Marfan Trust
Supporting Research into Inherited Aortic and Related Disorders

Loeys Dietz

CONNECTING THE UNCONNECTED AND STRENGTHENING LIVES

Growing Older with Marfan and Loeys-Dietz Syndromes

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What Are Marfan & Loeys-Dietz Syndromes?

Marfan and Loeys-Dietz syndromes are inherited genetic disorders of the body's connective tissue, affecting any gender, race or ethnic group. Connective tissue helps provide structure to the body, binding skin to muscle and muscle to bone. It also supports the internal organs.

Connective tissue is made of fine fibres and 'glue'. One fibre is called fibrillin. In Marfan syndrome (MFS), a change in the fibrillin-producing gene, fibrillin-1, means that this protein is deficient in connective tissue throughout the body, creating an unusual stretchiness and weakness of tissues. This has far-reaching implications and can affect the eyes, lungs, gut, nervous system, skeleton and, most dangerously, the cardiovascular system. Symptoms can vary widely from person to person with people experiencing mild to severe manifestations. MFS affects roughly 1 in 3,000 people which means that approximately 18,000 people in the UK have MFS. We estimate that half remain undiagnosed.

75% of patients inherit the condition whilst 25% develop it as a result of a spontaneous (new) gene change. Each child of an affected parent has a 50% chance of inheriting Marfan syndrome.

Every year, on average in the UK there are over 200 new cases of Marfan Syndrome diagnosed.

Marfan syndrome was first described by a French paediatrician, Dr Antoine Marfan, in 1896. It is caused by a change in the gene for fibrillin-1 on Chromosome 15.

Patients with Loeys-Dietz syndrome (LDS), were once thought to have Marfan syndrome, such are the similarities between the two conditions.

LDS was first described in 2005 by Drs Bart Loeys and Harry Dietz. It is caused by a variant in one of the genes in the transforming growth factor-beta signalling pathway, TGF-β. The genes that cause LDS are: TGFβR1, TGFβR2, SMAD3, TGFβ3 and TGFβ2. TGF-β is a crucial signalling pathway involved in various cellular processes, including cell growth and immune responses. It is a key player in development and tissue repair. When a gene change occurs, it has implications for many systems of the body. Whilst symptoms vary from patient to patient, with some being similar to those of Marfan syndrome, the most characteristic are: arterial tortuosity, aortic enlargement, bifid uvula, curvature of the spine, high-arched palate and over-crowded teeth.

This pamphlet is intended for patients with both Marfan and Loeys-Dietz syndromes.

Loeys-Dietz syndrome is much rarer than MFS and the incidence is currently gauged to be 1 in 100,000 although this is probably an underestimation.

While Marfan syndrome had first been described in 1896 and there was awareness of the condition, in the earlier half of the 20th century, the life expectancy of an individual with Marfan syndrome was low. In 1972 the average was around 32 years (Murdoch et al, 1972). This was largely due to the lack of effective monitoring and treatment options for aortic dilatation and dissection. With the advent of effective surgical options to treat the aortic complications of MFS as well as medical advances, the average life expectancy of an individual with MFS is now much greater and beginning to approach that of the general population (Jędrzeejewska-Rzezak, 2025).

The genetic advances that have come since the 1990s, identifying the gene responsible for MFS and describing other conditions (like LDS) that would previously have been described as MFS, mean that diagnosis, follow-up and treatment can be more tailored and targeted.

With these amazing advances we need to be aware that there is now a population of people with MFS who are experiencing aging for the first time. This raises a new set of questions, and it is important that your health care providers consider your MFS in the context of aging in order that your ongoing care is individualised to meet your unique needs.

Pyeritz (2018) discussed the need to consider aging in MFS and highlighted 3 questions that need to be addressed:

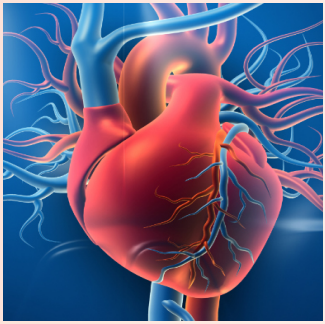
- How do the features of MFS change over time into the 5th/6th/7th decades of life?
- Do new features of MFS appear as individuals age that have not previously been described?
- Do the normal issues of aging affect people with MFS differently?

