



Chronically Adv♥cating

CHOOSING THE RIGHT HEALTH PLAN DURING OPEN ENROLLMENT:

A Guide for Patients with
Rare And Chronic Conditions

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HEALTH PLAN TYPES

HMO (Health Maintenance Organization)

How it works:

You must choose in-network doctors and usually need a referral from a primary care physician (PCP) for specialists.

Pros

- Usually lowest monthly premiums
- Lower out-of-pocket costs
- Strong care coordination when the network is good
- Predictable cost structure

Cons for Chronic/Rare Patients

- Severely limited specialist networks
- Referral bureaucracy
- Difficulty accessing out-of-network experts
- Appeals can be slower because decisions are tightly controlled
- Rare disease centers often not included

Best for: Patients with stable conditions who already have an established in-network team and do not require out-of-state specialty care.

HEALTH PLAN TYPES

PPO (Preferred Provider Organization)

How it works:

Allows in- and out-of-network care with no referrals required.

Pros

- Most flexible option
- No referral barriers
- Access to out-of-network specialists and academic medical centers
- Ideal for multi-specialty care, rare disease evaluations, and second opinions

Cons for Chronic/Rare Patients

- Higher monthly premiums
- Higher deductibles and coinsurance
- Out-of-network coverage may still be expensive

Best for: Complex, rare, or unstable conditions; those needing access to specialists across multiple systems; patients who frequently need second opinions.

HEALTH PLAN TYPES

POS (Point of Service)

How it works:

Hybrid of HMO + PPO; requires a PCP and referrals, but allows out-of-network care at a cost.

Pros

- More flexibility than HMO
- Some out-of-network options
- Usually mid-range premiums

Cons for Chronic/Rare Patients

- Referral requirements slow everything down
- Out-of-network benefits are often weak
- Not ideal for high-complexity care

Best for: Patients whose care is mostly in-network but want some options beyond an HMO.

HEALTH PLAN TYPES

EPO (Exclusive Provider Organization)

How it works:

Like a PPO but without out-of-network coverage except emergencies.

Pros

- Lower premium than PPO
- No referral requirements
- Simpler than HMOs

Cons for Chronic/Rare Patients

- Absolutely no out-of-network coverage → huge risk for rare disease
- Rarely contracts with specialty centers
- Can trap patients in a narrow network

Best for: Patients whose entire care network is in-network and do not anticipate rare disease referrals.

HEALTH PLAN TYPES

HDHP (High Deductible Health Plan)

How it works:

Very high deductible; eligible for an HSA.

Pros

- Low premiums
- HSA tax advantages
- Good for people who use very little care

Cons for Chronic/Rare Patients

- Almost never appropriate
- You must pay thousands before the plan pays anything
- Can create care delays
- High upfront costs for meds, labs, and imaging

Best for: Individuals with excellent health and minimal healthcare use.

Not recommended for chronic illness or rare disease patients.



FACTORS YOU MUST EVALUATE

A. Insurance Network & Specialist Access

Look specifically for:

- Your current specialists
- Academic medical centers
- Rare disease centers of excellence
- Neurology, rheumatology, immunology, GI, autonomic, genetic, and pain specialists

Red Flags

- A plan where "specialty clinics" bill as Tier 3 cost-share
- Plans that exclude centers of excellence
- Networks with only one rheumatologist or neurologist



FACTORS YOU MUST EVALUATE

B. Medication Coverage (Formulary Review)

Checklist:

- Are your current meds covered?
- Are they Tier 1, 2, 3, specialty tier?
- Are there quantity limits or step therapy?
- Do you need prior authorization for every refill?

Red Flags

- Plans where most of your medications are non-formulary
- Tier 4 copays that exceed \$150–\$400/month
- Mandatory step therapy before your current treatment



FACTORS YOU MUST EVALUATE

C. Durable Medical Equipment (DME) Policies

Important for patients using:

- Feeding tubes
- Mobility aids
- CGMs
- Oxygen
- Infusions, ports, or PICC supplies
- Compression garments

Red Flags

- DME vendors restricted to a single supplier
- Annual limits
- Coverage only for “temporary” conditions
- Non-coverage for wheelchairs or specialty mobility devices



FACTORS YOU MUST EVALUATE

D. Therapy Limits

Includes:

- Physical therapy
- Occupational therapy
- Speech therapy
- Mental health / psychotherapy

Red Flags

- Annual visit caps (e.g., “20 PT visits per year”)
- Non-covered conditions (many plans exclude chronic pain, ME/CFS, EDS)
- Requirement for re-authorization every 6–8 visits



FACTORS YOU MUST EVALUATE

E. Diagnostic Testing Flexibility

Patients needing ongoing testing should verify:

