposed cuts to dialysis care.

Education for Kidney Health Professionals

More than 59,000 healthcare professionals received continuing education from the NKF in 2013 through the Spring Clinical Meetings, online educational programs, and regional symposia. Throughout the year, 39 new continuing medical education courses, both online and live, delivered the most current information to physicians, nurses, dialysis technicians, dietitians, advanced practitioners, and other professionals involved in kidney care. Local professional education programs helped kidney specialists improve the care provided to their patients. As an example, the impact of Kidney Care Education Day in Sioux Falls will be felt by 2,500 patients per week throughout South Dakota, Iowa, Minnesota, and Nebraska.

Research

In 2013, the NKF funded original studies that will evaluate the effect of phosphorus on early-stage kidney patients, identify genetic markers that put people at risk for kidney disease, and test new treatment options to improve long-term transplant survival.

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For information about NKF affiliates, or the NKF Information Center, contact the national office:

National Kidney Foundation, Inc.
30 East 33rd Street
New York, NY 10016
(800) 622-9010
(212) 889-2210
Web site: **kidney.org**

STATE RENAL PROGRAMS

The National Organization for State Kidney Programs, Inc. (NOSKP) is a voluntary organization established in 1980. The purpose of the organization is to help state kidney programs offer the highest quality and most efficient service to individuals with chronic kidney disease.

There are only 15 remaining state kidney programs. Most of them are located in state health departments, although a few operate in state rehabilitation and other agencies and in association with medical schools and universities. The major use of funds is to assist in providing medical care to indigent chronic kidney disease patients. Some of the programs collect epidemiological data and carry out studies and demonstrations. Others are concerned not only with chronic kidney disease, but also the cause and prevention of kidney disease and diagnosis, treatment, and rehabilitation of the kidney patient.

Click here for a list of states with kidney programs, and their contact information.

For further information contact:
National Organization for State Kidney Programs, Inc.
c/o Missouri Kidney Program
Columbia, MO 65211
573-882-2506

AMERICAN KIDNEY FUND

The American Kidney Fund (AKF), founded in 1971, is the leading non-governmental source of direct financial assistance for treatment necessities for needy dialysis and transplant patients. Financial assistance from this organization can be made directly to the patient. The organization will also establish a $100 patient emergency fund that can be maintained at each facility.

Direct patient assistance programs include:

1. Safety Net Program (formerly known as the Individual and Pharmacy Grant Program)
2. Health Insurance Premium Program (HIPP)
3. Financial assistance is also provided through three additional programs:
4. Disaster Relief Program – Help is provided to kidney patients when environmental crises, such as tornado, hurricane, etc., strike their area
5. Pediatric Campership Program – Assists needy children to attend a special kidney camp of their choice.
6. The Genzyme Renal Patient Assistance Program – Provides assistance for those patients who have no other means to obtain Renvela®, such as through insurance or federal, state, or local programs.

In addition to direct patient assistance, the AKF supports:

1. Patient education
2. Public and professional education
    a. Regional conference series for renal healthcare professionals
    b. *Clinical Strategies*, newsletter for renal healthcare professionals
3. Community services
4. Kidney donor development
5. Clinical research

For further information contact:
11921 Rockville Pike, Suite 300
Rockville, MD 20852
Toll-free: (800) 638-8299
www.akfinc.org

AMERICAN ASSOCIATION OF KIDNEY PATIENTS

American Association of Kidney Patients (AAKP) is a voluntary, non-profit organization dedicated to promoting the interest and welfare of kidney patients. It is primarily a patient organization with more than 8,000 members and approximately 20 local chapters. Activities are carried out through the national office, Board committees, and local chapters. These activities include: patient services, patient advocacy, public education and publications.

For additional information contact the national office:
2701 N. Rocky Point Drive, Suite 150
Tampa, FL 33607
(813) 636-8100
(800) 749-AAKP
info@aakp.org
http://www.aakp.org

NATIONAL KIDNEY AND UROLOGIC DISEASES INFORMATION CLEARINGHOUSE

The NKUDIC is a service of the National Institutes of Diabetes and Digestive and Kidney Diseases, part of the National Institutes of Health, under the U.S. Public Health Service. Authorized in 1987, the clearinghouse provides information about diseases of the kidney and urologic system to people with such afflictions and to their families, health care professionals and the public. The clearinghouse answers inquiries; develops, reviews, and distributes publications; and works closely with professional and patient organizations and government agencies to coordinate resources about kidney and urologic diseases.