We don't have the answers to a lot of these questions yet, and more research is needed.

This information aims to highlight some of the aspects of the conditions that you might need to think about as you get older and draws on some of the valuable experiences of our wonderful membership who generously share in the hope of helping others with their journey. The aim is always to be living well with Marfan or Loeys-Dietz syndromes. As individuals with these conditions grow older, they may face unique challenges, but with proper management and awareness, they can lead fulfilling lives. This article explores the implications of aging with a connective tissue disorder and offers insights into navigating this journey.

Much of the following information refers to Marfan Syndrome (MFS), as most of the research and data collected so far has focused on individuals with this condition, mainly because Marfan Syndrome is less rare than Loeys-Dietz syndrome and has been recognised for a longer period of time. There is overlap between the two conditions. However, as you know, there is huge variability in how each individual is affected by their condition and this information cannot cover every experience. It needs to be read in the context of YOUR experience and further, specific advice, should be sought from your specialist medical team if you are in any doubt.

Lucy has Marfan syndrome



Young or old, one of the most important considerations is monitoring and surveillance as the cornerstone of maintaining your heart and aorta health, planning surgery appropriately to avoid emergency situations. Hopefully, by the time you get a bit older you have found a doctor with whom you have built up a trusting relationship and who is aware of your past medical history. This might be an ideal scenario, but some people move around, doctors retire, and you may need to find a new specialist you can trust.

It is important that you are organised and keep a record of letters, scan results, operation details and discharge summaries of any admissions you may have had. If you move to a new area or are referred to a new doctor this can help them build up a picture of the treatment you have been receiving and what might be necessary in the future.

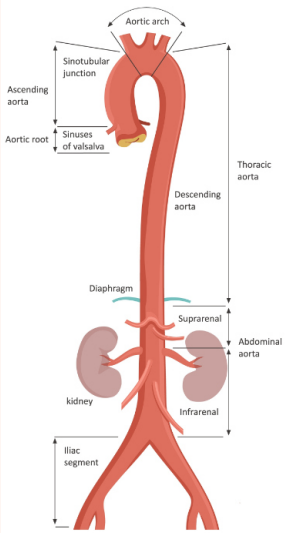
The majority of people with MFS will be taking some medication to prevent or delay issues with the aorta. It's important that these medications are taken regularly. Two groups of tablets are usually used, Beta Blockers (e.g. Bisoprolol, Atenolol) and Angiotensin Receptor Blockers (ARBs) (e.g. Losartan, Irbesartan).

Many people are now having aortic surgery at a young age and will need monitoring throughout their lives. Longterm outcomes in some of the newer types of surgery are not available so your experiences are really important to build up a picture of how people with Marfan syndrome are aging when they may have had one or more operations at a younger age.

As you know, the patient is often the expert where rare conditions are concerned. You can use the wealth of knowledge and experience you have gained to help educate the next generation of health care professionals. Your medical team may ask if you are willing to be examined by medical or nursing students; you might be asked to participate in some of the exams for trainee doctors. Do consider these opportunities or ask your doctor if they need volunteers for exams, doctors are much more likely to remember a condition and think about it if they have met, talked to and examined someone with that very condition.

In addition to the Marfan-related effects on the heart and aorta, as you age, you may find that other heart issues can arise, as happens within the general population. You may develop high blood pressure, heart rhythm disturbances or other problems like angina (chest pain caused by narrowing of the arteries supplying the heart muscle with blood) or risk factors for heart problems, like high cholesterol. It's important that your GP keeps an eye on these in addition to your Marfan syndrome. Don't ignore new symptoms if they arise; they may not all be attributable to MFS.

AORTIC SEGMENTS



Risk Factors

As we age, our risk for several conditions increases, for example, heart disease, diabetes, high blood pressure and stroke. To mitigate these in older age it is important to maintain a healthy lifestyle from a young age. Positive choices can reduce your risk of developing these problems.

