

# NAVIGATING HEALTH INSURANCE WITH CHRONIC ILLNESS: TIPS FOR CHOOSING THE BEST PLAN

by Lisa K. Magno

If you're living with spondylitis or a related chronic condition, you know that managing your health can feel like being underwater, and with insurance concerns added to the mix, you might feel like you're without a lifeline.

Especially if you're newly diagnosed, choosing the right health insurance can feel overwhelming. However, the more you learn about coverage for chronic conditions, the easier it will become to navigate the system and find the coverage that fits your needs.

Knowing how to select the right plan and maximize your benefits can significantly influence your well-being and financial health. To select the best health insurance plan for a chronic condition like spondylitis, experts recommend focusing on network coverage, medication costs, and total out-of-pocket expenses, not just the monthly premium.

## Assess Your Healthcare Needs

Before comparing plans, assess your current and future healthcare needs.

- **List all your providers:** Make a complete list of your primary care doctor, rheumatologist, pain specialists, physical therapists, and any other specialists you see.
- **Track your prescriptions:** Keep a record of every medication you take, including dosages, and investigate their costs. Drugs for spondylitis, especially biologics, can be expensive.
- **Account for services:** Include all essential services for the upcoming year, such as diagnostic tests, infusions, injections, and expected hospital stays.

## Compare Different Plan Types

Health insurance plans, like HMOs and PPOs, differ greatly in cost and flexibility. For chronic conditions, a PPO is usually recommended for its wider network and more flexibility, but an HMO may be better for those who prefer more coordinated, in-network care.

## Network and Specialist Access

You probably have a favorite doctor or specialist, and you're looking for a plan that includes them in your network. Remember that your condition might require other specialists. That's why choosing a plan with an extensive medical network or one that covers out-of-network care at a reasonable rate can be very important.

- **HMO vs. PPO:** Consider how you access specialists. An HMO requires you to choose a Primary Care Physician (PCP) and obtain a referral to see a specialist. A PPO provides more flexibility and usually does not require a referral.
- **Out-of-network coverage:** If you need to see a specific specialist outside your area or if your condition worsens, choosing a plan with good out-of-network coverage may be important.



OUT-OF-NETWORK

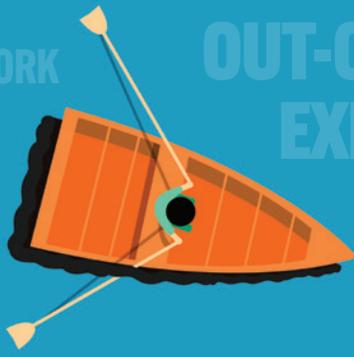
OUT-OF-POCKET  
EXPENSES

PRESCRIPTIONS

PREMIUMS

DEDUCTIBLES

MEDICARE



## Carefully Review the Details of Each Plan

After outlining your needs, review the summary plan description for each plan you're considering.

- ✓ **Check the provider network:** Make sure all your current doctors and preferred facilities are in-network. Since networks can change each year, call your doctor's office and the insurer to confirm.
- ✓ **Verify drug coverage:** Check the plan's formulary (list of covered medications) to confirm all your prescriptions are included. Find out which tier your specific medications fall under, as this affects your copay or coinsurance. Pay special attention to coverage for high-cost specialty drugs.
- ✓ **Review out-of-pocket costs:** Add up the total annual expenses, including the premium, deductible, and out-of-pocket maximum.
- ✓ **Higher premium, lower deductible:** For a chronic condition, selecting a plan with a higher monthly premium but a lower deductible can make costs more predictable and help reduce your overall expenses, since you'll likely meet your deductible each year.
- ✓ **Out-of-pocket maximum:** Compare the highest amount you will have to pay for covered services in a year. Once you reach this limit, the plan pays 100% of any additional costs.

## Administrative and Regulatory Barriers

Unfortunately, navigating the healthcare system remains difficult, even with the right insurance plan.

**Insurance barriers:** Patients with chronic illnesses often encounter more obstacles in accessing care due to insurance, such as prior authorization requirements for medications and procedures.

