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CHRONIC DISEASE

Autoimmune Diseases

Five Conditions That Cause Long-Term Dependency

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Overview

Autoimmune diseases occur when the immune system, which normally defends the body against infection, misidentifies its own tissues as foreign and attacks them. More than 80 distinct autoimmune conditions have been identified, collectively affecting an estimated 24 million Americans — roughly 7% of the population.

Five conditions stand out for their capacity to produce durable functional impairment and long-term dependency: multiple sclerosis, rheumatoid arthritis, systemic lupus erythematosus, systemic sclerosis (scleroderma), and myasthenia gravis. Women account for roughly 4 in 5 cases across most of these conditions.

The dependency profile of autoimmune disease differs from stroke or dementia: onset is often gradual, symptoms wax and wane for years before a pattern is recognized, and because most begin in midlife, families can face a caregiving arc spanning two, three, or even four decades.

24M Americans affected by autoimmune disease (about 7% of the population)	80% of autoimmune disease cases occur in women	65–90% of patients rate fatigue as a top-three disabling symptom
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How It Leads to Dependency

Fatigue — often invisible to observers — is nearly universal across these five conditions and frequently the single largest driver of activity limitation, with 65 to 90% of patients rating it a top-three symptom. Cognitive changes are increasingly recognized as a component of MS, lupus, and even rheumatoid arthritis.

Without disease-modifying therapy, multiple sclerosis patients need a cane at a median of 15 years and a wheelchair at a median of 30 years after diagnosis. Systemic sclerosis carries the highest case-specific mortality of any autoimmune rheumatic disease, and 56% of patients become work-disabled.

Diagnosis & Early Warning Signs

Diagnosis of autoimmune conditions typically requires a combination of clinical symptom patterns, specific antibody blood tests, and — for some conditions — imaging or biopsy. Because symptoms wax and wane and often mimic other conditions, diagnosis can take months or years, particularly for lupus and scleroderma.

Because fatigue and cognitive fog are largely invisible symptoms, family members, employers, and even some healthcare providers may not fully appreciate the extent of a patient's functional limitation — contributing to delayed diagnosis and treatment.

Typical Care Needs

Care needs vary substantially by which of the five conditions is present but commonly include mobility support as disease progresses (canes, walkers, and eventually wheelchairs for MS), joint protection and injection support for rheumatoid arthritis, and energy management strategies to work around pervasive fatigue.

Formal caregiving support becomes essential once a patient needs help with two or more activities of daily living — bathing, dressing, transferring, toileting, feeding, or continence — though many families delay this transition out of financial concern or a belief they should manage independently.

The Realistic Cost of Care

Because these five conditions often begin in midlife and progress over decades, the cumulative cost of care — and lost income for both patient and caregiver — compounds significantly over a multi-decade arc.

65–90% of patients rate fatigue as a top-three disabling symptom	26% of rheumatoid arthritis patients report difficulty with at least one ADL	Decades typical span of the caregiving arc given midlife onset
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- Disease-modifying therapies for multiple sclerosis and biologic drugs for rheumatoid arthritis represent significant ongoing medication costs, though they meaningfully slow disability progression when started early.
- Because onset is often in midlife, financial stress frequently comes from both directions: the patient's reduced work capacity and the caregiver's own reduced work hours.
- Long disease courses mean home modifications, mobility equipment, and in-home assistance needs evolve over many years rather than emerging suddenly, requiring different financial planning than acute-onset conditions.

THE CAREGIVER BURDEN

Because these conditions are typically slowly progressive and punctuated by flares, families rarely experience a single 'crisis moment' that would normally prompt outside help — the burden accumulates gradually, year over year, until it becomes unsustainable.

Planning Considerations

These considerations are general and educational. They are not financial or legal advice, and no specific product or provider is endorsed here.

- Starting disease-modifying therapy early, particularly for multiple sclerosis and rheumatoid arthritis, has strong evidence for slowing long-term disability progression.
- Because fatigue and cognitive symptoms are invisible, proactively educating employers, extended family, and schools helps prevent the isolation and skepticism that autoimmune disease patients and caregivers commonly report.
- Given the multi-decade course typical of these conditions, families benefit from revisiting care and financial plans periodically rather than creating a single plan at diagnosis and assuming it will remain adequate.

Sources & Further Reading

1. National Multiple Sclerosis Society — <https://www.nationalmssociety.org/>
2. Autoimmune Association — <https://autoimmune.org/>

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