



Working On Home Dialysis: What Dialysis Staff Should Know

This blog post was made by [Beth Witten, MSW, ACSW, LCSW](#) on August 16th, 2018.



Do you have patients on home dialysis? Do they get Social Security retirement, Supplemental Security Income (SSI) or Social Security Disability Income (SSDI)? Do they ever tell you they have more bills at the end of the month than money? Do they seem bored or depressed? Have you ever thought about suggesting they get a part-time or full-time job? Do you wonder how working might affect their benefits?

Medicare

If your patients have Medicare due to kidney failure (ESRD) and are on dialysis, *no matter how much they work, their ESRD Medicare will not be affected*. When they get a transplant, they can work and still keep ESRD Medicare for 36 months. If they can get a job with health insurance while they're on dialysis or soon after getting a transplant, they'll be in better shape when Medicare ends post-transplant.

Social Security Retirement

Here’s what you can tell your patients about working and Social Security retirement benefits: *If they took their Social Security retirement benefits at their full retirement age, they can work and earn as much as they can, and it won’t affect their Social Security retirement check.* If they retired *before* their full retirement age, they can work and keep their full retirement check until their work income is over \$1,470/month or \$17,640 for the year (in 2019).

If their work income is more than that, Social Security will reduce their retirement check \$1 for every \$2 they make from work over that amount. The year they reach their full retirement age, if their work income is more than \$3,910/month or \$46,920 for the year (in 2019), Social Security will reduce their check \$1 for every \$3 they make over that amount. *Remind patients that their work income can also increase what they get from Social Security.* Social Security calculates their benefits based on their top 35 years of earnings. See <https://www.ssa.gov/planners/retire/whileworking.html>.

Social Security Disability Benefits

If your patients are working and considering applying for disability, it’s important to *let them know that Social Security Disability Income (SSDI) only pays about 40% of what they were making from work and less if they had higher income.* Supplemental Security Income (SSI) only pays \$771 (in 2019). Some but not all states supplement this. If patients feel well enough to work, Social Security works with a number of government and non-government programs to help people prepare for, find, and keep a job. State and other similar vocational rehabilitation programs can assess your patients’ skills and interests and develop a plan to work toward their goals. You can read about these different programs and encourage patients to find help at <https://choosework.ssa.gov/findhelp/>.

Social Security has work incentive programs for those 18 through 64 who get SSI or SSDI. These programs allow people with disabilities to test whether they can work or not. Here’s a chart that briefly describes each of the work incentive programs. There is a checkmark to indicate whether the program works if the patient is getting SSI or SSDI. Some work incentives work if patients get either SSI or SSDI. You can read more about Social Security’s work incentive programs in the Red Book (Publication #05-10043). It’s published online at <https://www.ssa.gov/redbook/>. This booklet is available in English and Spanish and you can order it on that site in a different format (large print, Braille, or audio CD) if your patients need a different format. Dollar amounts change every year.

Work Incentive Programs for People with SSDI and/or SSI	SSI	SSDI
Trial Work Period allows your patients to work and earn as much they can for 9 months during a 5-year period while getting a full check. S/he		•