**Limited plan quality:** While all plans on the Affordable Care Act (ACA) marketplace must cover pre-existing conditions, the quality and scope of coverage can vary.

**Medicare and Medicaid complexities:** For eligible individuals, options like Medicare Advantage C-SNPs offer specialized care but can involve network and drug coverage challenges.

## Documentation and Record Keeping

Keeping detailed records is crucial for effectively managing insurance for any chronic condition. Important documents to keep include:

- Medical records and test results
- Prescription records and receipts
- Communication with insurance providers
- Prior authorization forms
- Claims documentation
- Appeals correspondence

## Additional support and guidance

You don't have to navigate this alone. For assistance, explore these resources:

- **HR representatives:** For employer-sponsored insurance, your human resources department can answer questions specific to your plan.
- **Drug manufacturer programs:** Patient advocates from pharmaceutical companies that produce your medication may offer insurance guidance specific to your treatment.
- **Navigators and Assisters:** These individuals and organizations are trained and certified by the Marketplace to help with the application and enrollment process. The official federal website, **HealthCare.gov**, provides access to trained professionals who can assist you at no cost.
- **SAA Advocacy ([spondylitis.org/advocacy](https://spondylitis.org/advocacy))** offers self-advocacy guidance for treatment denials, the appeals process, and more.

Choosing the right health insurance plan can be a daunting task. Making a good choice can safeguard both your health and your finances. This becomes especially crucial if you have a chronic condition, so take your time. The goal is to ensure you receive the care you need from your healthcare providers in a way that is consistent and affordable, protecting your health now and in the future.

# INSIGHTS FROM SAA'S FALL HEALTHCARE AND TREATMENT ACCESS SURVEY

The recent SAA Fall Healthcare and Treatment Access Survey highlights the main challenges people with spondyloarthritis face in accessing the medical care they need. Early findings indicate that although many respondents report general satisfaction with their healthcare, significant obstacles remain. Notably, one in four reported being denied coverage for biologic treatments, one in three faced issues with step therapy, and over a third experienced delays in receiving essential care due to financial constraints. Additionally, community members shared powerful personal stories that highlight the struggles they face within the healthcare system.

## Delays and Denials

*I have definitely had to battle getting referrals in a timely manner and have had to postpone appointments multiple times when that doesn't happen, which impacts work and daily life. – Teresa C.*

*My rheum fights with [my insurance] routinely to get me access; in between getting my RX approved, she gave me samples. Without the biologic, I would be bedridden. – Katharine C.*

*Not being able to access a biologic has been incredibly detrimental to my overall health. Not only are my AS symptoms in constant flare, but my skin, kidneys, and liver have been impacted as well. – Sara G.*

## Financial Strain

*I spend \$75,000 on out-of-pocket expenses. So many doctors and treatments are not covered and don't even apply to the deductible because they're out of network. – Rachel S.*

*I wish insurance would cover more of my costs because treatment is needed for the rest of my life, and we are a one-income family. – Breanna K.*

## Emotional and Daily Impact

*When I cannot get access to the medication I need, working is very difficult. I work with children and need to be very active. – Abby H.*

*Causes a lot of stress when having to change medication and dealing with insurance. They have taken at least eight weeks to review and approve. – Nannette H.*

*Dealing with delays, especially prior authorization, is miserable and makes me dejected. – Aaron F.*

*I was denied my biologic a few years ago. It caused a flare-up of pain and fatigue that lasted months. This reduced my efficacy at work. – Andy S.*

## Systemic Barriers

*The patient assistance program doesn't count toward my out-of-pocket costs. This defeats the purpose of assistance, and insurance co gets paid twice! – Heather K.*

*My chronic disease has me trapped in the pharmaceutical, health, and insurance industries. It's like a high-stakes game show where the rules change every round, the prize is just keeping my health in check, and the house—the pharma and insurance company shareholders—wins big on every single move. – Craig N.*

## Your Voice Matters

We want to hear from you. Please visit SAA's advocacy page to share your experiences with healthcare and access to spondylitis treatment through our quick survey. Your feedback helps us advocate for better access to care and resources for everyone in the spondylitis community.

