NATIONAL ALLIANCE FOR CAREGIVING

Medicare Drug Price Negotiation Program: IPAY 2028

Caregiver Advocacy Toolkit

This resource is prepared by the National Alliance for Caregiving (NAC) to support patient advocacy organizations and their advocates as they engage with the Centers for Medicare & Medicaid Services' (CMS) Medicare Drug Price Negotiation Program on the Initial Price Applicability Year 2028 (IPAY 2028).

In January 2026, CMS announced 15 drugs selected for the third cycle of negotiation. These 15 drugs affect approximately 1.8 million Medicare beneficiaries. Throughout April 2026, CMS is hosting a series of public engagement events that include patient focused roundtables on each selected drug and a livestream town hall on all selected drugs. All events are open to patients, representatives of patient advocacy organizations, and caregivers.

In this toolkit, you will find:

- An overview of family caregiving data and talking points drawn from Caregiving in the US 2025 (CGUS 2025), an ongoing data project from NAC and AARP. The data explore the characteristics, roles, and needs of family caregivers who provide ongoing support and care management for adults and children with complex medical conditions or disabilities.
- Sections that address each therapeutic area (e.g., immunology, mental health, oncology, etc.) covered by IPAY 2028 negotiations. Reference the relevant section when preparing remarks and comments for the CMS public engagement meetings. This information is constructed to complement disease-specific data and patient stories. Each section includes:
    - Context for family caregiver advocates
    - Key caregiving data
    - Talking points focused on the caregiver experience
- Resources and references including CMS materials, data sources, and additional advocacy resources.

WHY FAMILY CAREGIVERS MATTER: NATIONAL DATA

Caregiving in the US 2025 (CGUS 2025) is a comprehensive study of the American family caregiver. Conducted by NAC and AARP, the report explores the challenges and opportunities associated with caregiving across different populations and across the lifespan. It helps us understand such areas as the impact of caregiving on caregivers' health, the financial implications of caregiving, and the gaps in supports and services for family caregivers and their care partner.

To download the report and additional fact sheets and infographics, visit https://www.caregivingintheus.org.

The following data and talking points can help provide essential context for engagement with CMS. These figures can be cited across all condition areas to establish the scale, role, and value of the family caregiver in the conversations. The data reflect the caregiver experience, not clinical outcomes.

Key Data Points

63+ million	American adults provided complex, ongoing care to adults or children with a medical condition or disability in 2025 - a 45% increase since 2015.
47%	Of family caregivers experienced at least one major negative financial impact as a result of caregiving including debt, depleted savings, or inability to afford basic expenses like food.
27 hrs/wk	Is the average time family caregivers spend providing care weekly. One in four provides 40+ hours per week, the equivalent to a full-time job.
55%	Of family caregivers perform complex medical or nursing tasks such as administering medications, managing injections, and monitoring vital signs, yet only 22% received formal training.
64%	Of caregivers report moderate or high emotional stress. Nearly one in four (24%) report feeling alone.
56%	Of family caregivers felt they had no choice in taking on their caregiving role, and those caregivers experienced significantly worse mental health outcomes and greater isolation.

Talking Points

- **Family caregivers are essential partners in patient outcomes.** By providing daily support, monitoring symptoms, and reinforcing care plans between medical visits, caregivers help patients adhere to treatment and manage complex conditions more effectively.
- **Medication management often depends on family caregivers.** Caregivers frequently organize medications, ensure doses are taken correctly and on schedule, monitor side effects, and communicate concerns to healthcare providers. This management is critical for patients managing multiple prescriptions across multiple diseases or conditions and multiple providers.
- **Caregivers serve as the hub of care coordination.** They help schedule appointments, share information across providers, track treatment plans, and advocate for the patient within a complex healthcare system
- **Caregivers help people remain in their homes, the setting most patients prefer.** Through assistance with daily activities of living, symptom and medication management, and ongoing supervision, family caregivers enable many individuals to avoid or delay costly institutional care such as nursing homes or long-term facilities.
- **Family caregivers are the invisible infrastructure of the healthcare system.** Their unpaid work fills critical gaps in care, supporting patients day-to-day, and helping the broader healthcare system function more effectively and sustainably.

