

B. IMPROVE THE INDEPENDENCE, QUALITY OF LIFE, AND REHABILITATION (TO THE EXTENT POSSIBLE) OF INDIVIDUALS WITH ESRD THROUGH TRANSPLANTATION, USE OF SELF-CARE MODALITIES (E.G. PERITONEAL DIALYSIS, HOME HEMODIALYSIS), IN-CENTER SELF-CARE, AS MEDICALLY APPROPRIATE, THROUGH THE END OF LIFE

Withdrawal from Dialysis Trends

End Stage Renal Disease imposes a high mortality burden. Life on dialysis has improved, but complex medical and emotional challenges remain. As dialysis has become increasingly accepted as a routine medical intervention, the population receiving this difficult and intrusive treatment has become more elderly, sick, fragile and vulnerable.

It is well known that every year, a substantial proportion of patient deaths are preceded by discontinuation of dialysis treatment. Discontinuation of dialysis means that the patient's regular course of kidney replacement therapy was stopped with the expectation that it would not be resumed even in response to life-threatening complications, and that the patient and / or health care agent made an explicit decision that kidney replacement therapy should be stopped permanently.

CMS Form 2746, the Death Notification Form, has data elements about discontinuation of dialysis. The form also has questions inquiring about patient and family involvement in the decision to discontinue dialysis, whether the patient received hospice care and a cause of death item #104 related to "Withdrawal from dialysis/uremia". Code #104 means that dialysis was discontinued prior to death and that a complication of kidney failure contributed in a significant way to the patient's death. If a "yes" response to renal replacement therapy was discontinued prior to death, the reason for discontinuation was also recorded. Five choices are provided:

- A) Following HD and/or PD access failure
- B) Following transplant failure
- C) Following chronic failure to thrive
- D) Following acute medical complication
- E) Other

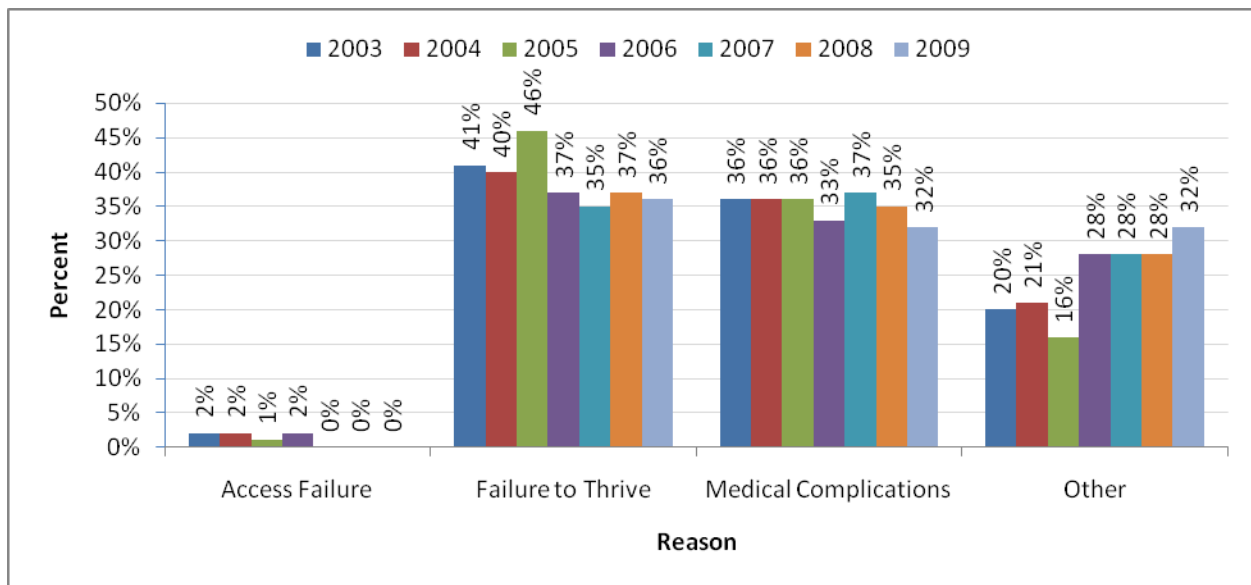
The Network of New England has followed the trends in this important area of end of life care. Table L contains the number of deaths reported in Network # for ESRD patients in the six states of New England from year 1995 to 2009. The data were analyzed for the number of patients that discontinued from dialysis prior to death and also by diabetes, the primary cause of ESRD (Figure 21 & 22). Withdrawal in the diabetic population due to failure to thrive is higher than the non-diabetic population. This is likely due to the complex multi-system complications experienced by many long-term diabetic patients. Based on data from the Annual ESRD Survey Report, the withdrawal from dialysis rate for this Network is one of the highest in the country.