- Give up smoking or vaping
- Drink alcohol in moderation (UK guidelines suggest 14 units a week or less for men and women)
- Eat a healthy, balanced diet
- Maintain a healthy weight
- Take regular exercise and remain as physically active as you can within the context of your Marfan syndrome
- Prioritise sleep and rest
- Try and limit stress in your life or develop strategies to help manage the inevitable stresses that cannot be avoided

Musculoskeletal system

Unfortunately, the musculoskeletal system can be affected from a young age with the familiar problems of joint hypermobility, scoliosis (spinal curvature), pectus problems (dip in or protrusion of chest), hip and foot problems being an issue for many people with MFS. Chronic pain and fatigue also go hand in hand and impact quality of life in MFS.

Encouragingly, there are now very good surgical techniques for correcting a degree of scoliosis and the NHS has recommissioned surgery for severe pectus excavatum (dip in chest). We have details on our website about pectus surgery in particular - **https://www.marfantrust.org/resources/pectus-problems**

It is possible to develop some of the musculoskeletal issues associated with aging alongside MFS and these include osteoarthritis and osteoporosis.

Osteoarthritis (**https://www.nhs.uk/conditions/osteoarthritis/**)

In osteoarthritis, the protective cartilage on the ends of your bones breaks down, causing pain, swelling and problems moving the joint. Bony growths can develop, and the area can become swollen and red (NHS, 2023). If symptoms are mild, lifestyle changes such as losing weight, wearing good shoes and taking regular exercise may help. If symptoms are more severe, painkillers, physiotherapy or surgery to the joint may be necessary.

Darren is a keen supporter of the Marfan Trust and volunteers his time and extensive graphic design skills generously to help with all our valuable publications. He also helps to run a large online Marfan support group via Facebook.

Darren has been affected by Marfan syndrome throughout his life although he didn't receive a formal diagnosis until he was a teenager. He lost his father when he was just a baby (his father died of complications of Marfan syndrome although this was not diagnosed at the time). Darren subsequently underwent extensive aortic surgery at the age of 14 and required redo aortic surgery in 2021. He has a chronic type B dissection that is monitored.

Unfortunately, Darren has also had eye and musculoskeletal problems that occur with Marfan syndrome. He had cataract surgery to both eyes in his early 40's and is anticipating further surgery as new ones are developing. Darren is now 54.

He has struggled with hypermobile joints throughout his life and is now experiencing arthritis in his lower spine, knees and neck as well as his foot and wrist. This is in addition to dural ectasia which causes significant pain.

Darren's advice is to try different strategies to find the ones that work for you. He uses medication, heat treatments and joint supports to help with his chronic pain but also finds it important to know his limits and be active and take exercise within these limits. By maintaining his physical activity, he hopes to maintain the levels of mobility he has.

Darren's volunteering is also important to him and enhances his mental health and feeling of wellbeing. He would encourage others to get involved and support a cause that is important to them. As we get older, we eventually retire or are unable to work but volunteering gives the opportunity to offer as much as you can of a valuable commodity, time.

Osteoporosis/Osteopenia (**https://www.nhs.uk/conditions/osteoporosis/**)

Osteoporosis means that the bones become gradually weakened and more prone to fracturing. It is sometimes only diagnosed when a fracture occurs. Osteopenia precedes osteoporosis and means that you have lower bone density than other people of your age.

Risk factors include:

- Women lose bone density after menopause due to falling levels of oestrogen
- Longterm steroid use
- Family history
- Low body mass index
- Heavy drinking and/or smoking
- No regular exercise

Echoing the previous section, lifestyle at a younger age can impact bone and joint health in later life so it's important to think about positive changes that can help prevent these problems occurring or deteriorating:

- Take regular weight bearing exercise – this means an exercise that requires you to carry your body weight, like walking, dancing, stair climbing, gardening etc. Swimming is still a great exercise for people with MFS but it is not weight bearing
- Yoga or Pilates are also exercises that can help with core strength and stability, which helps maintain balance and good posture
- A healthy diet rich in calcium and vitamin D can be beneficial (The UK recommends that everyone take a vitamin D supplement of at least 10 micrograms a day during autumn and winter as we don't receive sufficient sunlight.) Foods rich in Vitamin D include oily fish
- Women may consider using Hormone Replacement Therapy (HRT) both to prevent menopausal symptoms and to maintain bone density. Not everyone is able to take HRT and this will need to be discussed with your specialist doctors e.g. cardiologist.

