





#### **Preamble**

Obesity is a serious yet treatable chronic disease, just like diabetes, hypertension, and heart disease. Yet, <u>only about 10 percent of adults with obesity get medical attention</u> from health professionals.

The problem is not a lack of scientific research on how to treat obesity. Many medical societies, including the American Medical Association, agree that obesity is a complex disease requiring treatment. And today, new research linking obesity to dysfunctional signaling in the brain has led to a new class of safe and effective FDA-approved anti-obesity medications that achieve the meaningful weight loss associated with improved health outcomes by targeting receptors in the brain that control appetite and food cravings.

Why then are people living with obesity not receiving quality care? The reasons have to do with long held misperceptions about the cause of obesity among the public and pervasive weight bias on the part of health professionals, employers, insurers and even government agencies. Simply put, obesity is not considered on par with other serious chronic diseases because most Americans, including health professionals, still believe obesity results from a lack of willpower and is the person's fault, and that lifestyle strategies alone are enough to make a difference. Thus, most people with obesity do not seek care and those who do often face discrimination in the healthcare system based on their size.

It can't be overstated how harmful this outdated thinking is. Currently, 42 percent of the public – more than 100 million adults – are living with obesity, making obesity the most prevalent chronic disease in the United States. Yet, the burden of obesity is even greater in communities of color and among people aged 60 and older who have the highest rates and due to stigma, ageism, and lack of healthcare services and coverage, face higher rates of disability, disease and premature death. Furthermore, experiences of trauma in Indigenous populations contribute to the disproportionate impact of obesity and their related health conditions.

Compounding the problem, <u>obesity is a "co-morbid condition" for more than 230 chronic diseases</u> – meaning that as the amount of excess weight increases, these other diseases worsen in severity. Due to this direct link between obesity and chronic disease, <u>as many as 400,000 people in the United States are estimated to die</u> every year from obesity and the dollars spent on medical care, lost wages, absenteeism, lost productivity and other expenditures are estimated to be <u>\$1.72 trillion annually</u>.

Thus, addressing the persistent and pervasive problem of untreated obesity cannot wait. This means "breaking glass" to destigmatize obesity, end weight bias within the healthcare system, and confront the inequities in obesity care among people aged 60 and over and within communities of color.

This is the purpose of the *Obesity Bill of Rights* – to empower all adults to demand the respect of their health providers regardless of their age, gender, ethnicity, sexuality and weight status and to be screened, diagnosed, counseled and effectively treated for their overweight and obesity based on medical treatment guidelines.

Starting with the recognition that obesity is a treatable disease and that everyone with obesity deserves the same level of attention and care as those with other chronic conditions, the *Obesity Bill of Rights* ensures people with obesity have trusted science-based, easy-to-understand information about obesity; an accurate diagnosis from a qualified health professional; patient-centered obesity counseling; information about available treatment options; considerate, respectful, and nondiscriminatory care from medical professionals; and insurance that provides access to the treatments deemed appropriate by the health provider, including lifestyle interventions, FDA-approved anti-obesity medications, and bariatric surgery.

### **Empowering Americans as Equal Partners in Decisions About Obesity Care**

According to the latest national data on obesity in the U.S. population, <u>73.6 percent of US adults</u> has either overweight or obesity. This translates to three in four people ages 18 and older.

For too long, many of these adults have encountered a healthcare system that works against them. They have been stigmatized, discriminated against, not treated with respect by their health providers, and have faced significant hurdles and burdensome requirements to receive obesity care.

On behalf of all adults, the National Consumers League, National Council on Aging and leading obesity, public health and aging leaders say enough! Now is the time to give people with obesity the knowledge, skills and confidence so they can obtain the same attention and quality care as those with other chronic diseases.

This is the purpose of the first-ever *Obesity Bill of Rights*, which establishes and promotes aware-ness of eight major rights as the core requirements for adults with overweight or obesity to receive person-centered quality obesity care. And, to ensure these requirements are met, the *Obesity Bill of Rights* lays out a set of guarantees associated with these rights. Collectively, these guarantees will empower adults to take charge of their care – from prevention, screening and receiving a diagnosis of obesity to making informed decisions about their care and having access to the full contingent of treatment options as prescribed by their health providers.