Table L: Network 1 Annual Number of Deaths, Discontinuations by Diabetic Status

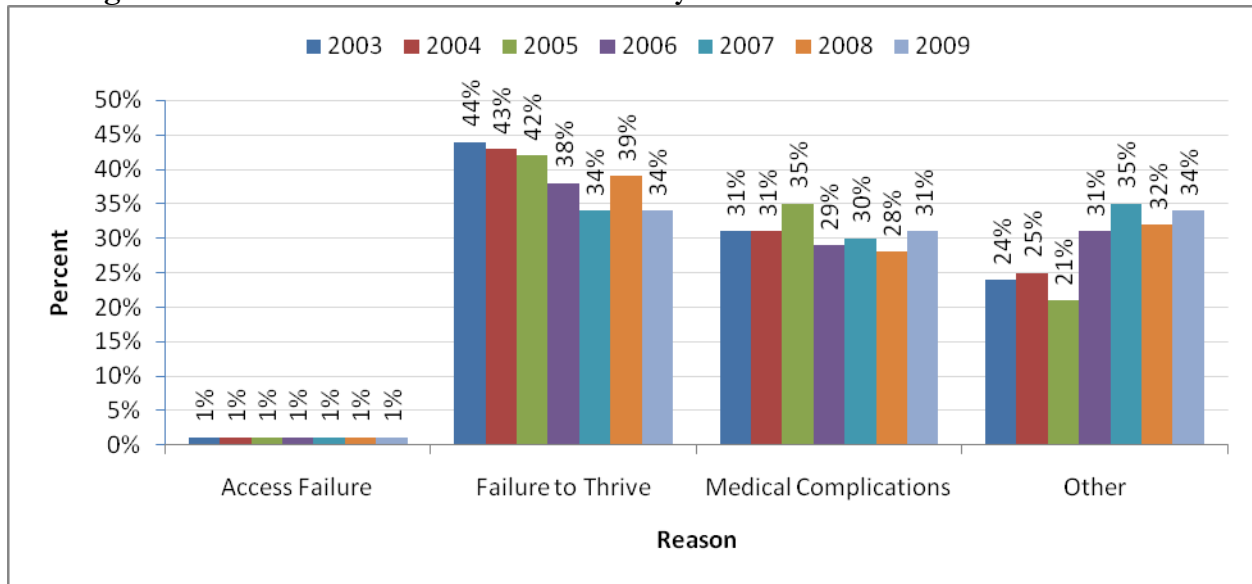
	Patient Deaths			Patient discontinued		Total Discontinued	
	Diabetic	Non-Diabetic	Total	Diabetic	Non-Diabetic	N	%
1995	760	1,298	2,049	167	317	484	23%
1996	865	1,341	2,203	201	355	556	25%
1997	852	1,406	2,218	231	350	581	26%
1998	983	1,426	2,395	240	434	674	28%
1999	1,104	1,510	2,593	297	452	749	28%
2000	1,081	1,583	2,665	261	552	813	31%
2001*	1,118	1,630	2,748	349	534	883	32%
2002**	1,139	1,638	2,777	338	558	896	32%
2003***	1,234	1,615	2,853	387	574	961	33%
2004	1,217	1,668	2,885	398	620	1,018	35%
2005	1,102	1,848	2,956	378	656	1,034	35%
2006	1,067	1,790	2,857	362	687	1,103	39%
2007	1,090	1,614	2,804	391	633	1,024	36%
2008	1,103	1,620	2,723	393	666	1,059	39%
2009	1,191	1,579	2,770	402	717	1,119	40%