- Imaging policies for MRI, MRA, CT
- Genetic testing coverage
- Specialized lab tests
- Out-of-network flexibility for rare lab panels

Red Flags

- “Experimental / investigational” denials for necessary specialty tests
- Only 1–2 imaging centers contracted



FACTORS YOU MUST EVALUATE

F. Out-of-State or Multi-State Care Needs

For patients seeing:

- Mayo Clinic
- Cleveland Clinic
- Stanford
- CHOP
- Rare disease or dysautonomia centers

Prioritize:

- PPO
- Multi-state networks

Avoid:

- HMO
- EPO
- Regional plans with narrow networks



EXCLUSIONS & LIMITATIONS THAT HURT YOU THE MOST

Never choose a plan with these if you can avoid it:

- Annual caps on PT/OT
- No out-of-network coverage when you rely on specialty care
- Prescription exclusions for injectables, infusions, biologics, GLP-1s, migraine meds, immunology meds
- Coverage only for “acute conditions”
- DME exclusions for chronic conditions
- Lack of mental health parity
- No coverage for telehealth or out-of-state telehealth
- Plans filed under different states (e.g., ERISA plans filed in New York but sold in Colorado) because state protections don’t apply

CHOOSING A PLAN BASED ON YOUR FINANCIAL REALITY

A. Understand the 4 financial components

1. Premium → what you pay monthly
2. Deductible → what you must pay before insurance kicks in
3. Copays / Coinsurance → what you pay per visit
4. Out-of-pocket Maximum (OOP max) → the MOST you can spend in a year

For chronic illness patients, **the OOP max is the most important number.**

CHOOSING A PLAN BASED ON YOUR FINANCIAL REALITY

B. How to match a plan to your financial situation

If your healthcare use is very high:

Choose a plan with:

- Low deductible
- Low OOP max
- Higher premium

Why: You will hit the OOP max early and then the plan pays 100%.

CHOOSING A PLAN BASED ON YOUR FINANCIAL REALITY

B. How to match a plan to your financial situation

If you rely on many specialists across systems:

Choose:

- PPO
- Large national network
- Reasonable OOP max
- Flexible telehealth/second opinions

CHOOSING A PLAN BASED ON YOUR FINANCIAL REALITY

B. How to match a plan to your financial situation

If you use expensive meds (biologics, infusions, rare disease meds):

Prioritize:

- Plans that cover your medication
- Specialty tiers with capped copays
- No mandatory step therapy

Avoid plans with:

- Coinsurance percentages (10–50% of a \$5,000 med = unaffordable)

CHOOSING A PLAN BASED ON YOUR FINANCIAL REALITY

B. How to match a plan to your financial situation

If cash flow is a limitation:

Choose a plan with:

- Lower monthly cost but still reasonable deductible
- Copays instead of coinsurance
- Predictable care costs
- Avoid HDHPs unless truly necessary



CHOOSING A PLAN BASED ON YOUR FINANCIAL REALITY

B. How to match a plan to your financial situation

If you have unstable symptoms or risk of hospitalization:

Focus heavily on:

- OOP max
- Emergency department cost structure
- Inpatient hospitalization copays
- Access to specialists who can prevent hospital admissions



HOW TO MAKE A DECISION

Step 1: List your non-negotiables

- Essential specialists
- Medications
- DME
- Hospitals/systems
- Diagnostic needs

Step 2: Run each plan through this filter

1. Are my specialists covered?
2. Are my medications on formulary?
3. Will my DME be covered?
4. Is my hospital system in-network?
5. Does the plan offer out-of-network flexibility?
6. Does the plan have exclusions that directly affect me?
7. Can I afford the OOP max if I have a bad year?
8. Would I still have access to out-of-state or rare disease care?

If a plan **fails more than two**, eliminate it.

WHAT TO DO IF ALL YOUR PLAN OPTIONS FAIL THE TESTS

A. Rank Your Medical Priorities in Order of Danger

If every plan is bad, you must decide:

Which failures would cause the most harm to my health or finances?

Use this ranking system:

1. Medication Access

- If your necessary medications are not covered or require step therapy, this is the biggest red flag.
- Lack of coverage for biologics, infusions, immunology meds, migraine injectables, cardiac meds, or GLP-1s can destabilize health quickly.

2. Specialist Access

- If losing your specialists could result in hospitalization, severe flare, or delayed treatment, prioritize a plan that keeps the most critical ones.

3. Hospital System Access

- If you rely on a specific hospital (neurosurgery, GI motility, EDS surgeons, autonomic specialists), choose the plan that keeps that system in-network.



WHAT TO DO IF ALL YOUR PLAN OPTIONS FAIL THE TESTS

4. Out-of-Pocket Maximum (OOP Max)

- If you know you will hit the OOP max, choose the lowest one available, even if the premium is higher.