Government publications are not copyrighted, so you may freely reproduce them.
http://kidney.niddk.nih.gov/

DIALYSIS PATIENT CITIZENS (DPC)

DPC is a nationwide, non-profit, patient-led dialysis organization with membership open only to dialysis and pre-dialysis patients and their families. DPC is working to improve the quality of life for all dialysis patients through education and advocacy, and promoting empowerment.

They offer a newsletter, blog and educational materials.

900 7th Street NW, Suite 670
Washington, DC 20001
(866) 877-4242
www.dialysispatients.org

THE WILLIAM B. DESSNER MEMORIAL FUND

The William B. Dessner Memorial Fund was founded in January 1973 in memory of Mr. William B. Dessner, a former dialysis patient.

The purpose of the Fund is to provide financial assistance ($50 per patient) to kidney dialysis and transplant patients in the United States. Emergency needs approved for funding include but are not limited to assistance with medication, food, utility bills, and general cost of living expenses.

The majority of the requests received come from social workers on behalf of their patients. There is no formal application form; an explanatory letter with details of the patient's situation and needs will suffice. The requests are answered promptly with a check mailed directly to the patient.

One can contact the Fund at the following address:

The William B. Dessner Memorial Fund, Inc.
2200 Colorado Ave. Suite #503
Santa Monica, CA 90404
(310) 264-1525

SCHOLARSHIPS FOR KIDNEY PATIENTS

Local NKF offices may offer scholarship for local patients. Patients should also check out resources for paying for education on the **Department of Education's website**.

Other resources:

- **Kidney & Urology Foundation** (national)
- **Transplant Recipients International Organization** (members/several states, also includes a list of other scholarships)
- **Dialysis Scholarship Fund**
- **Izzie's Gift of Hope Foundation**
- "**Financial Aid for Disabled Persons and their Families 2012-2014**" from Resource Service Press
- **National Center for Parents with Disabilities** – scholarships specifically for high school seniors or college students who have parents with disabilities:

SUMMER CAMPS FOR DIALYSIS AND TRANSPLANT PATIENTS

Summer camp is an important element of any childhood and can be especially so for children living with ESRD. Camp offers social skills, independence, a sense of belonging, and opportunities to try new things and expand horizons.

Three types of camp experiences are available for children living with ESRD:

> **Family Camps** offer camp experiences for the whole family. Medical staff is available, but parents remain responsible for their child's care and treatment during camp.
>
> **Dialysis/Transplant Camps** offer children on dialysis or who have had a transplant to go to camp with other children with ESRD. Camp is staffed by medical providers and is offered exclusively to children with special health care needs.
>
> **Integrated Camps** are traditional youth camps that offer one or two sessions staffed by dialysis and transplant providers allowing children with ESRD to attend camp alongside their healthy peers.

The **American Kidney Fund Summer Enrichment Program** offers financial assistance for children and their families in attending a kidney camp of their choice. Individual camp programs may also offer scholarships to qualifying children. For information and a list of participating camp locations contact:

RENAL SUPPORT NETWORK

The Renal Support Network (RSN) is a nonprofit, patient-focused, patient-run organization that provides non-medical services to those affected by chronic kidney disease (CKD). RSN strives to help patients develop their personal coping skills, special talents, and employability by educating and empowering them (and their family members) to take control of the course and management of the disease. A vital role of RSN is to provide lawmakers and policymakers with the patients' perspective on the needs and capabilities of people with CKD.

The Renal Support Network was founded in 1993 by Lori Hartwell—a kidney disease survivor since 1968—to instill health, happiness, and hope into the lives of those affected by chronic kidney disease (CKD).

The influence of this patient-run organization—which started out as a local "grassroots" effort—now extends across America. RSN's mission is to identify and meet the non-medical needs of people affected by CKD, whether they are in the early stages of the disease, on dialysis, or living with a kidney transplant.

RSN accomplishes this by providing service, support, and advocacy to patients and their families, and by building coalitions within the renal community. RSN—a nonprofit, patient-focused, patient-run organization—strives to help CKD patients develop their personal coping skills, special talents, and employability by educating and empowering them, as well as their family members, to take control of the course and management of the disease.

1311 N. Maryland Avenue
Glendale, CA 91207
(818) 543-0896
(866) 903-1728
www.rsnhope.org

LIFE OPTIONS

Life Options is a program of research, research-based education, and outreach founded in 1993 to help people live long and live well with kidney disease. A national panel of doctors, researchers, patients, nurses, social workers, dietitians, and ESRD Network directors reviews all Life Options materials and helps guide research.

