THE MARFAN FOUNDATION

AGING WITH MARFAN SYNDROME

Marfan syndrome is a progressive disorder, which means that features can worsen as a person ages. Still, as awareness has grown and treatments have improved, people with Marfan syndrome and related disorders can now reasonably expect to live a lifespan comparable to the general population. Our Help & Resource Center frequently speaks with people in our community who are over the age of 60, 70, and even 80 years old!

This achievement can be celebrated, but it also means members of our community are facing additional challenges as they age. Parents of children with Marfan syndrome and related disorders may also be wondering what their child will experience in later years.

It is understandable to have a new set of questions about medical and quality of life issues and about all the practical implications of aging with Marfan, from a potentially shortened work life to chances of getting to be a grandparent. Gaining a better understanding of what to expect can allow one to prepare early and find support for staying informed and keeping up the fight.

What will aging with Marfan syndrome or a related disorder be like?

Regular Effects of Aging Apply - People with Marfan syndrome are not immune to all that regularly comes with age. However, because many of these age-related changes involve joints, general aches and pains, and eyesight, the combination can amplify certain challenges. In addition, in Marfan syndrome, some of the problems related to aging happen earlier than in the general population. Marfan syndrome is a connective tissue disorder. Connective tissue is part of all organs and systems of our bodies, so each of these systems may be affected by age.

What are some of the specific conditions people with Marfan syndrome and related disorders need to be checked regularly for, especially as they age?

EYES ▸

• *Glaucoma* People with Marfan often get early glaucoma and need to be checked regularly.

• *Pre-senile Cataracts* This is a clouding of the eye lens before age 60. Cataracts are common in older people who do not have Marfan syndrome, but people with Marfan syndrome can get cataracts at younger ages—even before age 40.

• *Lens Dislocation* For people with Marfan syndrome, this complication is most likely to happen in people under 20, but it can happen at any age. If and when it does happen in older people with Marfan syndrome (age 70 or over), the dislocation happens very quickly and it is likely to happen in both eyes.

BONES AND JOINTS ▸

• *Osteopenia and Osteoporosis* People with Marfan syndrome or related disorders need to check bone density at an earlier age. The joint laxity that is characteristic of Marfan can lead to osteopenia and osteoporosis with more prevalence and at much younger ages than in the general population.

• *Protrusio acetabulae* In some people with Marfan syndrome, the hip sockets become deep during growth. This is called protrusio acetabulae. The acetabulum is the socket of the hip joint. The cause of this condition is not known. It does not cause problems or symptoms in childhood. In adulthood, the deepened sockets can lead to earlier arthritic change, which is noted with aching in the hips or groin. This affects less than five percent of people with Marfan syndrome. Some people with this diagnosis need to have artificial hips in middle age or later.

• *Dural ectasia* A unique feature of Marfan syndrome is swelling (or ectasia) of the spinal cord sac (dura), and it becomes more prevalent in people with Marfan over age 36. The condition occurs when the spinal cord sac cannot withstand the pressure of the spinal fluid. If swelling occurs, it is frequently in the lower part of the lumbar or sacral spine. Sometimes, the enlarged sac will actually press into adjacent spaces, such as the pelvis.

HEART AND BLOOD VESSELS ▸

It is true that complications with the aorta — the large artery that takes blood away from the heart – are more common in younger people. Unfortunately, the aorta can enlarge even in older adults with Marfan syndrome. Therefore, life-long monitoring is necessary to safeguard against problems affecting the heart and aorta.

Remember that much about aging with Marfan syndrome and related disorders is still unknown. And, because the disorder manifests differently in everyone, it is hard to predict. For more information on the effects of Marfan syndrome and related disorders on the various bodily systems, see our downloadable fact sheets.

Will Marfan syndrome affect my ability to work as I age?

There is no definite answer for every individual on working ability. However, many people with Marfan syndrome do find it harder to maintain full-time or even part-time work as the disorder progresses.

If I find it difficult or impossible to work, what is the process for applying for Social Security disability?

It's important to note that Marfan syndrome and related disorders are not enough, by themselves, to qualify for Social Security disability status.

Impact of the disorder and functional limitations must be demonstrated clearly. To prepare for applying, get copies of all medical records and keep a daily health journal listing all your activities (including any problems doing them), symptoms, appointments, test results, etc.

Even then, initial applications may be denied. Don't lose heart if that first application is denied. There are further steps you can take, and The Marfan Foundation can help with this process by providing information about Marfan syndrome and related disorders that supports your application.

For more tips on the process of applying for Social Security disability, please contact our Help & Resource Center, **support@marfan.org.**

Are there any support groups specifically aimed at the older demographic of people with Marfan syndrome or related disorders?

Yes! We have a 50+ phone support group. Topics covered include everything from comfortable shoes to concerns about when it's Marfan or something else causing an issue. And research shows it is tremendously beneficial to participate in support groups—for emotional, medical and practical reasons.

For example, in a survey of 174 Marfan syndrome patients, researchers found that educating others about the condition assisted them in coping[1]. Respondents also reported that involvement with the Foundation was a critical component for alleviating the stigma they felt as a result of their condition[1]. In addition, in a separate qualitative study of 68 people who participated in self-help groups that were primarily health-related, the researchers found that the three greatest benefits were creating a sense of togetherness, learning from each other, and developing mutuality[2].

To learn more about our phone support groups and how to participate, please visit **http://www.marfan.org/phone-support-groups.**

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1 Peters, K. F., Apse, K. A., Blackford, A., McHugh, B., Michalic, D., & Biesecker, B. B. (2005). Living with Marfan syndrome: Coping with stigma. Clinical Genetics, 68(2), 6-14.

2 Avis, M., Elkan, R., Patel, S., Walker, B., Ankti, N., & Bell, C. (2008). Ethnicity and participation in cancer self-help groups. Psycho-Oncology, 17, 940-947.