The following are the core requirements for quality obesity care established through the *Obesity Bill of Rights*.

## The Right to Accurate, Clear, Trusted and Accessible Information

All people have the right to accurate, science-based, accessible and patient-informed information on obesity as a treatable chronic disease.

Specifically, people have the right to:

- Accurate, trusted information in culturally appropriate and easily understandable language that explains obesity as a complex chronic disease requiring personalized treatment.
- Accurate, trusted information about diet and lifestyle behavior changes that can improve health and prevent or reduce the risks associated with overweight and obesity.
- Accurate, trusted information about how to screen for overweight and obesity and how clinicians make their assessment and diagnosis.
- Accurate, trusted information about how obesity is treated across the care continuum and the different treatment options, ranging from lifestyle change counseling and FDA-approved anti-obesity medications to bariatric surgery.
- Free access to this information in clinics, health care offices, community-based organizations and through a wide variety of channels
- ► Free access to accurate, trusted information on obesity care from reputable sources, including academic institutions, medical and public health organizations, advocacy groups, online patient communities, and community/state/federal government agencies.
- Free access to tools and resources to navigate through the challenges of managing a complex chronic disease.

# The Right to Respect

All people with overweight and obesity have the right to receive timely, effective obesity screening, counseling and treatment delivered by all members of the integrated care team in a considerate and respectful manner.

Toward this end, people with obesity have the right to:

- Demand treatment without discrimination or bias regardless of their size or weight.
- Expect the same professional conduct and access to care for their obesity as is routine for other chronic conditions.
- Ask questions about their weight status during all healthcare visits and receive answers and appropriate referrals in a timely manner.
- Receive information from their health providers in "patient-first" language, which puts a person before a diagnosis, describes the condition the person "has," and gives the person a sense of dignity when selecting a treatment plan and interacting with members of the care team.
- Speak in confidence with members of the care team and have the health information protected.
- Expect a clinical setting that allows for privacy and maintains the person's dignity.

## The Right to Make Treatment Decisions

# All people with overweight and obesity have the right to make decisions about their health goals and obesity care in consultation with their health provider.

Because obesity is different in every person and requires individualized care, individuals with obesity have the right to:

- Receive a clear, understandable diagnosis based on their degree of excess fat accumulation and their risk factors, such as age, smoking, family history and the presence of obesity-related comorbid conditions.
- Expect accurate and thorough information from their health provider about all safe and effective treatment options for their care. These include behavior modification, community-based programs, access to nutritional and/or mental health counseling, medical obesity management, FDA-approved anti-obesity medications, and bariatric surgery.
- Expect information about treatment outcomes in easily understood language on the risks and benefits associated with each treatment and what options are not covered by health insurance.
- Seek and have coverage for a consultation with a health professional knowledgeable in obesity care regarding treatment options.
- Have time to carefully consider the different treatment options before making a decision.
- Give or withhold informed consent.
- Refuse treatment.

### The Right to Treatment from Qualified Health Providers

# All persons with overweight and obesity have the right to receive counseling and treatment from health providers with expertise in obesity care.

Just as there are specialists trained in caring for people with diabetes, osteoarthritis and other chronic diseases, a growing number of health professionals have received training that qualifies them to understand how to address the root cause of obesity and how best to use obesity medicines in both clinical and community settings.

Taking advantage of this positive development, adults with obesity have the right to:

- Ask and receive full information from their health provider about that professional's knowledge, experience and credentials in obesity care.
- Know if the practice includes a dietitian and/or health educator trained to counsel people with excess weight on appropriate obesity-related care and eating disorders.
- Be informed of the medical and related services available at the facility.
- Be referred to and have insurance coverage for a specialist in obesity medicine to provide comprehensive obesity care.

- Be referred to and have insurance coverage for a diverse range of credentialed health professionals (including dietitians, nurses, and health educators) to deliver intensive behavioral therapy (IBT) in a variety of locations. IBT involves counseling patients on nutrition, physical activity and behavior change and is an important yet underutilized component of obesity care because it is often restricted to primary care physician offices.
- Have access to telemedicine to receive care from obesity trained physicians and health providers, especially in rural and medically underserved areas.