Life Options has extensive resources for kidney professionals and patients, including Kidney School, numerous materials on patient rehabilitation, Home Dialysis Central, and KDOQI Complete.

http://lifeoptions.org/

NATIONAL KIDNEY DISEASE EDUCATION PROGRAM (KDEP)

The National Kidney Disease Education Program is a National Institutes of Health program that provides patients and professionals with educational materials about kidney disease and its treatments.

http://nkdep.nih.gov

MEDICATION ASSISTANCE PROGRAMS

- **Partnership for Prescription Assistance**
- **RxAssist**
- **The Medicine Program**
- **Needy Meds**

PEDIATRIC RESOURCES

Pediatric dialysis and transplant patients have unique needs and issues. Below are some general resources important for pediatric patients. Each of these resources may have local state or regional contacts

- ***Help for Children from Infancy to Adulthood***
  This is a directory of national organizations, agencies, hotlines and other resources.
  It is available from:

  Rocky River Publishers
  P.O. Box 1679
  Sheperdstown, WV 25443
  (304) 876-2711

- ***The Association for the Care of Children's Health***
  This organization focuses on children who need special health care. It has publications for children and families, meetings and a regular newsletter. For information, contact:

  3615 Wisconsin Avenue, NW
  Washington, DC 20016
  (202) 244-1801

- ***The Starlight Foundation***
  This foundation grants the wishes of chronically ill children internationally who are between the ages of 4 and 18. For information, contact:

  12424 Wilshire Boulevard, Suite 1050
  Los Angeles, CA
  (800) 274-7827

- ***Children's Organ Transplant Association***
  For information, contact:
  2501 COTA Drive
  Bloomington, IN 47401
  (812) 336-9972

- ***Make-A-Wish Foundation***
  For information, contact:
  (800) 722-WISH

- ***State Bureau of Children's Special Needs* (formerly Crippled Children's Program)**
  For location and phone number, contact local health departments.

WEBSITES:

- **Pediatric Toolkit,** from NKF-CNSW Professional Resources
- **Kidney Kids**
- **KidsHealth**
- **kTalk: an e-community for young people with kidney disease**
- **Kidney Directions: KD Kids**
- **Nephkids Cyber-Support Group for Parents of Children with Kidney Disease**

BOOKS:

Bock, G., Ruley, E., & Moore, M. (1993). *A parents' guide to kidney disease.* Minneapolis: University of Minnesota Press.

Zukerman, E., Ingelinger, J. (1997). *Coping with prednisone.* New York, NY: St. Martin's Press.

Clermont, C. & Clermont, J. *The ABCs of pee dee with Zee.*
(available through www.kidneystuff.com)

Waibel, S.R. (2012). *Rudy's incredible kidney machine*. Published by W.D. Waibel on 8/25/12.
(available through www.rudyslittleworld.com)

Waibel, S. R. (2012). *Rudy gets a transplant*. Published by W.D. Waibel on 8/11/12.
(available through www.rudyslittleworld.com)

National Kidney Foundation of Indiana, Inc. *Adventures at Riverside Park: A story about pediatric dialysis.* (Available through National Kidney Foundation of Indiana, Inc., (800) 382-9971, www.kidneyindiana.org).

National Kidney Foundation. ***Children With Chronic Kidney Disease: Tips for Parents***. Available through NKF, (800)622-9010 or (212) 889-2210, www.kidney.org.

American Kidney Fund. *Kidney Disease in Children Kidneys for Kids "The Kid," a booklet written for children*. Available through AKF, (800) 638-8299 or (301) 881-3052, www.kidneyfund.org.

TRANSIENT RESOURCES

Transient is the term used for "traveling patients" in the dialysis arena. Social workers can encourage patients to travel as part of their rehabilitation. Social workers can also work with their interdisciplinary teams to identify the best team member to oversee transient needs for patients (both incoming and outgoing), as such arrangements require a great deal of paperwork and clerical duties that is likely beyond the time available by social workers.