Note: * Primary diagnosis was missing for 26 patients. ** Primary diagnosis was missing for 10 patients. ***Primary diagnosis is missing for 4 patients. These patients were grouped in the non-diabetic column for all years.
 Source: CMS Form 2746

Figure 21: Reason for Withdrawal from Dialysis: Trend for Diabetic Patients



Source: CMS Form 2746

Figure 22: Reason for Withdrawal from Dialysis: Trend for Non-Diabetic Patients

Source: CMS Form 2746

Withdrawal from Dialysis Special Project

In 2005-2006, this Network, in partnership with Networks 5 and 12 conducted a special project funded by CMS. The project design was structured telephone interviews with provider professionals that had the most knowledge about the patient that withdrew from dialysis prior to the patient's death event. The CMS Death Notification Form (Form 2746) was used to randomly select patients. The focus of the project was twofold:

- To better understand the level of understanding professionals have about the availability of hospice services and
- To determine if the lack of definitions for "cause of death" #104 "withdrawal from dialysis/uremia" and lack of instructions on dialysis discontinuation was confusing to individuals that complete Form 2746.

The major results were:

- Dialysis staff may not be clear about the clinical meaning of the terms withdrawal and discontinuation. Definitions are needed on the Form 2746.
- Fewer than half of patients participated in the decision to discontinue dialysis. More involvement of the clinical care team in end-of-life discussions with patient needed. Advance directives prior to terminal crisis would help staff and family handle discussions in a better manner.
- Lack of information on patients that die in the hospital indicates poor coordination and communication. A more integrated care system would benefit all parties.

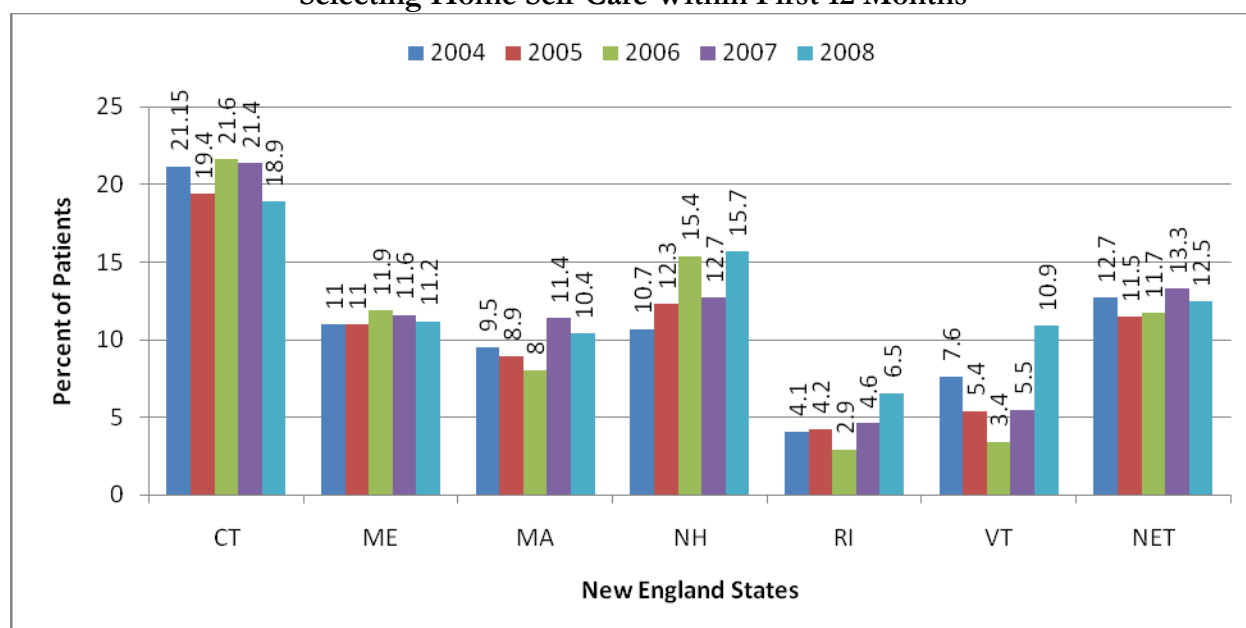
The results of this project were published in Nephrology News and Issues Volume 23, #9 August 2009 titled "Knowledge and Participation of Front-line Dialysis Facility Staff in End-of-Life Discussions" by Jaya Bhargava, PhD, CPHQ., Michael Germain, MD, Jenny Kitsen, BA, Lewis M. Cohen, MD and Klemens B. Meyer, MD.