Philippa shares her experiences of coping with growing older and the work she does to stay healthy and free from pain.

I'm a 55 year old female and was diagnosed with a heart murmur at 13 and Marfan Syndrome at 24. I count myself as lucky as I haven't needed any surgery to date and have lived a full and active life. I'm married with two children (one with Marfan Syndrome) who are now in their early 20s. I started taking beta blockers in my early 40s and have recently started taking ramipril for my mitral valve prolapse. One of the things I have learnt over the years is that I need to be very proactive in managing my symptoms and that I feel much better when my self-care is a priority. I have suffered with back and joint pain since my early 20s and in those days, I relied on osteopaths (with limited success), painkillers and Pilates. These days my back and joint pain are better than they were when I was younger. I have a weekly one to one yoga therapy session, do a tai chi class at my local gym, have Alexander Technique lessons, do a weekly meditation class, as well as my own practice, and I try to walk or stretch every day to keep everything moving. To be honest it feels like a full-time job just maintaining my body and staying as pain free as I can. When I start skipping the things I do regularly or there's a long summer break I feel my body start to seize up and I usually end up feeling stuck, miserable, in pain and needing to see an osteopath to get me moving again. I've also done quite a bit of therapeutic work on myself which has included dealing with feelings of anxiety about having Marfan Syndrome (and passing it on to my daughter), how I feel about my body and how it felt feeling very different to my peers and siblings when I was younger (including being bullied at school). This work has meant I have started to see myself in a different way and I feel more confident about the things I can do rather than worrying about the things I can't do. I can move my body in my yoga practise in ways that I couldn't have managed in my younger days which feels good. I'm fortunate that I don't work and am able to dedicate so much time to my physical and emotional wellbeing and I understand not everyone has that luxury. I'm due to talk to a surgeon in the coming months about having my mitral valve repaired or replaced and my aim in the lead up to that is to feel as strong as I can both physically and mentally. The one thing I still find difficult is managing my fatigue which feels like an invisible symptom and I don't think people around me understand quite how tired I feel on some days. I'm also not great at explaining my levels of fatigue to others or allowing myself to rest when I need to. But I'm working on it.

Eyes

Most people with MFS who have ectopia lentis (dislocated lens) experience this in the first two decades of life but it can occur at any age. The risk of glaucoma, cataracts and retinal detachment are all increased in MFS so regular eye health checks are important throughout life. If surgery is required, an ophthalmic surgeon with experience of treating individuals with MFS is recommended.

The use of protective equipment such as goggles or protective headwear is recommended for some sports, for example squash, to prevent eye injury.

Regular eye tests and hearing tests into old age are also important to ensure that glasses and hearing aids are used as appropriate. They can help to reduce the risk of falls. Note: Ectopia Lentis is not seen in LDS, it is specific to MFS.

Respiratory

Some of the skeletal features of Marfan syndrome can affect the respiratory system, for example, kyphosis (outward curving of the spine causing hunching), scoliosis (side to side curving of the spine) and pectus abnormalities. These can deteriorate with age and may reduce lung volume. As mentioned previously, many of the problems are dealt with during adolescence and the period of rapid growth but this needs to be monitored over time to pick up any deterioration.

Pneumothorax, sometimes called a collapsed lung, means that there is air in the cavity between the chest wall and the lung. The risk of pneumothorax is higher in Marfan syndrome than in the general population and it is estimated that between 4 and 11% of people with MFS will suffer from a spontaneous pneumothorax (Hao et al, 2017). Older people may be more likely to develop blebs or bullae in their lungs which can increase the chance of pneumothorax (these are air filled sacs that can form in the lungs when the delicate tissue of the air sacs or alveoli in the lungs break down). There is not much that can be done to prevent this occurring (apart from not smoking) but awareness is important.

