



American Pain Foundation Fibromyalgia Talking Points

- **Fibromyalgia is a chronic pain disorder characterized by widespread musculoskeletal pain that has lasted for at least three months.**
 - People with fibromyalgia report general tenderness and soreness, stiffness (especially in the morning), flu-like aching, poor sleep as well as fatigue.
 - An estimated six million Americans have fibromyalgia, most of them women.

- **As with other chronic pain conditions, many people with fibromyalgia will consult multiple health care providers and often live with the pain for years before it is properly diagnosed and managed.**
 - Only one in four people with fibromyalgia are actually diagnosed with this condition.
 - On average, it takes five years to be correctly diagnosed.
 - Unlike many conditions, fibromyalgia cannot be detected through a blood test or X-ray.
 - Because fibromyalgia can mimic other diseases, such as low thyroid (hormone) production, lupus, multiple sclerosis and rheumatoid arthritis, it can be challenging for many health care providers, especially in the primary care setting, to diagnose fibromyalgia.
 - It is important to communicate openly with your health care provider about specific symptoms, other medical conditions you might have, as well as ways in which the pain interferes with your everyday life.

- **Fibromyalgia continues to be poorly understood. Fibromyalgia is real and can be devastating for people living with it and their family members.**
 - While the exact causes of fibromyalgia are not fully known, it is recognized as a legitimate medical condition by reputable experts and professional groups, including the National Institutes of Health, the American Medical Association and the American College of Rheumatology, among many others.
 - Undiagnosed or untreated fibromyalgia can affect relationships with a person's family members, friends and employers.
 - Lost work days and disability payments can impose a large economic burden on the person with fibromyalgia as well as society.
 - Direct costs (diagnostic tests, provider visits, prescriptions) and indirect costs (lost productivity due to fibromyalgia) cost on average \$35,000 a year per person with fibromyalgia.

- **Pain doesn't discriminate. It affects people of all races and socio-economic status and at all stages of life — from our very young to our elders.**
 - Fibromyalgia occurs in men and women; however, 90% of those diagnosed are women.
 - The prevalence of fibromyalgia increases with age.

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- **Unjustified stigmas and barriers often prevent people with fibromyalgia symptoms from being properly diagnosed and treated.**
 - Because of the difficulty in diagnosing fibromyalgia, people with fibromyalgia symptoms are often not believed or thought of as “hypochondriacs” or “drug seekers.”
 - Many providers, often in the primary care setting, are not trained to diagnose someone with fibromyalgia.
 - Insurance carriers often deny access to approved medical treatments and non-medical therapies for managing fibromyalgia.

- **As with many other types of pain, appropriate and timely treatment is important to reduce suffering and help people with fibromyalgia take back their lives. When pain is appropriately treated, many people can resume daily activities and can be productive citizens again.**
 - Presently, there is no cure for fibromyalgia, but there are treatments that can help.
 - Many people have found ways to have a good quality of life while living with fibromyalgia.
 - The bottom line is — people with fibromyalgia have a right to timely and effective care.

References:

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NOTE: These messages should build on and reinforce core APF/Action Network messages about the undertreatment of pain as a major public health crisis that results in needless suffering, as well as the challenges faced by people living with pain.

See <http://www.painfoundation.org/take-action/action-network/documents/talking-points-pain-care-advocacy.pdf>.

Talking points specific to fibromyalgia should be integrated into outreach as needed.

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