A listing of facilities willing to accommodate traveling dialysis patients can be found in the following:

- "The List," published annually by *Dialysis and Transplantation*
- **Dialysis Centers**
- **Dialysis Finder**
- **The Nephron Information Center**

TRANSPLANT RESOURCES

Professional Organizations

- **Council of Nephrology Social Workers (CNSW)**
- **Society of Transplant Social Workers**
- **North American Liver Transplant Social Workers**

Educational Materials for Patients

- **National Kidney Foundation**
  A variety of kidney transplant recipient and donor related materials
- **Lifesource**: Writing to Donor Families
- **UNOS**: Financing Transplantation: What Every Patient Needs to Know

Transplant-Related Internet Resources for Staff and Recipients

United Network for Organ Sharing (UNOS)
Patient statistics, news, information and links to resources

National Kidney Foundation
Information for recipients and donors, disease specific information, resources and events for patients

American Association of Kidney Patients (AAKP)

American Kidney Fund

Center for Medicare and Medicaid Services (CMS)

Children's Organ Transplant Association

Department of Health and Human Services

Health Information Library

HealthWell Foundation

Kidney Helper Charts

Life Options Rehabilitation Resource Center

National Institute of Diabetes and Digestive and Kidney Disease

NIDDK: Health Resources
National Kidney and Urologic Disease Information Clearinghouse

Renal Support Network (formerly iKidney)
Health library

Social Security Administration

The Nephron Information Center

Transplant Health

Medscape weekly subscription transplant information

Transplant Recipients International Organization, Inc. (TRIO)

American Society of Transplantation
Patient education, publications and information about upcoming scientific meetings

University of Michigan Transplant Center: All About Transplant

National Foundation for Transplants
Assists patients with fundraising

Help Hope Live (formerly National Transplant Assistance Fund)
Assists with fundraising guidance

Travel Resources to Assist Transplant Recipients

American Organ Transplant Association (AOTA)

National Air Transport Helpline

Air Life Line

Life Link

TRIO

Transplant Living

Southwest Airlines Medical Grants

7. INTERNET RESOURCES FOR SOCIAL WORKERS

www.kidney.org/professionals/CNSW
Includes the CNSW mission statement, goals and objectives, membership information, CNSW officers, professional education, research grants, and links to related Internet sites.

www.naswdc.org
The National Association of Social Workers Web site includes professional education, career opportunities, publications, advocacy, code of ethics, chapters, and links to related Internet sites.

www.op.nysed.gov/prof/sw
The World Wide Web Resources for Social Workers is jointly sponsored by New York University's Ehrenkranz School of Social Work and the Division of Social Work and Behavioral Medicine, Mount Sinai School of Medicine. The primary focus is the direct link to full text, professionally relevant documents.

www.aswb.org
The Association of Social Work Boards provides information on licensing requirements and testing procedures for each state.

www.bls.gov
This site provides a description of what social workers do, social workers education and certification/licensure, salary ranges, and links to other resources.

www.esrdnetworks.org
Forum of ESRD Networks Web site contains information regarding the Networks' Scope of Work, SIMS database project, patient and facility education articles, U.S. dialysis unit database.

www.nraa.org
National Renal Administrators' web site.

www.sti-innovations.com
Symptom Targeted Interventions outlines a therapeutic method for social workers to help patients manage depression using brief interventions.

health.nih.gov
The Combined Health Information Database is a bibliographic database produced by health-related agencies of the Federal Government. This database provides titles, abstracts, and availability information for health information and health education resources. Using a "detailed search," one can find information that is available in many languages and formats.

www.cms.gov
The main Web site for the Center for Medicare and Medicaid Services (CMS). Contains links to the ESRD program, Medicare, and other CMS related sites, SSA, legislative information, publications including information on Medicare coverage of kidney dialysis and transplant services. This site houses Dialysis Facility Compare, facility-specific information for consumers about dialysis facilities.

www.unos.org
United Network for Organ Sharing. This organization maintains the recipient registry for all patients in the U.S. who are waiting for donated organs, and facility-specific transplant success rates. Publications include information on transplantation for patients and professionals.

www.medicare.gov/nursinghomecompare
CMS's Nursing Home Search National Nursing Home Database. This site provides understandable information about the performance of every Medicare and Medicaid certified nursing home in the U.S. Contains summary information about nursing homes' performance during the last state inspection.

cihi.ca
Canadian Institute of Health Information Web site. Information on Canada's Senate Democratic Technology and Communications Committee.

www.ssa.gov
Official Web site of the Social Security Administration

www.usrds.org
National data system which collects, analyzes, and distributes information about ESRD in the U.S. The USRDS is funded directly by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) in conjunction with the Center for Medicare and Medicaid Services (CMS). The USRDS Coordinating Center is operated under a contract with the Minneapolis Medical Research Foundation.

www.nlm.nih.gov
MEDLINE, the world's most extensive collection of published medical information including free abstracts of articles from many journals and access to full articles for a fee. Coordinated by the National Library of Medicine.

