



Coping with & Paying for Kidney Disease

Your Dialysis Clinic or Transplant Program Has a Social Worker...

With a master's degree in social work and counseling skills to help you:

- Cope with your illness
- Navigate the healthcare system
- Advocate for yourself
- Get physical, vocational, other rehab services
- Access financial help as needed & available
- Plan care with your team to meet *YOUR* goals

Your Social Worker Knows Resources

- Treatment-related transportation
- Programs to pay for drugs
- Food assistance
- Independent living
- Financial help
- Housing assistance
- Low vision, dental, hearing



Coping with Kidney Disease



When Faced with Kidney Disease, It's Normal to Feel...

- Shocked
- It's not true (denial)
- Sad or depressed
- Angry
- Impatient
- Anxious
- Alone or lonely
- Out of control
- Numb
- Hopeless or helpless
- Worried about your future
- Afraid of becoming dependent on others
- Worried about how long & well you'll live
- Worried about money & bills



Shared Beliefs of Patients with 15+ Years Dialysis Experience

Shared Beliefs	Actions That Helped Patients Do Well
I want to live	Write down what you're grateful for, live for more than dialysis, ask for support
I am still me	Think positively, don't define yourself by your disease, ask others what did/didn't help, & make time for non-dialysis activities
I am still valuable	Do what makes you feel worthwhile, own your successes, appreciate who you are
I am in control	Know your options, seek information, ask questions, take control where you can

Life Options, *Renal Rehabilitation Report*, 2001

Choose a Positive Attitude

- Ask for help if you're sad 2+ weeks
- Expect to have ups & downs
- Record your moods in a journal
- Write 1 good thing about you daily
- Do something creative
- Avoid self-destructive behaviors
- Live for today, but set future goals



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Ask for Help When Needed

- Your social worker
- Other mental health professionals
- Cognitive-behavioral therapy can help change mindset/ behaviors/phobias
- Your spiritual leader
- Your family & friends
- Community agencies
- Advocate with elected officials



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Seek Education & Support from Others with Kidney Disease



- Attend classes & support groups
- Ask for a mentor
- Use trusted social media
- Research new options



Confirm what you read or hear from these sources with your team

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Talk with Supportive People About...

- How you are feeling emotionally, physically
- How kidney disease affects you & your loved ones
- How you can work together to meet your goals
- Consider having an advance directive in case you're unable to communicate your wishes:
 - A *living will* states your wishes
 - *Durable power of attorney for healthcare decisions* names someone you trust to decide on your behalf
 - Find state-specific forms on www.CaringInfo.org

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Discuss Sexuality or Intimacy Concerns with Your Social Worker &/or Doctor

- Relationship issues
- Body image
- Changes in your sexual interest or functioning
- Desire to have children
- Family planning



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Stay As Active As You Can

- Work or volunteer
- Go to school
- Exercise
- Have a hobby
- Spend time with friends & family



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How Do I Choose a Treatment?

- Most have many options
- May do more than one or all types over a lifetime
- Weigh pros & cons of each—see Compare Treatments chart (in binder) &/or use MyDialysisChoice.org
- Talk with your doctor about your lifestyle, goals
- Seek referral for transplant evaluation if desired
- Tour the dialysis clinic, meet staff & ask about rules, expectations & which treatments are offered
- Talk with other patients & families

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In Choosing a Treatment, Think About Your Lifestyle

- Work or school
- Sex life
- Swimming, baths
- Pets
- Need for control
- Activities you like to do
- Fertility
- Child/adult care



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Think About Your Health Goals

What treatment can help you:

- Feel well from day to day
- Sleep as well as possible
- Have the best chance for transplant
- Avoid taking as many pills
- Protect your heart
- Protect your bones, joints, & nerves
- Limit hospitalization
- Live as long as possible



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Travel & Treatment (Treatments in Other Modules)