SECTION I: MENTAL HEALTH

Mental health conditions, including serious psychiatric illness, treatment-resistant depression, and the behavioral and psychological symptoms of dementia (BPSD), create some of the most demanding caregiving situations. In CGUS 2025, mental or emotional illness ranked among the top primary conditions requiring care, and younger caregivers are disproportionately represented: caregivers under age 50 are twice as likely to be supporting someone with a mental or emotional health condition (7%) compared to caregivers age 50 and older (4%).

IPAY 2028 Drug(s) in this Category

Rexulti	Major depressive disorder; Schizophrenia; Agitation associated with dementia due to Alzheimer's disease

Key Data Points: Mental Health Caregiving

5%	Of family caregivers identify mental or emotional illness as the primary condition for which they provide care, representing an estimated 3+ million adults nationwide.
33%	Of LGBTQ+ caregivers care for someone with an emotional or mental health challenges.
11% + 19%	Of care recipients have Alzheimer's or other dementias as their primary condition (11%), with an additional 19% of all caregivers reporting their recipient is living with cognitive impairment – meaning more than 1 in 4 caregivers are navigating memory-related behavioral challenges.
64%	Of all family caregivers experience moderate or high emotional stress, a figure that is even higher among those managing behavioral health symptoms without adequate support or resources.

Talking Points

On the caregiving burden of mental health conditions:

- Family caregivers of individuals with serious mental illness, major depression, and dementia-related behavioral symptoms face unique burdens that go largely unrecognized in standard clinical assessments. These include managing psychiatric crises, maintaining safety in the home, navigating medication regimens, and making high-stakes decisions about care settings.
- Agitation in Alzheimer's disease is not merely a behavioral symptom; it is a leading driver of caregiver burnout and premature nursing home placement. Effective treatment for agitation directly reduces caregiver burden and helps families avoid far more costly institutional care.
- Younger caregivers managing mental health conditions are twice as likely to be providing this care as their older counterparts, yet they often have fewer financial resources and less access to workplace flexibility to sustain long-term caregiving.

On access and affordability:

- When CMS negotiates prices for drugs treating mental health conditions, the stake extends beyond the individual patient. Caregivers coordinate refills, manage side-effect monitoring, provide transportation to appointments, and absorb the financial costs of care. High drug costs translate directly into caregiver financial strain.
- Nearly half of all family caregivers experience at least one major financial impact from caregiving. For those managing long-term psychiatric or neurological conditions, out-of-pocket drug costs can be a tipping point toward debt, depleted savings, or reduced care quality.
- For families managing dementia-related agitation, access to affordable medication options can be the difference between keeping a care partner at home and placing them in a costly memory care facility.

SECTION II: ONCOLOGY

Cancer is the fourth most common primary condition driving family caregiving in the United States, cited by 7% of family caregivers in CGUS 2025 as their recipient's primary illness. Cancer caregiving is among the most demanding and financially destabilizing forms of caregiving.

NAC's Cancer Caregiving Collaborative (CCC), convened with patient advocacy organizations, academic medical centers, and cancer-focused nonprofits, has produced extensive data on financial toxicity in cancer caregiving, the gaps in caregiver integration into clinical care workflows, and the structural barriers to sustaining caregiving over the course of a cancer diagnosis and treatment.

For access to NAC's cancer caregiving reports, data, and fact sheets, visit https://www.caregiving.org/cancer-caregiving-collaborative.

IPAY 2028 Drug(s) in this Category

Kisqali	Breast cancer
Verzenio	Breast cancer
Erleada	Prostate cancer
Lenvima	Thyroid cancer; Endometrial cancer; Liver cancer: Kidney cancer

Key Data Points: Cancer Caregiving

7%	Of family caregivers identify cancer as the primary condition for which they are providing care. This represents approximately 4 million caregivers of individuals with active cancer diagnoses.
47%	Of family caregivers experience at least one negative financial impact from caregiving. For cancer caregivers, financial toxicity compounds rapidly: transportation to treatment, time off work, managing complex medication regimens, and out-of-pocket costs can devastate family finances across the arc of a cancer diagnosis.