Sleep apnoea

Sleep apnoea is a sleep disorder in which your breathing stops and starts overnight, your breathing can pause or be very shallow for periods of time. This can happen frequently throughout the night. The most common type is Obstructive Sleep Apnoea (OSA).

OSA happens when the upper airways are narrowed to start with and can become blocked during the night when you sleep. One of the main risk factors is overweight and obesity but research has shown that people with Marfan syndrome (MFS) can also be at increased risk, probably due to some of the craniofacial features, for example, a setback lower jaw and the increased collapsibility of the upper airways. The prevalence of sleep apnoea in MFS is estimated to be between 30-42% in the literature (Gessler et al, 2022).

OSA is a cause of significant fatigue and daytime sleepiness so it's important to rule this out as a possible reversible fatigue.

https://www.nhs.uk/conditions/sleep-apnoea/

Amanda (name changed) will be 67 this year and shares some of the important things she prioritises every day to maintain her quality of life.

Her main issues include chronic fatigue and serious back and hand pain that affect her daily, these can significantly limit what Amanda can do. She has found it important to limit her activities and not try to do too much on a good day because she will suffer the next day. It may be that she is able to do a short shopping trip with a friend but after that she needs to rest and recuperate to ensure that her pain symptoms and fatigue do not flare.

Due to the extensive musculoskeletal issues that Amanda has faced, a great physiotherapist has been one of the vital keys to maintaining her health which she describes here:

"I have worked hard WITH my physiotherapists, and it is so important for me to maintain a physio devised daily exercise program. In the early 80s when I was around 20 years old, I was lucky enough to be treated at the local cottage hospital by a physio who quickly developed a keen interest in MFS. When she set up on her own, I became one of her first patients. Everybody in the area loved her & still do. I would say she is the Magdi Yacoub of our town in the physio scene!

We learnt about Marfan together and she has always been a tremendous support.

Actually, I've been twice blessed because the physio who eventually took over the practice worked alongside my first physio for many years and has for over 20 years now been the greatest support with her thorough understanding of MFS. She appreciates my need for knowledge & willingly explains things in detail. She too has become a good friend.

I'm sure I have taught her a lot over the years. And she, has taught me a lot. it is a partnership. I have implicit faith in her. That is so important. She is patient and kind and on numerous occasions has fitted me into her busy schedule when I really needed it and countless times has been on the end of the phone for me. She really cares. She goes above and beyond. She is the Gold Standard as was my first physio.

Over the years she has devised a tailor-made program of daily maintenance exercises for me, which we review from time to time. She has also referred me to other specialist physios when appropriate for continence/vestibular problems.

It's important to spend time doing some research and finding a physiotherapist you can trust and work with. I am very fortunate & I know from speaking to other people that it is not always possible to see the same physiotherapist. But if you can, then I think it is important to do so.

I know I have said this before but, "A patient with Marfan Syndrome is like a vintage car, treatment should be a partnership with somebody who understands the idiosyncrasies & wants to learn from the owner."

I would say the most important things in my armoury are my acupuncture pen and a machine with ultrasound and interferential. These are indispensable to my daily life. Well worth the long-term investment."

Another invaluable piece of advice Amanda offers is the importance of pelvic floor exercises from a young age. These are important for everyone but somebody with a connective tissue disorder may struggle more with a weak pelvic floor as they age. These exercises are easy to do but they are also easy to forget! Amanda recommends sticking a few red dots around your house, when you see them, they will trigger your memory and encourage you to do a few exercises before you go on your way.

Finally, Amanda does not underestimate the importance of her supportive partner and family in helping her manage her Marfan syndrome.

Gastrointestinal symptoms

As people age, their nutritional needs will change, and their tastes might too. Some people prefer to eat smaller meals more often or lose their appetite. It's important to maintain good nutritional intake as this helps your body maintain health.