Profile Analysis of ESRD Incidence Population

Network 1 annually profiles the utilization of treatment options available to new patients with ESRD. Network 1 is interested in understanding facility selection of modality options by new patients during the first twelve months of their individual ESRD experience with the emphasis being on self care dialysis or transplantation. In order to accomplish a twelve-month retrospective analysis of “new patient” experiences, a full year must lapse for all patients in the study cohort. Therefore, the most recent data analyzed is representative of the 2008 incidence patient census by first ESRD provider of service.

Network of New England promotes new patients select home dialysis within first one year of ESRD. This rate is 12.5% for the Network in 2008. In recent years home hemodialysis is on the rise. However, the individual state experience ranged from a high of 18.9% in Connecticut to a low of 6.5% in Rhode Island (Figure 23).

Figure 23: 2005, 2006, 2007 and 2008 Incidence Patients by First Provider of Service Selecting Home Self-Care Within First 12 Months



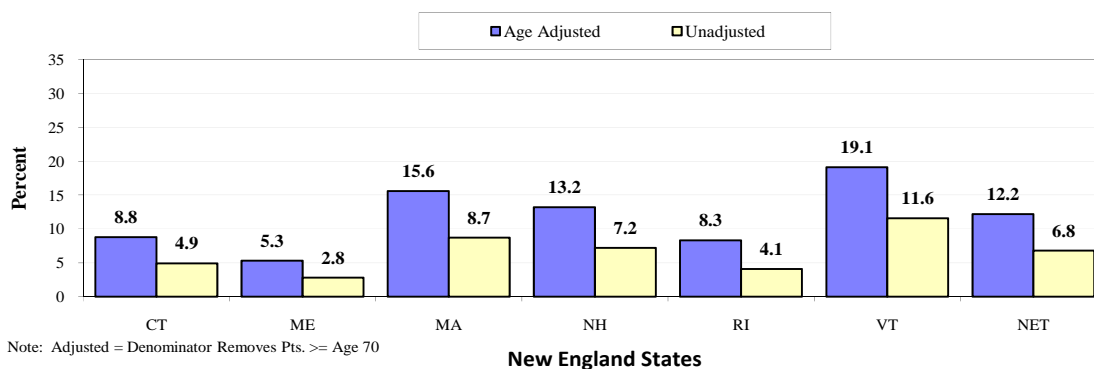
Note: Home patients for each state or Network are divided by the incident population for that state or Network. Source : SIMS data files

There continues to be high utilization of in-center treatment and steady slow growth in the total number of ESRD providers in New England. New England providers continue to expand the number of treatment stations at existing facilities or open treatment centers at new locations. This increased availability of treatment resources may be one factor contributing to a low percent of patients selecting home/self care. Incident patients selecting home/self care is; 1994 - 27.8%; 1995 - 24%; 1996 - 19.9%; 1997 - 17.7%, 1998 - 16.8%, 1999 - 19.7%, 2000 - 15.7%, 2001 - 14.9%, 2002 - 13.7%, 2003 - 13.1%, 12.7% - 2004, 11.5% in 2005, 11.7% in 2006, 13.3% in 2007 and 12.5% for 2008.