31%	Of family caregivers have stopped saving money due to their caregiving responsibilities. An additional 24% have used up their short-term savings, and 13% have drawn on retirement or education accounts.
55%	Of family caregivers perform complex medical or nursing tasks. Tasks especially prevalent and complex in cancer caregiving, including managing infusion schedules, monitoring for side effects, administering supportive medications, and communicating with oncology teams.

Talking Points

On the caregiving burden of cancer:

- Cancer caregiving does not end at the clinic door. Family caregivers manage complex oral chemotherapy and targeted therapy regimens at home, monitor for adverse events, coordinate between subspecialists, and provide the physical and emotional support that makes treatment adherence possible. The caregiver is a critical part of the treatment team, yet they are rarely visible in treatment assessments.
- Financial toxicity in cancer caregiving begins at diagnosis and compounds over time. Caregivers reduce or leave employment, absorb transportation and lodging costs, take on debt, and deplete savings.
- More than 30% of family caregivers have been providing care for five or more years, and cancer can be a chronic, long-term caregiving condition. The sustained burden of managing ongoing hormone therapy, maintenance regimens, or surveillance must be factored into assessments of access and affordability.

On access and affordability:

- Cancer caregiving is a financial emergency in slow motion. Every month of treatment brings new out-of-pocket costs, and when drug costs are unaffordable, it is the caregiver who absorbs the impact: missed work, depleted savings, and the impossible calculation of which expenses to cut.
- Insurance barriers and coverage limitations can delay or restrict treatment options. Family caregivers frequently spend substantial time navigating prior authorizations, coverage appeals, and assistance programs to secure access to necessary cancer therapies and supportive care.
- The high cost of cancer care creates significant financial strain for families. Caregivers often help manage out-of-pocket costs for medications, infusions, supportive therapies, transportation, and lodging during treatment, while also balancing potential lost income due to caregiving responsibilities.

SECTION III: IMMUNOLOGY/AUTOIMMUNE

Autoimmune diseases and conditions such as rheumatoid arthritis, lupus, psoriatic arthritis, Crohn's disease, and related inflammatory diseases are chronic, often unpredictable, and frequently disabling. The caregiving landscape for these conditions is defined by complexity, duration, and the relentless management hardship that falls on families when flares are unpredictable, and medication regimens are intricate.

A defining feature of autoimmune disease caregiving is its indefinite timeframe; these are not time-limited diseases or conditions but rather result in lifelong management needs. CGUS 2025 data show that 30% of caregivers have been providing care for five or more years, and autoimmune conditions are among the most common drivers of sustained, long-term caregiving.

IPAY 2028 Drug(s) in this Category

Orencia	Rheumatoid arthritis; Psoriatic arthritis
Xeljanz	Rheumatoid arthritis; Psoriatic arthritis; Ulcerative colitis
Cimzia	Crohn's disease; Plaque psoriasis; Psoriatic arthritis; Rheumatoid arthritis
Cosntyx	Plaque psoriasis; Psoriatic arthritis
Entyvio	Crohn's disease; Ulcerative colitis

Key Data Points: Autoimmune Disease Caregiving

73%	Of care recipients experience at least two categories of health conditions simultaneously. Many autoimmune diseases have comorbid conditions, compounding the caregiving complexity for family managers.
5.5 years	Is the average duration of caregiving in the US. For autoimmune conditions, caregiving frequently extends across decades—amplifying the lifetime financial, physical, and emotional impact on family caregivers.

45%	Of family caregivers experience moderate or high physical strain. For those managing autoimmune conditions in loved ones, the caregiver's own physical toll—assisting with mobility, administering injectable therapies, managing flare-related crises—is significant.

1 in 3	Caregivers find care coordination "challenging." Autoimmune disease care typically involves multiple specialists (e.g., rheumatologists, gastroenterologists, dermatologists), creating coordination demands that fall heavily on family caregivers.

