GLP-1 Medications and Marfan Syndrome and Related Conditions: What You Should Know

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Maintaining a healthy weight can be challenging for anyone, and people with Marfan, Loeys-Dietz, VEDS, Stickler and related conditions are no exception. As GLP-1 receptor agonists (GLP-1RAs), commonly known as GLP-1 medications, become more widely used, people in our community may be wondering whether these medications are appropriate for them. While they can offer significant benefits, there is still much we don't know about their use in people with these conditions.

Mary Sheppard, MD, an Assistant Professor of Medicine and Co-Associate Director of the Saha Aortic Center at the University of Kentucky, who also lives with Marfan syndrome, shares what those in our community should consider before deciding whether a GLP-1 medication is right for them.

Are GLP-1 medications considered safe for people with Marfan syndrome and related conditions?

Right now, we simply don't have enough data to know that GLP-1 medications are safe for all people with Marfan syndrome and related conditions. However, we can at least specify subgroups for whom data suggests that GLP-1 medications are NOT safe. Across the board, GLP-1 medications are contraindicated in pregnancy and breastfeeding. They should also be used with caution in people with severe gastroparesis or significantly delayed gastric emptying. Certain genetic aortic and vascular conditions are known to cause abnormalities in gut motility. In the general population, people with pre-existing motility disorders are advised to undergo a baseline motility assessment prior to starting GLP-1 medications.

What conversations should community members have with their healthcare team before taking a GLP-1 medication?

It is important to weigh the risks against the benefits of therapy on an individual basis, which should include syndrome-specific factors. For example, which health risks are already associated with your syndrome? Is there any overlap with known side effects of GLP-1 medications? If so, your individual risk to benefit ratio might not justify the use of GLP-1 medications. Alternative approaches to weight loss might be advisable. For example, people with Marfan and related conditions have an increased risk of migraines. Migraines are often triggered by specific foods, drinks, and sleep patterns. GLP-1 medications are known to impact appetite, which may also impact fluid intake and sleep. Therefore, shared decision-making with a provider who is aware of your entire medical history, which includes a sensitivity to migraines, is critical.

What does emerging research tell us about GLP-1 medications and aortic health?

One retrospective study of people with thoracic aortic disease has shown that people taking GLP-1 medications experienced improvements in aortic dissection incidence as well as cardiovascular and overall mortality. However, it is important to explain that people with Marfan, Loeys-Dietz, and Ehlers-Danlos, and related conditions comprised less than 2% of the people in the study. Therefore, we do not have enough information to make definitive conclusions, especially for people with these specific types of conditions.

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How important are nutrition and exercise while taking these medications?

Attention to nutrition and exercise is critical. Rapid weight loss can cause a decrease in lean muscle mass. Maintaining adequate protein intake is an important way to help preserve lean muscle mass. Whether these GLP1-related risks are increased in people with Marfan and related conditions is unknown.
In addition, GLP-1 medications appear to decrease bone mineral density in the general population, but not in people with type 2 diabetes. The impact of GLP-1 medications on bone mineral density in people with these conditions is unknown, as well as any subsequent impact on fracture risk. However, regular weight-bearing exercise is key to maintain bone health and prevent bone loss in all people.

Are there other potential concerns?

Appetite: GLP-1 medications suppress appetite, so it can be helpful to establish routines and/or set reminders to eat even when you do not feel hungry.

Dehydration: in the FDA Adverse Event Reporting System pharmacovigilance study, dehydration was the most frequent adverse event contributing to serious outcomes for several GLP-1 medications. Many people with connective tissue disorders take high doses of angiotensin receptor blockers (ARBs) and/or beta-blockers, which could increase their risk of adverse effects related to dehydration. This might include lightheadedness, fainting, or even acute kidney injury. Therefore, it is important to ensure adequate fluid intake while taking GLP-1s, even though you might not feel thirsty.

Long-term use: GLP-1 medications may need to be considered a long-term treatment rather than a short-term approach to weight loss. A 2025 meta-analysis of eight randomized controlled trials involving 2,372 participants from the general population with a BMI of 27 or higher found that weight regain after stopping GLP-1 therapy was proportional to the amount of weight originally lost, even with lifestyle interventions. Before starting treatment, it is important to consider how weight loss will be maintained over time. This may mean continuing the medication long term, with cost and access as important considerations, or working with a healthcare team to develop another strategy for maintaining a healthy weight.

Before starting a GLP-1 medication, talk with your cardiologist, geneticist, or other healthcare provider about the factors currently affecting your overall health and how the medication might improve or worsen them. The answer may be different for every person and among each condition.

For answers to non-urgent medical questions about Marfan, Loeys-Dietz, VEDS, Stickler, and related conditions, contact the Marfan Foundation's Help & Resource Center at marfan.org/ask.