5. DME & Therapy Coverage

- Feeding tubes, wheelchairs, PT/OT, infusion supplies, CGMs, and home medical equipment must remain covered.

6. Diagnostic Testing Flexibility

- If imaging or specialty labs are essential, prioritize the plan that covers the most options even if the network is limited.

You are choosing based on what would destabilize your health the fastest.

WHAT TO DO IF ALL YOUR PLAN OPTIONS FAIL THE TESTS

B. Pick the Plan That Has the Fewest *Catastrophic Barriers*

When all plans are bad, choose the one that avoids catastrophic outcomes like:

- Losing access to a life-sustaining medication
- Losing your top specialist
- Being unable to afford care until hitting a \$7,000–\$10,000 deductible
- Losing DME or supplies that are non-negotiable
- Lacking a hospital that can manage your specific disease

If the plan has flaws but won't severely destabilize your health, it may be the "least harmful" option.

WHAT TO DO IF ALL YOUR PLAN OPTIONS FAIL THE TESTS

C. Document and Prepare an Appeal Strategy *Before* the Plan Year Begins

If you're forced into a restrictive plan, plan ahead:

Prepare your appeal toolkit before January 1:

- Letters of medical necessity from each specialist
- Documentation of failed treatments in your medical records (for step therapy)
- Specialist notes supporting need for out-of-network care
- Evidence of rare disease guidelines that require specialty centers
- Prior authorization templates ready to submit
- An organized medical binder or digital file system

This increases your approval chances once the new plan begins.

WHAT TO DO IF ALL YOUR PLAN OPTIONS FAIL THE TESTS

D. Use Employer Leverage If the Plans Are Unsafe

If your employer's offerings are **dangerously inadequate**, you can:

1. Request a one-off accommodation or exception

Ask HR for:

- A plan exception for a specialty medication
- An accommodation due to disability under the ADA
- An alternative formulary tier
- Coverage exception for out-of-state specialists

2. Educate HR on plan deficiencies (professionally)

Many HR departments do not understand:

- Rare disease
- Immunology
- Complex care coordination
- The impact of limited networks

Providing them with:

- A letter from your specialists
- A medical summary
- A request for "reasonable accommodation"

...can significantly shift outcomes.

WHAT TO DO IF ALL YOUR PLAN OPTIONS FAIL THE TESTS

D. Use Employer Leverage If the Plans Are Unsafe

3. Use the ADA / disability accommodation pathway If a health plan:

- Removes coverage for a disability-related medication
- Restricts needed specialty care
- Eliminates access to medically required equipment

You can file a workplace disability discrimination complaint or request accommodations. This is often effective and does not require legal counsel at the first stage.

WHAT TO DO IF ALL YOUR PLAN OPTIONS FAIL THE TESTS

E. Evaluate External Options (When Legally Allowed)

If employer plans are insufficient, consider whether alternative coverage is allowed:

1. Marketplace/ACA plans

Some families can decline employer insurance and buy on the exchange if the employer plan is:

- Unaffordable (costs more than 9.02% of household income for employee-only coverage to get subsidies)
- Lacks adequate coverage
- Has an unacceptable deductible or OOP max

2. Medicaid / Medi-Cal

Available if income qualifies or in certain disability-related categories.

3. Dual Coverage (Primary + Secondary)

1. Sometimes:

- A spouse's plan
- Medicaid
- Medicare (for disabled patients)

...can act as secondary coverage to fill gaps.



WHAT TO DO IF ALL YOUR PLAN OPTIONS FAIL THE TESTS

E. Evaluate External Options (When Legally Allowed)

4. Patient Assistance Programs

For high-cost medications not covered.

Important: Some ERISA employers block dual enrollments or reimbursement for outside plans. This must be evaluated case-by-case.

WHAT TO DO IF ALL YOUR PLAN OPTIONS FAIL THE TESTS

F. If the Plan's Weakness is Strictly Financial **Use This Triage Strategy**

Choose the plan with:

- Lowest OOP max
- Most predictable copays
- Lowest coinsurance percentages
- Best specialty med coverage
- Access to your highest-cost specialists

Avoid:

- High-deductible plans
- Coinsurance-based specialty tiers
- Plans with no OON coverage if you need specialists
- Plans whose formularies exclude half of your meds

WHAT TO DO IF ALL YOUR PLAN OPTIONS FAIL THE TESTS

G. If All Plans Are Equally Harmful Choose Based on “Survival Priorities”

When nothing meets medical needs:

Priority Order for Chronically Ill Patients

1. Medication access → You cannot replace a lifesaving med
2. OOP max → Controls total financial exposure
3. Access to your most critical specialist
4. Hospital network
5. DME and therapy limits
6. Diagnostic testing access

Medications + Specialist Access + OOP Max matter most.