### The Right to Person-Centered Obesity Care

All people with overweight and obesity have the right to receive obesity care that is personalized, reflects their cultural beliefs, meets their specific health goals and considers their whole health, not just their weight status.

Because obesity is a complex chronic disease, individuals with obesity are entitled to the same best standards of care as those with other chronic conditions. This necessitates the expertise and services of a range of health providers working to provide coordinated care. As such, people with obesity have the right to:

- Demand that caregivers, family members or friends are included in consultations with the lead clinician and care team.
- Choose an interprofessional care team with expertise in obesity care to provide care coordination, counseling and treatment. Optimally, the care team comprises a physician or physician assistant, a nurse or nurse practitioner, and a dietitian or related specialist who provides direct counseling and patient support. Other team members can include an exercise physiologist, social scientist and mental health specialist.
- Agree on a personalized care plan prior to the start of treatment that lays out the roadmap for ongoing obesity care. Included in the plan are regular medical appointments; physical activity and behavior modification interventions; use of evidence-based treatment options such as anti-obesity medications and bariatric surgery when appropriate; and long-term assessment and follow-up.
- Have questions answered by the care team in a timely manner.
- Be informed that commonly prescribed drugs taken for health problems other than obesity such as beta blockers, contraceptives and antidepressants may work differently because obesity affects the activity of these drugs. In some situations, this can lead to underdosing and ineffective treatment. In other cases, concentrations of the drug may stay significantly longer in the body with the potential for adverse effects.
- Receive considerate, respectful and compassionate care in a safe setting.

- Have access to and insurance coverage for a health educator trained in obesity management as a key part of the care team. Currently, a national network of diabetes care and education specialists works with patients to set and achieve behavior change and medication management goals. The same types of health professionals could be trained quickly to play this role for adults with obesity.
- Voice a complaint and ask for changes to the care team or treatment plan without fear and interruption of care.
- Make a formal complaint to a local or state governing board of a health professional exhibits bad behavior or engages in discriminatory practices associated with weight bias.

## The Right to Accessible Obesity Care and Services from Health Systems

All people living with obesity have the right to receive obesity care in health systems that are equipped and accessible for larger body sizes.

Well over 15 million US adults have severe obesity, a serious medical condition characterized by more than 100 pounds of excess weight or having a body mass index (BMI) of 40 or higher. Yet, because these individuals face rampant discrimination in the health system, they are unlikely to receive quality obesity care. Instead, the 9.2 percent of adults with severe obesity routinely encounter health spaces and diagnostic equipment that do not accommodate larger body sizes, receive drug doses often based upon standard body sizes, are misdiagnosed by health providers unequipped to provide care, and are refused surgeries that are medically necessary due to their size.

Putting an end to these injustices is a goal of the obesity community, which calls for redesigning health care settings as places of dignity and respect for all people with obesity, regardless of size. For this to happen, adults with obesity must have the rights to:

- A clinical setting that allows for privacy and maintains the person's dignity. This includes access to wider furniture in waiting rooms, wider doors, gowns in larger sizes, a private weighing room and other welcoming accommodations.
- Health spaces and equipment within the clinical environment that are size-and weight-accessible, such as larger hospital beds, lifts and stretchers, examination tables, wheelchairs, scales, and diagnostic/medical equipment in examination and treatment rooms.
- Diagnostic services from trained radiologists using specialized imaging and image-guided interventions, such as CT scans and MRI machines that are designed for large body sizes.
- Medically necessary obesity treatment without step-therapy or an overly burdensome preauthorization process.

- Access and health coverage for bariatric surgery and medically appropriate surgical interventions (such as total knee and hip arthroplasties) without restrictions based on BMI.
- Obesity treatment support from patient advocates and patient navigators to address the individual's transportation, nutrition, and financial assistance needs.

### The Right for Older Adults with Obesity to Receive Quality Obesity Care

People aged 60 and over who have overweight, and obesity face different health challenges when seeking obesity care and deserve respect and a comprehensive care approach consistent with their personalized medical needs.