The percent of new patients in 2008 who were transplanted in their first twelve-month experience was 6.8%. Adjusted for age by excluding patients over age 70 of the 2008 incidence population

reveals a higher transplant activity rate of 12.2% (Figure 24). Network of New England promotes new patients select transplantation within the first year of ESRD based on age-adjusted population. Table M provides the actual number of incident patients for the past three years.

Figure 24: Transplantation 2008: Incident Patients Receiving Transplant Within First 12 Months



Note: Transplantations for each state or Network are divided by the incident population for state by residence or Network. Age adjusted category removes patients of age >=70 from the denominator.

Source: SIMS data files

Table M: 2006 - 2008 Incident Patients by State of Residence Selecting Home Dialysis By 1st ESRD Provider: First 12 Months ESRD Experience

State	New Patients			Transplanted			Home		
	2006	2007	2008	2006	2007	2008	2006	2007	2008
CT	990	991	1004	29	55	49	214	212	190
ME	344	268	322	23	17	9	41	31	36
MA	1794	1723	1762	156	164	154	144	196	183
NH	259	268	249	17	23	18	40	34	39
RI	311	326	338	26	17	14	9	15	22
VT	146	128	147	17	25	17	5	7	16
Total	3870	3732	3859	268	301	261	452	495	483
Total %	100	100	100	6.9	8.1	6.8	11.7	13.3	12.5

Note: 27 patients residing in NY or other states are not in state totals for New England for YR 2006

28 patients residing in NY or other states are not in state totals for New England for YR 2007

37 patients residing in NY or other states are not in state totals for New England for YR 2008

Source: SIMS data files

Prevalence Population and Employment Status

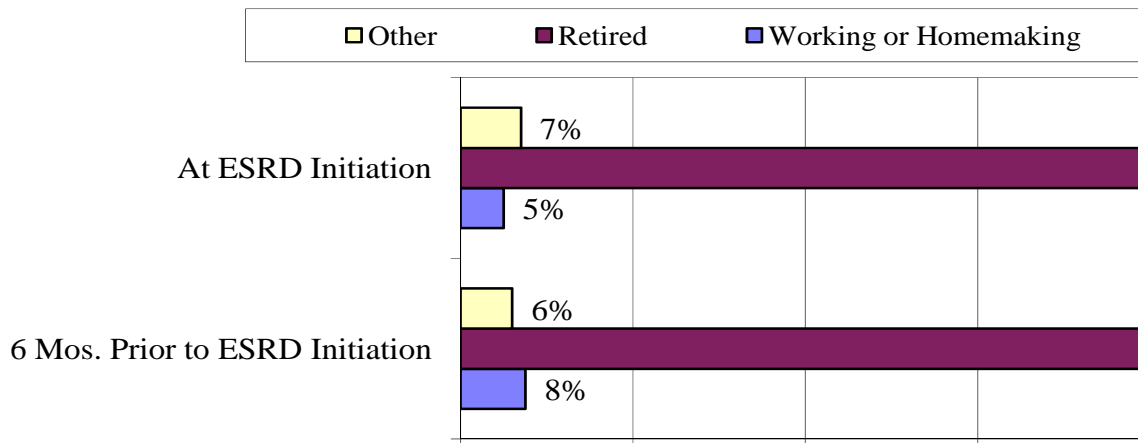
One of the functions of the ESRD Networks consistent with sound medical practice, is to encourage participation of patients and providers in utilizing the services of vocational rehabilitation (VR) programs. As part of the new 2744 (annual facility survey) form, the Networks collect information on vocational rehabilitation referrals, employment and student status among patients between the ages of 18 to 54. This age-range cohort is often referred to as “working age”.