- Good protein intake is important for maintaining muscle mass
- Ensure adequate hydration
- You may need to supplement Vitamin D and calcium to help maintain bone health

Some older people suffer from constipation, this can hopefully be avoided by staying hydrated, eating adequate amounts of fibre and remaining active. If it is still a problem, do speak to your pharmacist or GP as new medications or changes in your diet could exacerbate this.

As with constipation, other bowel symptoms should not be ignored as they could be a sign of more serious illness and require investigation. The UK has a national bowel cancer screening programme (different eligibility ages apply in England, Scotland, Wales and N. Ireland so please check your area). You will be invited to provide a sample every 2 years. **https://www.nhs.uk/conditions/bowel-cancer-screening/**

Red Flag symptoms - need to be reported to the GP for further investigation

- Bleeding from the rectum
- Weight loss of more than half a stone without trying
- Any persistent change in bowel habit (more than a month) for no obvious reason like change to diet, new medication, stress
- Persistent fevers or tiredness

Research has demonstrated a link between connective tissue disorders and functional gastrointestinal disorders (FGIDs). A large amount of this research is the in Ehlers Danlos population (EDS) and shows a higher prevalence of symptoms than in the Marfan population and the general public. More work is needed in the MFS population as these are symptoms that are often described by our members and require investigation by their medical specialists.

What is a Functional Gastrointestinal Disorder (FGID)

A group of disorders characterised by chronic gastrointestinal (GI) symptoms in the absence of obvious, demonstrable pathology. This means that often, despite tests and investigations, some patients do not find a cause for their symptoms. This can feel frustrating.

Any significant change to bowel habit should be discussed with the GP who can arrange appropriate investigations. There may be structural causes for the symptoms that require treatment, and these can be diagnosed with tests such as blood tests, colonoscopy, gastroscopy.

More detailed information is available in our gastrointestinal information leaflet which can be found here. - https://www.marfantrust.org/resources/information-guides-

Genito-Urinary Issues

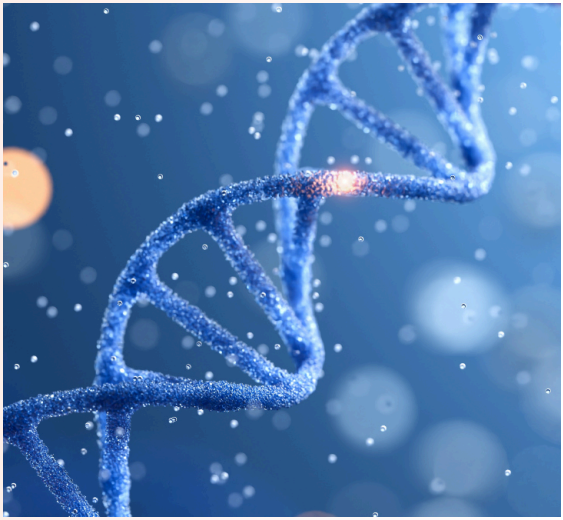
Unfortunately, genitourinary issues can be more prominent in MFS. The risk of these problems rises with age in the general population but for people with MFS, the risks are greater still. Von Kodolitsch et al (2020) reported a greater frequency of incontinence symptoms in people with MFS than in controls from the general population. This was regardless of the lower number of pregnancies experienced by women with MFS.

Pelvic floor exercises can be helpful in reducing these symptoms but if you are experiencing issues, the most important thing to do is talk to someone. These symptoms are common and can contribute to problems like social isolation because people are less willing to leave their house and risk less access to a toilet. GPs are able to help and make a referral to a specialist if required.

Genetics and Genetic Counselling

Vast leaps have been made in the field of genetic testing and diagnostics. Some older people will have been diagnosed with MFS prior to the advent of genetic diagnosis. Your family members may also have received a clinical diagnosis too, based purely on their symptoms and your family history.