Talking Points

On the caregiving burden of autoimmune diseases:

- Autoimmune disease caregiving is unpredictable like the diseases themselves. Flares can be sudden and severe, requiring caregivers to instantly shift from their own lives and work to crisis-level support. The episodic but chronic nature of these conditions makes it nearly impossible for caregivers to plan or sustain economic stability.
- Many autoimmune treatments are administered via injection or infusion. Family caregivers often administer these medications, manage storage requirements, monitor for serious side effects, and navigate complex prior authorization and specialty pharmacy processes. This invisible labor is a direct extension of the treatment regimen.
- For conditions like rheumatoid arthritis, treatment adherence is directly tied to caregiver support. When high drug costs force patients to skip doses, ration medications, or delay treatment, caregivers bear the downstream consequences in the form of more intensive hands-on care during flares and setbacks.

On access and affordability:

- Autoimmune disease patients and their caregivers frequently face coverage gaps, step therapy requirements, and prior authorization barriers that delay access to prescribed medications. Accounting for the real-world access challenges that affect patients and their caregivers is vital.
- For autoimmune patients, a missed dose or delayed refill can trigger a flare that puts them in the hospital. When medications are hard to access, patients ration medications, and caregivers absorb the crisis that follows. Affordable access to maintenance therapy is a caregiver health issue, not just a patient health issue.

SECTION IV: INFECTIOUS DISEASES

Infectious disease conditions requiring ongoing medication management create distinct caregiving dynamics shaped by long-term treatment adherence, stigma, social isolation, and the intersection of physical and mental health needs. CGUS data includes HIV/AIDS as a surveyed condition in which the reality reflects that many Americans living with HIV require family caregiver support.

Infectious disease caregiving often occurs in contexts of heightened vulnerability: caregivers may themselves face health risks, stigma-related stressors, and limited access to support services. The need for consistent medication adherence makes drug affordability especially critical. Missed doses or treatment interruptions in infectious disease management can have serious health consequences that cascade quickly into more intensive caregiving demands.

IPAY 2028 Drug(s) in this Category

Biktarvy	Human immunodeficiency virus type 1 infection

Key Data Points: Infectious Disease Caregiving

47%	Of all family caregivers report at least one negative financial impact from caregiving. For caregivers managing chronic infectious disease conditions over years or decades, cumulative financial strain compounds significantly.
56%	Of caregivers felt they had no choice in their caregiving role. Those caregivers—who are disproportionately managing complex, long-term conditions—report nearly twice as many poor mental health days as caregivers who felt they had a choice.
24%	Of caregivers report feeling alone, a number that rises sharply for caregivers managing conditions with social stigma. Isolation is both a driver and consequence of under-supported caregiving in infectious disease contexts.
64%	Of family caregivers report moderate or high emotional stress. Caregivers managing infectious disease conditions carry the added hardship of navigating stigma, disclosure decisions, and their own anxiety about the care recipient’s prognosis.

Talking Points

On the caregiving burden of infectious diseases:

- For people living with HIV and other managed infectious diseases, medication adherence is the cornerstone of health stability. Caregivers play a critical role in supporting adherence by managing refills, monitoring side effects, facilitating transportation to providers, and providing the emotional support that sustains treatment engagement over decades.
- Stigma compounds the caregiving burden. Caregivers of individuals with HIV/AIDS may not feel they can disclose their caregiving role to employers, neighbors, or extended family, limiting their access to support, flexibility, and community resources.

On access and affordability:

- The long-term nature of infectious disease management means that even modest per-prescription cost reductions, compounded over years, can meaningfully reduce the cumulative financial burden on caregiving families.
- For low-income caregiving families, who are disproportionately represented in infectious disease care contexts, out-of-pocket drug costs can force impossible trade-offs. CGUS 2025 data shows that 14% of caregivers have been unable to afford basic expenses like food and utilities.
- When there are barriers to accessing medication, infectious disease management fails rapidly. Unlike some chronic conditions where suboptimal dosing has a gradual impact, infectious disease treatment interruptions can have immediate and serious consequences that caregivers must respond to, often without warning.
- Consistent access to antiretroviral medication is not optional. It is the difference between health and crisis. Family caregivers manage nearly every aspect of that access: scheduling, refills, transportation, and insurance navigation.