www.healthfinder.gov
HealthFinder is a service of the U.S. Department of Health and Human Services. This user-friendly site is a gateway to help consumers find health and human services information quickly.

www.niddk.nih.gov
National Institute of Diabetes and Digestive and Kidney Diseases. Health information and educational programs; information regarding patient recruitment for NIDDK studies/research. Information clearinghouse for NIH publications, annotated bibliographies, directories, and topical literature searches.

www.nih.gov/health
The National Institute of Health information page provides a single access point to the consumer health information resources of the NIH.

cihi.ca/wedo/hscorr.htm
Canadian Organ Replacement Register (CORR). Information regarding the level of activity and outcomes of dialysis and Transplantation throughout Canada.

www.hhs.gov
Department of Health and Human Services.

www.renalweb.com
Dialysis industry Web site and online "daily newspaper" for the dialysis/nephrology community. Features Dialysis Yellow Pages, discussion forums for patients and renal professionals, and resource listings. RenalWEB has a moderated discussion forum for social workers.

www.eneph.com
Official Web site of the journal *Dialysis and Transplantation* archives and article indexes, renal care news, renal care resource information, and "The List" of facilities accepting traveling dialysis patients.

www.nephnews.com
Web site for the publication, *Nephrology News and Issues*.

www.dialysisfinder.com
A comprehensive resource for patients and staff to use in locating clinics across the U.S. for transient dialysis or transfer. This program will locate clinics in a specified geographical area, and provide maps, and directions, and contact information.

www.lastacts.org
Information regarding end-of-life issues.

www.partnershipforcaring.org
Partnership for Caring, Inc. State-specific Advance Directives forms are available on this site.

www.transweb.org
Transweb is a comprehensive site that offers a tremendous amount of useful information and related links for transplantation.

www.renalworld.com
Numerous tools for all aspects of kidney disease, including transplantation.

www.transplantfund.org
National Transplant Assistance Fund. Non-profit resource serving organ and tissue transplant patients/families. Provides fund-raising expertise for patients raising money for medical expenses.

www.hdcn.com
Hypertension, Dialysis and Clinical Nephrology (HDCN) Up-to-date information on kidney disorders and treatment.

pkdcure.org
Polycystic Kidney Disease Research Foundation web site with information on Polycystic Kidney Disease.

www.diabetes.org
American Diabetes Association Official Web site. Extensive site providing information regarding diabetes, treatment, and research.

www.nephron.com
This site contains many resources for professionals and patients including dialysis/transplant centers in the USA, and easy access to Medline.

www.caregiver.org
Family Caregiver Alliance Web site. Provides information on long-term care.

www.acmaweb.org
The goal of the American Case Management Association is to provide the highest quality professional developmental services such as mentoring, resource information, educational forums, and new opportunities for networking.

www.lungusa.org
The American Lung Association is the leading organization working to save lives by preventing lung disease and improving lung health through education, advocacy, and research. The main goals of the organization are to stop tobacco use and tobacco-related lung disease, improve the air we breathe, and reduce the burden of lung disease on patients and their families

www.apha.org
The American Public Health Association is made up of and represents a diverse group of health professionals and others who are concerned about their health or the health of their communities. The association aims to protect families and communities from preventable, serious health threats and to ensure accessible education within the community regarding health services and disease prevention.

www.aosw.org
The Association of Oncology Social Work (AOSW) is a not-for-profit organization geared toward improving the psychosocial services of clients with cancer and their families. AOSW strives to improve services through education, advocacy, networking, research, and resource development.

www.aposw.org
The mission of the Association of Pediatric Oncology Social Workers is to enhance pediatric psychosocial oncology care through clinical social work practice, advocacy, research, education, and program development. Some of their goals include advocating for both national and international policies that will improve the lives of children with cancer and their families as well as promote the ethical standards of social workers working in pediatric oncology.

www.astho.org
The Association of State and Territorial Public Health Social Workers is a not-for-profit organization that represents the public health agencies of the United States, U.S. territories, the District of Columbia, as well as its own public health employees. The agency's main focus is to create and influence sound public health policies as well as ensure excellence in state-based public health practice.

www.cswe.org
The Council on Social Work Education is a partnership of educational and professional institutions, social welfare agencies, and individual members that is the only recognized accrediting agency for social work education in the country by the Council for Higher Education Accreditation.

www.epilepsyfoundation.org
The Epilepsy Foundation is a voluntary agency dedicated solely to the welfare of patients and their families with epilepsy. The agency strives to ensure that people with seizures are able to engage in all life experiences, to improve how people with epilepsy are viewed within society, and to promote research.