Treatment Type	Travel Considerations
In-center HD	Arrange in-center HD 30-60 days ahead
Standard Home HD	Arrange in-center HD 30-60 days ahead
NxStage Home HD	Take machine & supplies; arrange ahead
CAPD (manual PD) or CCPD (cycler)	Take machine/supplies; arrange ahead; if CCPD at home, can do CAPD on trips
Transplant	Ask about adjusting meds for time zones

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Your Team Can Help You Travel

If on dialysis:

- Ask clinic staff about how you can travel
- Find out cost & coverage (Medicare pays in US)



For everyone:

- Ask if time zones will affect drugs' schedule
- Travel with records, drugs, & supplies
- Don't vacation from diet, drugs, or treatment

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Special Message for Loved Ones

- Thanks for your support & encouragement!
- Expect the patient to do all they can (trade tasks)
- Do what you enjoy (even if the patient doesn't want to go along); sacrificing your life can make you angry & resentful
- Eat healthy, exercise & get checkups to reduce your chance of getting sick
- Ask for help when you need it

<https://www.caregiver.org/>

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Paying for Treatment A Common Concern



Options to Pay for Treatment

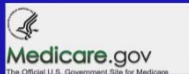


New
Medicare
Card
2018



- Medicare with or without a Medigap plan
- Employer plan with or without Medicare
- Individual health insurance on/off marketplace
- Medicaid with or without Medicare

Do I Qualify for Medicare?



- Age 65 with enough work credits to get Social Security or Railroad Retirement (call SSA at 800-772-1213)
- OR**
- Received Social Security disability checks 24 months
- OR**
- Kidney failure needing dialysis or transplant with enough work credits OR spouse or child of worker

What Is Original Medicare?

Hospital (Part A) for inpatient services

- Those who have enough work credits pay no premium
- Those 65 or older without enough credits can pay to have Part A & B
- Deductible/admission unless readmitted in 60 days
- State may pay if you qualify

Medical (Part B) for outpatient services

- Monthly premium, annual deductible & coinsurance
- State may pay if you qualify

What Is Medicare Advantage?

- Also called Medicare Part C or MA plans
- Sold by insurance companies
- Covers what Original Medicare covers
- May cover vision, dental; most include drug plan
- Provider networks may limit dialysis & transplant choices; may limit drug coverage
- Out-of-pocket costs up to \$6,700/year plus Part B premium; Original Medicare with Medigap is less
- Can only switch to Original Medicare at certain times and may be unable to get Medigap plan

What If I Take Medicare But Have No Other Insurance?

- Medicare has deductibles, copays, and coinsurance so other insurance is needed
- In MO, IL & KS, you can buy a **Medigap (Medicare supplement)** plan to pay all or most costs; plan can't deny for 6 months after you get Part B (ask insurance dept if you have other "guarantee issue" rights)
- Check with your state insurance department at www.medicare.gov/Contacts/

When Can My Medicare Start?

- **Transplant as first kidney treatment**
 - 1st day of the month of your transplant
- **Home/self-care dialysis (PD or HD)**
 - 1st day of month dialysis starts if you start a training program before the 4th month of dialysis
- **Center hemodialysis (HD)**
 - 1st day of the 4th month of dialysis

When Will Medicare End If I Have Kidney Failure?

- Never if you are on dialysis & pay premiums
- 36 months after transplant unless you are:
 - 65 or older
 - Disabled due to non-kidney condition

What If I Have an Employer Plan?

- Does it have affordable premiums & out-of-pocket costs (deductibles, copays, coinsurance)?
- What is the out-of-pocket before it pays 100%?
- Is your MD, dialysis clinic, transplant program in its provider network?
- Are your drugs on its formulary (covered drugs)?
- How will it coordinate with Medicare after 30 months? Your employer plan is primary for 30 months from the date you could get Medicare whether you take it or not.

Why Take Medicare If I Have an Employer Plan?