SECTION V: RESPIRATORY

Respiratory conditions are among the most physically demanding caregiving situations. CGUS 2025 data show that lung disease and Chronic Obstructive Pulmonary Disease (COPD) are common conditions requiring care, with caregivers often managing continuous monitoring, oxygen or nebulizer equipment, and emergency response. Respiratory caregiving also requires managing environmental triggers, coordinating with specialists, and maintaining medical equipment. As many respiratory conditions worsen with age, caregiving intensity often increases over time.

IPAY 2028 Drug(s) in this Category

Anoro Ellipta	Chronic obstructive pulmonary disease
Xolair	Asthma; Chronic spontaneous urticaria

Key Data Points: Respiratory Conditions Caregiving

55%	Of family caregivers perform complex medical or nursing tasks. In respiratory caregiving, these tasks include operating nebulizers, oxygen tanks, and suctioning equipment. This specialized care is often performed without formal training.
22%	Of caregivers who perform medical/nursing tasks say those tasks are difficult. Caregivers managing complex respiratory equipment and emergency protocols are disproportionately represented among those reporting difficulty.
28%	Of caregivers have had difficulty finding affordable services for their care recipients over the past decade including home health aides and equipment support. This figure rises to 34% in rural areas.

Talking Points

On the caregiving burden of respiratory conditions:

- Respiratory caregiving is often physically exhausting and emotionally relentless. Caregivers of individuals with severe asthma or COPD are on high alert around the clock monitoring breathing, managing acute exacerbations, maintaining equipment, and responding to emergencies that can escalate rapidly.
- Many respiratory conditions worsen progressively, meaning caregiving demands increase over time. Caregivers who begin with medication management and monitoring often transition to managing home oxygen systems, feeding tubes, or ventilator equipment. This caregiving trajectory has enormous physical and financial implications.

- Biologic therapies for severe asthma have been transformative for patients by reducing exacerbations, hospitalizations, and emergency room visits. For caregivers, this translates into reduced crisis caregiving and improved quality of life and caregiver well-being.

On access and affordability:

- Biologic therapies for severe asthma can cost tens of thousands of dollars annually. For Medicare beneficiaries and their caregiving families, cost-sharing requirements can make these drugs effectively inaccessible.
- Uncontrolled severe asthma and COPD are among the most common drivers of preventable hospitalizations. When drug access is limited, patients are undertreated, exacerbations increase, and caregivers absorb the care burden of repeated crises.
- Caregivers managing COPD and severe asthma don’t just manage medications; they manage equipment, coordinate pulmonology visits, respond to emergencies, and calculate whether we can afford next month’s refill.

SECTION VI: METABOLIC DISORDERS

Metabolic disorders are a growing driver of family caregiving needs, particularly as conditions like Type 2 Diabetes become more prevalent and complex to manage over time. Caregivers often assist with daily disease management, including monitoring blood glucose, managing medications such as insulin, supporting nutrition and physical activity, and coordinating care across multiple providers.

Because metabolic disorders are closely linked to complications such as heart disease, kidney disease, and vision loss, family caregivers play a critical role in helping to manage symptoms, preventing complications, and sustaining long-term health outcomes.

IPAY 2028 Drug(s) in this Category

Trulicity	Type 2 diabetes; Type 2 diabetes and cardiovascular disease or multiple cardiovascular risk factors

Key Data Points: Metabolic Disorders Caregiving

44%	Of caregivers are in high intensity care situations, often performing complex medical or nursing tasks such as medication management or injections.
70%	Of family caregivers monitor health conditions and coordinate care for their care recipient. These tasks are central to managing metabolic diseases that require ongoing monitoring, medication adherence, and lifestyle management
64%	Of family caregivers report experiencing emotional stress related to caregiving, which can be heightened when managing long-term conditions such as metabolic diseases that require continuous monitoring and lifestyle adjustments

Talking Points

On the caregiving burden of metabolic disorders:

- Metabolic disorders require constant daily management. Family caregivers often help monitor blood glucose, manage medications such as insulin, support nutrition and physical activity changes, and track symptoms, making caregiving a continuous, hands-on responsibility.
- Caregivers are essential to preventing serious complications. Because metabolic disorders are closely linked to conditions such as heart disease, chronic kidney

disease, and diabetic retinopathy, caregivers play a critical role in helping manage risk factors and ensuring consistent treatment and monitoring.