Based on the prevalent population as of December 31st 2009, there were 3,125 dialysis patients in New England within the working-age range (See Table 8 in data tables sections). Seventy Seven patients, or 2.4% were referred to or receiving VR services during the reporting year. Twenty six percent (26%) of this patient group were reported as either working or students. Combined, 28% of New England dialysis patients are actively involved in traditional life pursuits (employment or education).

Incident Population and Employment Status

Analysis of the Network of New England’s incident data gives insights into patients’ employment status 6-months prior and at the initiation of the ESRD. CMS’s Medical Evidence Report and Registration (Form 2728) form contains data elements, which provide comparison between patient employment status, six months prior to initiation of ESRD treatment, and at the initiation of ESRD treatment. This form also captures data on the type of employment, such as whether a patient is a student, homemaker, retired due to disability, or retired due to age/preference. In 2009 a total of 3,892 individuals were registered as new patients for the New England states. Of those patients, 56% were over the age of 65 when first becoming ESRD patients. Analysis of the employment status of the incident population over the age of 65, 6-months prior to initiation of ESRD, indicates that 86% were retired due to disability, age or by preference, while 8% were working or homemaking. However, analysis of the employment status of the same population at the initiation of ESRD indicates that the number of retired increased to 88 % (Figure 25).

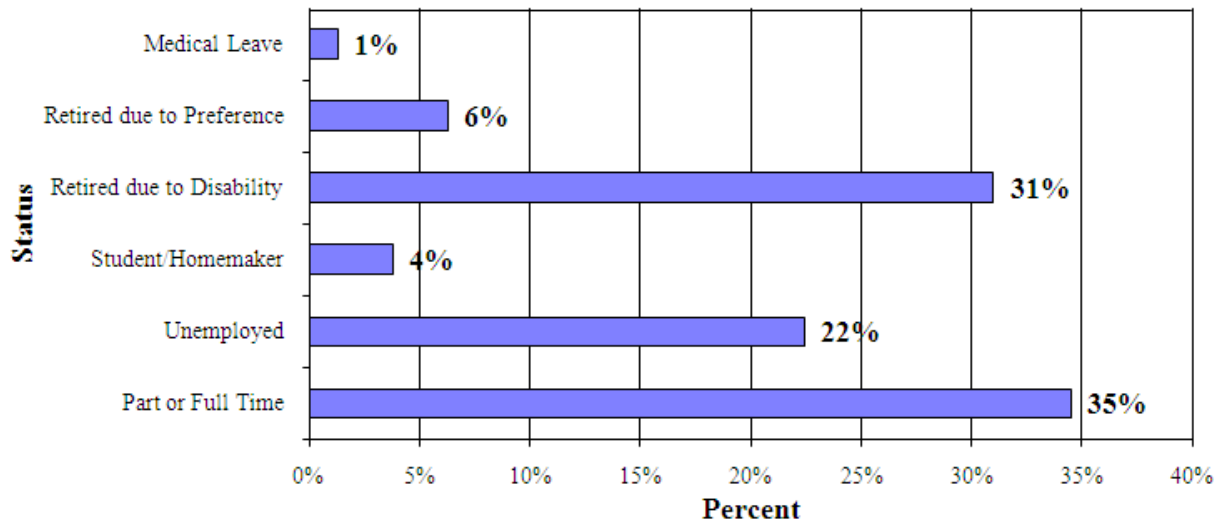
**Figure 25: 2009 Incidence Patients ≥ 65 *
Role Functioning Status (N = 2,179)**



* Percent will not equal 100, due to other functional status categories not included in this figure.
Source: CMS Form 2728