- Medicare may cover what your plan doesn't cover
- Having Medicare limits what providers that "accept assignment" can bill you
- Medicare's premium may be less than your employer plan's out-of-pocket costs
- Don't take Part A without B, or you'll pay a higher premium later (10%/year you waited to take B)
- Employer plans may not pay primary after 30 months when Medicare should be primary

Medicare As a Primary Payer

Transplant

- Inpatient stay after Part A deductible; copays if lengthy
- 80% anti-rejection drugs
- 80% physician
- 100% live donor's hospital; doctor visits for limited time & 6 month follow-up visit

Dialysis

- Inpatient stay after Part A deductible; copays if lengthy
- 80% in-center or home dialysis
- 80% physician
- 80% outpatient access surgery

See [Medicare Coverage for Kidney Dialysis & Kidney Transplant Services](#)



State/federal matching funds pay:

- Some medical bills & transportation if you are elderly or disabled & have limited income
- Some costs for eligible children/families
- Medicare premiums &/or out-of-pocket costs if you qualify for a "Medicare Savings Program"

MO & KS had not yet expanded Medicaid (spring 2018); IL & over 30 other states had

ACA Health Insurance Marketplace

- Future is uncertain
- Only available for citizens & those in U.S. legally
- Not needed if you have Medicare or other insurance
- Most say Medicare is better if you have that choice & you'll pay more for Medicare if you delay enrollment
- Low income? You may get premium tax credits & help to pay medical costs, but not if you have Medicare
- Low premium plans have higher out-of-pocket costs
- Enroll Nov. 1 to Dec. 31; some can apply other times
- Call **(800) 318-2596** or go to www.healthcare.gov/

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Other Types of Coverage

- **COBRA (continuation coverage)**
 - Can get COBRA if you already have Medicare
 - **WARNING:** Will lose COBRA if you later enroll in Medicare
- **Veterans Administration** covers veterans' care in VA hospitals & contract facilities
- **TRICARE** covers active-duty & retired military who have Medicare Part A & B, and their dependents
- **Indian Health Service** covers American Indians and Alaska Natives in federally-recognized Tribes

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Help for Prescribed Drugs

- Health plans (employer or other)
- Medicare Part D
- Part D extra help, if you qualify
- Medicaid, if you qualify
- State pharmacy assistance program, if available & eligible
- Physician samples
- Discount drug cards: rxassist.org
- Drug co. programs: pparx.org or needymeds.org
- Missouri Kidney Program (for qualifying MO residents)



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Missouri Kidney Program Helps som.missouri.edu/MOKP

- Patient education
- Financial help for qualifying Missourians with transplants or on dialysis (apply through social worker)
 - Centralized drug program
 - Transplant grants
 - Transportation help
 - Limited premium help



(800) 733-7345

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Social Security Helps

<https://www.ssa.gov>

- Apply in-person or online for:
 - Medicare
 - Part D extra help (limited income, assets)
 - Social Security Disability Income (SSDI)
 - Supplemental Security Income (SSI)
 - Retirement benefits
 - Survivors benefits
- Ask about programs that help you work when disabled



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Help to Keep or Find Work

- **Disability replaces only part of prior earnings**
- Doctor & team can keep you healthy enough to work
- State, company human resources
- Ticket to Work's Choose Work **Find help** database:
 - Vocational Rehabilitation (VR)
 - Employment Networks



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Anti-Discrimination Laws Protecting You



- Rehabilitation Act
- Americans with Disabilities Act
- Family & Medical Leave Act
- Age Discrimination in Employment Act

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Other National Program Sites

- [American Association of Kidney Patients](#)
- [American Diabetes Association](#)
- [American Heart Association](#)
- [American Kidney Fund](#)
- [Home Dialysis Central](#)
- [Kidney School](#)
- [Life Options](#)
- [National Kidney Foundation](#)
- [UNOS Transplant Living](#)

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Your Team Can Help You Plan Your Future with Kidney Disease



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