can earn less than \$850 in 2018 and/or work 80 hours or less if self-employed without using a trial work month.		
Extended Period of Eligibility provides 36 months after using all trial work months and get a full check any month his/her earnings are not “substantial” - \$1,180 / \$1,970 if legally blind in 2018.		•
Continuation of Medicare allows your patient if still disabled to keep free Medicare Part A for 8.5 years after the 9-month trial work period if he/she loses disability cash due to work. This can help people with a transplant who have another disability besides ESRD. Medicare isn’t affected if a dialysis patient works.		•
Unincurred Business Expenses allows Social Security to deduct from a patient’s work earnings expenses IRS would count as business-related. Examples: Donated business equipment or a friend who works for no pay.		•
Special SSI Payments for Persons Who Work – 1619a allows a patient to keep his/her work earnings and some SSI cash until income is above a “break-even point.” To calculate when earnings from work stop SSI cash, double the SSI federal benefit and add \$85. In 2019, this is \$1,627/month. Find the federal SSI benefit at https://www.ssa.gov/oact/cola/SSI.html .	•	
Medicaid While Working (Section 1619b) allows patients to keep Medicaid even if they lose their SSI cash benefit due to work. Workers with disabilities can have much higher income and keep Medicaid than those who don’t work. The amount varies by state. For the amount in your state, see https://www.ssa.gov/disabilityresearch/wi/1619b.htm .	•	
Earned Income Exclusion allows Social Security to exclude the first \$65 a patient earns from work plus half of their work earnings and another \$20 (general income exclusion) when figuring how much SSI to pay when working.	•	
Student Earned Income Exclusion allows Social Security to not count \$1,820 per month or up to \$7,350 a year 2018 when figuring how much SSI to pay when a patient is under age 22, regularly attending school, and working.	•	
Expedited Reinstatement if a patient loses his/her cash benefit and has to stop working due to the condition for which s/he got disability within 5 years, s/he can ask Social Security to re-start checks with no application or waiting period.	•	•
Impairment-Related Work Expenses your patients have to pay to work and stay healthy, can be deducted from work earnings if Social Security approves them. Examples include medical costs not paid by	•	•

other sources, drug copays, a home dialysis helper, medical equipment, taxi if the patient can't use public transport, self-employment expenses due to his/her condition.		
Continued Payment under Vocational Rehabilitation or Similar Program (Section 301) allows the patient to keep SSI or SSDI if s/he medically recovers while in a VR program whose goal is to end his/her need for benefits. (NOTE: If the transplant patient keeps getting SSDI under Section 301, s/he can keep Medicare longer than 36 months post-transplant.	•	•
Plan to Achieve Self-Support (PASS) allows the patient to set aside some of his/her resources or cash from SSI (or SSDI in some cases) into a separate account for a work goal that will reduce or end SSI or SSDI. A PASS cadre can talk with the patient and help him/her set up a PASS at www.socialsecurity.gov/disabilityresearch/wi/passcadre.htm .	•	•

If patients are getting help with food (SNAP) or housing (HUD), advise them to check with those agencies about how work earnings will affect the amount of help they can get. You can suggest that patients talk with a Work Incentives Planning and Assistance (WIPA) counselor. Your patients can also get free legal help when asking for workplace accommodations, when there are questions about transportation or housing rights, or in help to understand an employment contract through Protection and Advocacy for Beneficiaries of Social Security (PABSS). For more information, see <https://choosework.ssa.gov/findhelp/>.

If you've worked for any time in dialysis, you know that being on dialysis can be work limiting. This is especially true if your patients do in-center dialysis where dialysis schedules don't always work well with their work schedule, where how dialysis is done can leave them feeling sick during dialysis and washed out for hours afterwards. Doing home dialysis – peritoneal dialysis or home hemodialysis – makes it easier for patients to schedule dialysis around work and other responsibilities. *Doing dialysis longer or more often may limit their dialysis symptoms and allow them to avoid the "dialysis hangover" that many have doing in-center dialysis.* Getting a transplant offers even more flexibility to work in a couple of months if the patient is in stable health. If your patients have told you they want a transplant, they need to know that *any time after the first year, Social Security can ask them to go through a medical evaluation, find them not disabled, and stop their SSI or SSDI checks.* If your patients want a transplant, encourage them to use the time on dialysis or shortly after transplant to prepare for and get a good job that provides a living wage and health insurance.

Working has many benefits. Most dialysis patients do better physically, emotionally, socially, and financially. One home HD patient I know recently told me, *"I'll be honest...work has truly saved me and not just financially. It was the much-needed distraction*

and the only gratification I got for several years – when the rest of my life felt so very dark and hopeless. I pushed through and now I'm in a much better place."

If your home dialysis patients are not currently working, please share with them information about work incentives and links to helpful resources. ***Consider using working patients who are doing well emotionally and physically as mentors.*** They may be able to help motivate patients who are on the fence about working. Encouraging your home dialysis patients to work could go a long way to improving the quality of their lives.