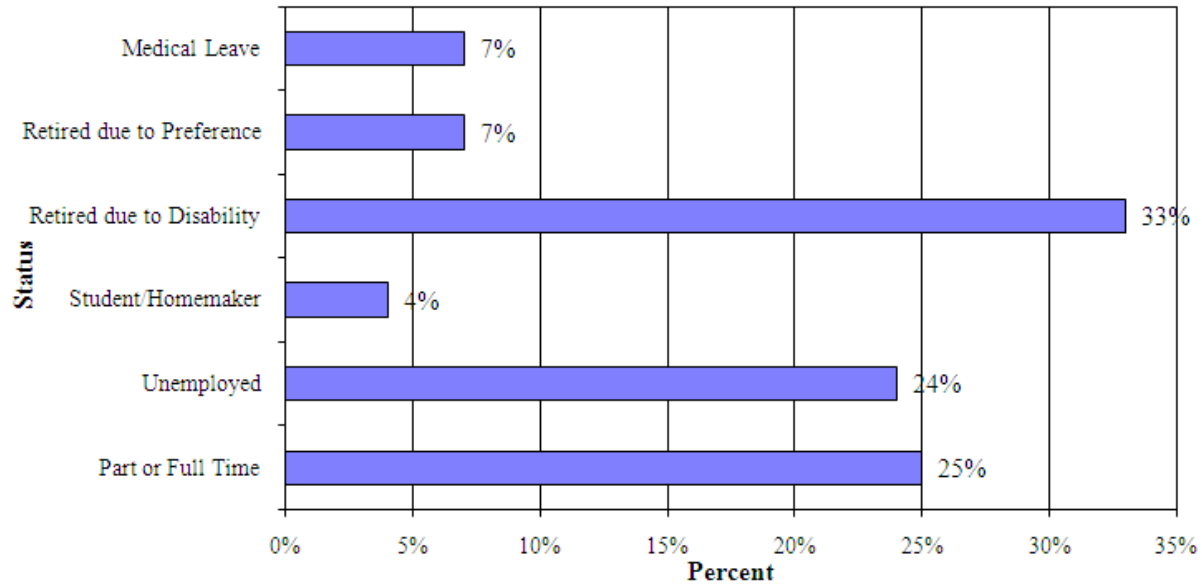
In 2009 there were 1,713 (44%) incident ESRD patients who were under age 65. Six months prior to initiation of ESRD treatment, 35% of this cohort group was working, 4% were students or homemakers and 38% reported retired due to disability or age preference. Looking at the same group at the initiation of ESRD, 25% were working, 4% were students or homemaker, and 40% were reported retired due to disability or age preference (Figures 26 and 27).

**Figure 26: 2009 Adult Incidence Patients Age <65 Functional Status
6 Mos. Prior to ESRD Initiation (N = 1,713)**



Source: CMS Form 2728

Figure 27: 2009 Incidence Patients Age < 65 Functional Status At Initiation of ESRD Treatment (N = 1,713)



Source: CMS Form 2728

Vocational Rehabilitation

Of the approximate 12,000 ESRD prevalence patients residing in the six New England states, only about 3,200 are of “working age” which is defined as between the ages of 18 to 55. That number represents 27% of the New England dialysis population.

Among the working age patients treated with dialysis 29% are working, going to school or are receiving vocational rehabilitative services. This is a decrease from 2008 reported for New England. Even with a slight decrease this percentage of patients who are engaged in work related life activities is a relatively good outcome. This outcome is considered reasonable when taking into account the number of challenges associated with the demands of a thrice-weekly dialysis schedule, fatigue, medical complications and barriers to employment (Table N).