www.childrenshospitals.net
The National Association of Children's Hospitals and Related Institutions is a not-for-profit agency made up of children's hospitals, large pediatric units in medical centers, and related health systems. This agency is a voice for healthcare systems and ensures children's' access to services and hospitals' ability to provide services that are needed by children.

www.napsw.org
The National Association of Perinatal Social Workers provides support and a forum to communicate for perinatal social workers and the unique situations in which they work, sharing knowledge as well as ensuring excellence in social work practice regarding families and individuals during pregnancy and the first year of life.

www.nhpco.org
The National Hospice and Palliative Care Organization is dedicated to enhancing end-of-life care and expanding access to hospice care with the goal of profoundly improving quality of life for people dying in the United States and their families.

www.nationalmssociety.org
The National Multiple Sclerosis Society helps individuals throughout the nation fight the challenges associated with living with multiple sclerosis (MS). The society funds research to prevent, treat and cure MS and provides advocacy and education for communities as well as services for individuals and their families dealing with MS.

www.socialworkpolicy.org
The Social Work Policy Institute is a think tank created under the National Association of Social Workers (NASW). Their main ideals are to strengthen social work's voice in public policy, to educate policymakers through the collection and disbursement on the effectiveness of social work, and to create a forum to discuss issues in health care and social service delivery.

www.sswlhc.org
The Society for Social Work Leadership in Health Care is committed to promoting the universal availability, accessibility, coordination, and effectiveness of health care in regards to the psychosocial components of health and illness.

www.transplantsocialworker.org/
The Society for Transplant Social Workers is dedicated to promoting and ensuring ethical social work practice and encourage research and publication on psychosocial issues related to transplants.

www.va.gov/healthbenefits
The Veterans Health Administration serves the needs of U.S. veterans by providing primary care, specialized care, and related medical and social support services.

INTERNATIONAL SOCIAL WORK ORGANIZATIONS

www.ifsw.org
The International Federation of Social Workers is a worldwide organization striving for social justice, human rights, and social development through the growth of social workers, ethical practices, and the international cooperation and communication of social workers and their professional organizations.

The following countries have websites for their national social work organizations:

Asian and Pacific Association for Social Work Education: **www.apaswe.com**

Australian Association of Social Workers: **www.aasw.asn.au**

Brazilian Congress of Social Workers: **www.cfess.org.br**

British Association of Social Workers: **www.basw.co.uk**

Canadian Association of Social Workers: **www.casw-acts.ca**

Danish Association of Social Workers: **www.socialrdg.dk**

Finland Union of Professional Social Workers: **www.talentia.fi**

France Association of Social Workers; **www.anas.fr**

Hellenic Association of Social Workers: **www.skle.gr**

Hong Kong Social Workers Association: **www.hkswa.org.hk/chi**

Icelandic Association of Social Workers: **www.felagsradgjof.is**

Israel Association of Social Workers: **www.socialwork.org.il**

Italy: **www.assnas.it**

Japanese Association of Psychiatric Social Workers: **www.japsw.or.jp**

Japanese Association of Social Workers: **www.jasw.jp**

National Association of Professional Social Workers in India: **https://www.facebook.com/NAPSWI/info**

Irish Association of Social Workers: **www.iasw.ie**

Korea Association of Social Workers: **www.welfare.net/site/global/globalEng.jsp**

Luxembourg: **www.anasig.lu**

Aotearoa New Zealand Association of Social Workers: **anzasw.org.nz**

Portugal: **www.apross.pt**

Singapore Association of Social Workers: **www.sasw.org.sg**

Spain: **www.cgtrabajosocial.es**

Sri Lanka Association of Professional Social Workers: **www.slapsw.org/index.html**

Sweden: **www.akademssr.se**

Swedish Union of Local Government Officers: **www.sktf.se/Default.aspx**

Switzerland: **www.avenirsocial.ch**

Uruguay: **www.adasu.org**

APPENDIX A

POSTER:

Has Anything Changed Since the Implementation of the 2008 Conditions for Coverage? 2010 Nephrology Social Work Caseloads, Salaries, and Implications for Chronic Kidney Disease Care in the U.S.

Teri Browne, University of South Carolina College of Social Work
Joseph R. Merighi, Kathleen Bruder, and David Kealey, Boston University School of Social Work

APPENDIX B

PRESENTATION:

Quality Assessment Performance Improvement (QAPI): The Social Work Role

Teri Browne, PhD, MSW
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