The simple truth is that older adults face not only weight bias but also ageism when seeking obesity care. Living with these stigmas presents unique challenges in the health care system, especially because <u>older adults have a different physiology</u> than those younger than age 60. A key issue among older adults is the combination of obesity and the naturally occurring decline in skeletal muscle mass called sarcopenia, which increases the risk for disease and requires tailored treatment.

Recognizing these challenges, people over age 60 living with obesity have the right to:

- Expect obesity care from health providers who are both specialists in the diseases and illnesses of older adults and are knowledgeable in obesity care.
- Be screened with diagnostic tools that account for loss of muscle mass. This may entail combining BMI and waist circumference measurement.
- Be evaluated for treatment based on the person's functional ability, chronic illness, and social determinants of health outcomes and daily challenges such as transportation and health literacy.
- Have a care plan tailored to the person's health goals, stage of life and medical needs.
- Have access to and full coverage for all obesity treatments across the continuum of care, including lifestyle change counseling, FDA-approved anti-obesity medications (AOMs), and bariatric surgery.
- Have access to and full coverage for a health educator in obesity as a key part of the care team.
- Receive community-based weight management and obesity treatment services, including support from patient advocates and patient navigators to address the individual's transportation, dietary needs and financial assistance needs

### The Right to Coverage for Obesity Treatment

All people living with obesity have the right to the full contingent of treatment options for their disease as prescribed by their physicians through health insurance that is widely available, comprehensive and affordable.

Today, many employers and both public and commercial insurers exclude obesity management services or place access barriers that delay or deny treatment. Consequently, obesity remains largely undiagnosed and undertreated, leading to higher rates of costly chronic diseases.

To change this situation, obesity should be a covered benefit in health insurance so those with the disease are afforded the same rights and access to care as they are for other chronic diseases. Therefore, adults with obesity must demand the right to:

- Comprehensive coverage for obesity prevention, treatment, and care as an essential health benefit required for all health plans.
- Comprehensive coverage for obesity treatment under Medicaid plans.
- Medicare policies that are equitable for all older adults. This requires modernizing the outdated interpretation of Medicare Part D rules that exclude coverage for FDA-approved anti-obesity medications (AOMs) and Medicare Part B rules that restrict access to intensive behavioral therapy solely to primary care providers.
- Coverage that considers obesity treatment as a personal decision that is best left to the individual and his/her healthcare provider.
- Coverage that removes discriminatory benefit design language from health plans, which severely restricts obesity treatment services. This means ending lifetime limits on treatment, caps on the number of visits (for example, one dietitian visit a year), high co-pays and deductibles, and policies that require step-therapy or an overly burdensome preauthorization process.
- Coverage allowing the individual to be referred to and treated by a credentialed health provider trained in obesity care.
- Coverage allowing the individual to receive support from a health educator trained in obesity care.
- Benefit from the discounts and rebates their health plan receives from drug manufacturers to lower the cost of anti-obesity medicines.
- Patient assistance programs for anti-obesity medications to make these medications equitable and affordable for adults with lower incomes.

#### The Call to Action

Psychologist Nathaniel Branden said, "The first step toward change is awareness. The second step is acceptance."

For leading obesity experts and the nation's medical, public health, aging and consumer orga-nizations, these steps are only the start of what is needed for people with obesity to receive quality obesity care. Overcoming the difficult challenges that preclude so many people from getting screened, diagnosed and treated for their obesity requires systems change at every level of the healthcare delivery system.

But movement is only possible when there is a national will to act and the *Obesity Bill of Rights* can be the spark.

By defining quality obesity care as the right of all adults, the *Obesity Bill of Rights* provides the call to action for the public to demand the same respect, attention, and access to treatment for people with obesity as those with other chronic diseases receive.

As such, the *Obesity Bill of Rights* can be the impetus for reversing the trajectory of the nation's obesity epidemic by advancing awareness of untreated obesity, acceptance that obesity can no longer be discounted, and the insistence that health professionals, employers, insurers and policymakers expand the opportunities for the prevention and treatment of obesity at all stages across the life course.