- Care coordination across multiple providers adds complexity. Caregivers frequently help navigate appointments and treatment plans across primary care providers, endocrinologists, dietitians, and other specialists, serving as the central coordinator of care.

On access and affordability:

- The ongoing expenses associated with managing conditions like Type 2 Diabetes including medications, glucose monitoring supplies, healthy food, and frequent medical visits can place significant financial pressure on households, often forcing caregivers to absorb additional out-of-pocket costs.
- Access to consistent treatment and supplies is critical for effective disease management. When medications, monitoring technology, or specialist care are difficult to access or afford, caregivers must spend additional time navigating insurance barriers, coordinating prescriptions, and advocating for the care their loved ones need.

SECTION VI: NEUROLOGICAL CONDITIONS

Neurological conditions are a significant and growing driver of family caregiving needs, particularly as conditions such as chronic migraine and spasticity become more widely recognized for their long-term impact on daily functioning and quality of life. Caregivers often help manage the day-to-day realities of these conditions, including supporting medication management, assisting with mobility and physical limitations, monitoring symptoms, and coordinating care across multiple providers and therapies.

Because neurological conditions can affect movement, cognition, and the ability to perform everyday activities, family caregivers play a critical role in helping individuals manage symptoms, navigate treatment options, and maintain independence and quality of life over time.

IPAY 2028 Drug(s) in this Category

Botox; Botox Cosmetic	Chronic migraine; Overactive bladder; Spasticity; Other movement disorders

Key Data Points: Neurological Conditions Caregiving

1 in 4	Caregivers report providing 40 or more hours of care per week, the equivalent of a full-time job. This reflects the significant daily support often required for people with neurological symptoms affecting mobility, cognition, or daily functioning.
60%	Of family caregivers are employed while providing care, and many experience works disruptions such as arriving late or leaving early, or reducing hours in order to coordinate care, attend medical appointments, or manage symptoms.

Talking Points

On the caregiving burden of neurological disorders:

- Neurological conditions often require intensive, ongoing care. Family caregivers frequently help manage complex symptoms such as chronic pain, mobility limitations, muscle stiffness or spasticity, and cognitive challenges, while coordinating care across multiple specialists and treatment plans.
- Daily disease management places significant demands on caregivers. For conditions such as chronic migraine and neurological disorders that cause spasticity, caregivers assist with medication management, transportation to frequent appointments, monitoring symptoms, and supporting activities of daily living.

- Many caregivers must reduce work hours, miss work, or leave the workforce entirely to meet the unpredictable and often time-intensive needs associated with neurological conditions.
- Managing chronic and often invisible neurological symptoms can create ongoing stress, uncertainty, and fatigue for caregivers who must remain constantly attentive to changes in their care partner's condition.

On access and affordability:

- Access to specialized neurological care often depends on caregiver coordination. Family caregivers frequently navigate complex referral systems, long wait times, and travel to specialty providers to ensure their care partner receives appropriate diagnosis, treatment, and ongoing management.
- The cost of neurological care can place significant strain on families. Caregivers often help manage out-of-pocket expenses for medications, therapies, mobility supports, and transportation to frequent appointments, which can create substantial financial pressure over time.
- Insurance and coverage gaps can limit access to needed treatments. Family caregivers frequently advocate for coverage of medications, rehabilitation services, and supportive therapies, spending significant time navigating prior authorizations and appeals to ensure their care partner receives appropriate care.

RESOURCES & REFERENCES

Centers for Medicare and Medicaid Services (CMS) Resources

- Medicare Drug Price Negotiation Program
- Selected Drugs for IPAY 2028
- Public Engagement Events

Family Caregiving Advocacy Resources

- Caregiving in the U.S. 2025 Data Hub
- Caregiving in the U.S. 2025 National Report
- Caregiving in the U.S. 2025: Caring Across States
- National Alliance for Caregiving IPAY 2028 Comment Letter

Additional Advocacy Resources

- National Health Council IPAY 2028 Patient and Provider Toolkit

For additional information or questions, please contact
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