Everything else can often be fought with appeals, peer-to-peer reviews, or exceptions.

WHAT TO DO IF ALL YOUR PLAN OPTIONS FAIL THE TESTS

H. If You Need Help Choosing, Use This “Tie-Breaker” Question

When all plans are equally bad, ask:

Which plan gives me the best appeal pathway?

PPO > POS > HMO > EPO > HDHP

ERISA plans > state-regulated plans (for appeals, ERISA is faster but less protective)

Large insurers > small regional ones

Choose the plan where you can fight and win.

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Choosing a Health Plan:

Chronic Illness & Rare Disease Patient Checklist

(Do this for each plan you are considering)

Before starting the checklist on the following pages, to properly consider health plans be sure you have:

Summary of Benefits and Coverage (SOB)

and/or the

Evidence of Coverage Booklet (EOC)

for each plan you are considering

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Choosing a Health Plan:

Chronic Illness & Rare Disease Patient Checklist

(Do this for each plan you are considering)

1. Specialist & Provider Access

- ☐ My essential specialists are in-network
- ☐ My primary care provider is in-network
- ☐ My hospital system is in-network
- ☐ My rare disease/tertiary centers are included
- ☐ My out-of-state specialists are covered (if needed)
- ☐ Out-of-network benefits are available

2. Medication Coverage (Formulary Review)

- ☐ All my medications are covered
- ☐ No drugs are listed as non-formulary
- ☐ Specialty medications (biologics, infusions, injectables) are covered
- ☐ Copays are predictable (not high-percentage coinsurance)
- ☐ No step-therapy requirements for my current treatment
- ☐ No restrictive quantity limits

3. Therapies & DME

- ☐ PT/OT/Speech therapy limits meet my needs
- ☐ DME (wheelchair, CGM, feeding tube, mobility aids) is covered
- ☐ Supplies and disposables are covered
- ☐ DME vendors are accessible and adequate

4. Diagnostics & Procedures

- ☐ MRI, MRA, CT, ultrasound, and specialty tests are covered
- ☐ Genetic testing is covered (if needed)
- ☐ My preferred imaging center is in-network
- ☐ No exclusions for “experimental/investigational” tests I rely on

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Choosing a Health Plan:

Chronic Illness & Rare Disease Patient Checklist

(Do this for each plan you are considering)

5. Telehealth & Care Coordination

- ☐ Telehealth visits are covered
- ☐ Out-of-state telehealth is allowed (if applicable)

6. Financial Structure

- ☐ I can afford the monthly premium
- ☐ I can afford the deductible
- ☐ Copays are predictable
- ☐ Coinsurance percentages are manageable
- ☐ The out-of-pocket maximum is affordable in a worst-case scenario

7. Plan Type

- ☐ PPO (preferred for complex care)
- ☐ POS (acceptable if specialists are in-network)
- ☐ HMO (only if all providers are accessible)
- ☐ EPO (avoid if I need specialty or OON care)
- ☐ HDHP (usually not appropriate for chronic illness)

8. Appeal & Exception Readiness

- ☐ Plan has a clear appeals process
- ☐ My providers will support exceptions/authorizations
- ☐ ADA accommodations may be available for employer plans

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Choosing a Health Plan:

Chronic Illness & Rare Disease Patient Checklist

(Do this for each plan you are considering)

9. Red Flags

- ☐ Key specialists excluded
- ☐ Medications not covered
- ☐ Only coinsurance for specialty medications
- ☐ No out-of-network benefits
- ☐ Strict therapy caps
- ☐ DME exclusions
- ☐ Narrow networks
- ☐ Unaffordable OOP max

10. If All Plans Are Suboptimal

- ☐ I ranked “catastrophic needs”:
Medications → Specialists → Hospitals → OOP max → DME → Testing
- ☐ I identified the least harmful plan
- ☐ I evaluated ADA and HR accommodation options
- ☐ I prepared letters of medical necessity for January

Final Decision

Does this plan allow me to:

- ☐ Access required specialists
- ☐ Access all medications
- ☐ Afford worst-case costs
- ☐ Maintain or improve health stability

If not, reconsider.



SCHEDULE A 60-MINUTE HEALTH PLAN REVIEW SESSION

If you're feeling unsure about which plan is the safest, most cost-effective, and most accessible for your situation after reading this booklet, I offer a **60-minute Health Plan Q&A Session** designed to help you make a confident and informed decision.

I can answer any further questions you may have to make it easier for you to choose your health plan.

You can book that session at:
chronicallyadvocating.com/health-plan-review-session/

CONTACT INFORMATION

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