**Table N: Vocational Rehabilitation by State
Patients Aged 18 - 55 as of December 31, 2009**

PROVIDER STATE	NUMBER OF DIALYSIS PATIENTS AGED 18 –54 (NETWORK LIST)	NUMBER OF DIALYSIS PATIENTS RECEIVING SERVICES FROM VOC REHAB AND OTHER VOC REHAB RELATED SERVICE PROVIDERS (PUBLIC OR PRIVATE)	NUMBER OF DIALYSIS PATIENTS EMPLOYED FULL-TIME OR PART-TIME	NUMBER OF DIALYSIS PATIENTS ATTENDING SCHOOL FULL-TIME OR PART-TIME
CT	1,024	15	241	25
MA	1,370	46	321	44
ME	222	11	55	6
NH	176	0	49	2
RI	249	3	50	2
VT	84	2	20	5
Network	3,125	77	736	84

Source: CMS Form 2744

The Network of New England continues to encourage individual patients to retain or pursue their careers upon initial diagnosis of ESRD and throughout their adjustment to treatment. Network 1 posts current contact information for the six New England State Vocational Rehabilitation programs on its website and distributes educational materials to patients and providers regarding the importance of employment retention for dialysis and transplant patients. Network 1 also serves as an advocate on behalf of patients when requested by Social Workers or patients when a patient is threatened with job loss. In these cases advocacy takes the form of telephone conferencing, directing correspondence to existing or potential employers and referral to partner agencies such as Life Options, the Medical Education Institute, AAKP and the Americans with Disabilities Act administered by the US Justice Department.

Network 1 Staff Provide Community Educational Materials

Pre-dialysis, dialysis or transplant patients and staff rely on the ESRD Networks as a resource for educational materials. Network 1 warehouses printed materials in large quantities for distribution at no cost to renal healthcare providers upon request. The four most often requested educational products in 2009 were: *Your New Life* (New England PAC), *Preparing For Emergencies – A Guide for People on Dialysis* (CMS) *ESRD Medicare Coverage for Dialysis and Transplantation* (CMS), and “BEE” *Informed of Your Rights and Responsibilities*. Network 1 difficulties this year were that some of the requests could not be fulfilled because CMS exhausted stock of both *Preparing for Emergencies* and the *ESRD Medicare coverage booklet*. These four popular multi-page booklets are designed to orient and educate members of the renal community, both patients and providers, on the many aspects of End Stage Renal Disease.

The following types of educational information or materials given to patients and providers of CKD/ESRD healthcare throughout the year:

- QI Information
- Data Research Information
- Complaints and Grievances
- Treatment Options
- Vocational Rehabilitation Information
- Information on Dental Services
- Transient Care
- Website Referral (DFC)
- Reimbursement Issues and Questions
- Coordination of Benefit Questions
- KDQOL questions
- Other Requests

Network 1 Collaborative with Donated Dental Services

In 2009, The Network of New England become aware of an organization called Donated Dental Services (DDS) which can assist renal patients with severe dental problems. According to the Founder, DDS is a national humanitarian initiative through which 14,000 volunteer dentists assisted by 2,800 laboratories have contributed \$150 million in comprehensive therapies to 90,000 needy disabled, elderly, and medically compromised individuals in the United States.

This program is a helpful resource for patients who have exhausted every other financial option seeking needed assistance for dental work. Only the most severe patient cases are considered for these services.

The Network has collaborated with DDS to serve as a “middle man” to help the patients needing essential dental care services. The Network notified all the ESRD clinics and transplant facilities in all six states of this program by mailing the application and the medical triage form with the Network newsletter. The Network does not choose which applications will be submitted to this program. The Network coordinates the application process. When the applications from the facilities are submitted, they are coded and sent to the appropriate address by state. The Network staff received many calls from providers who had questions about the Donated Dental Service and who wanted applications and the medical triage form.

Achieving Network 1 Goals in Quality of Life for ESRD Patients

The importance of patient quality of life has been a high priority for Network 1. The provision of educational materials on the website and distribution efforts to patients and professionals is an ongoing activity. Random feedback of utilization and effectiveness of these materials is conducted by Network staff. The conduct of the withdrawal study illustrates commitment to quality of life. In addition, Network 1 leadership serves on the steering committee of the ESRD National End of Life Coalition. Analysis of access to services and employment status of dialysis population is reported annually to the Network Board to assure adequate regional availability of dialysis treatment to help employed patients.