It is worth deciding if your family would benefit from genetic testing to establish whether there is an identifiable gene change responsible for your condition. . This could be useful for diagnosis in other family members or for the prevention of passing on the gene change to future generations. Technology has developed to allow Preimplantation Genetic Diagnosis (PGD) in which In Vitro Fertilization (IVF) techniques are used to create embryos. Only those embryos unaffected by the gene change will be reimplanted. This is only possible if the specific gene change affecting your family is identified.



If you or your family have never been offered genetic testing, you may want to consider this. Begin by speaking with your GP or one of your specialist team who can arrange a referral to a geneticist for you.

Social Isolation

Social isolation is a problem experienced by many older people and can be due to a range of issues. These include:

- Declining physical health
- Frailty or disability which makes it difficult to go out
- Financial constraints
- Death of friends and loved ones
- Lack of transport or mobility
- Retirement

It's important to try and maintain a social network around you and build connections. You could try volunteering for a cause that you feel passionate about once you have more time on your hands. Keep up the connections you already have with friends and family and try building new ones. Take up a new hobby you have been longing to try for ages or join a local club. The Marfan Trust has local support groups springing up all across the country. Visit our website to find your nearest group of friendly members, **https://www.marfantrust.org/pages/local-support-groups**

Most importantly, talk to someone about how you are feeling, whether it be a friend, your GP or us via the helpline.

Mental Health As a result of social isolation or the strain of living with a chronic health condition, mental health can suffer in MFS. People with this condition report lower health related quality of life than the general population on average.

Chronic pain and/or fatigue, living with uncertainty and repeated surgeries or hospitalizations can affect our mental health, and this can increase with older age.

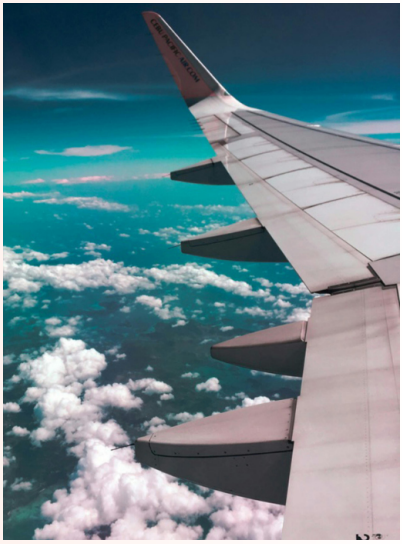
Again, the advice is to talk to a trusted friend, family member or professional who can help you work through the issues and seek further help if necessary.

Insurance – Travel, Life and other

TRAVEL

Obtaining insurance can be a problem throughout life for individuals with MFS. The way in which you are affected, the number of surgeries you may have had or the monitoring you are undergoing, can all feed into your insurance risk and make it more difficult and expensive to obtain the insurance you need.

In these circumstances, we recommend you speak with either an insurance broker or a specialist firm who can offer insurance despite your more complex needs. It is possible to obtain insurance, it may just take longer. We have comprehensive information about insurance on our website - **https://www.marfantrust.org/resources/5-travel-insurance-information**



Conclusion

Great scientific advances in the diagnosis of MFS/LDS along with improvements in surveillance, treatment and management mean that people with these conditions are often living longer, healthier lives.

Your experiences are important and will help answer some of the many questions we still have about these connective tissue disorders.

Mrs Val Greatorex is a grandmother with MFS mainly affecting her eyes. Her poem summarises a lifetime of experience with the condition in herself, her children and grandchildren.

So often we wonder what life has in store
The future is hazy ,vague pictures we draw
Sometimes gloomy and hopeless, then hopeful, less dim
Yet always uncertain, not knowing is grim

We listen to stories and try to explore
All pathways of happenings to others, not sure
That perhaps indications might lead us to think
This could happen to me, let's panic and shrink

Do stay open minded, let order prevail
Our syndrome can vary, not fixed on a trail
We are different, yet similar, this is the key
So we hope for the future, and just wait and see

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The Marfan Trust

Co-founded in 1988, the Marfan Trust is the sole charity in the United Kingdom dedicated to improving and saving the lives of those with Marfan syndrome. It is estimated that approximately 18,000 people are living with Marfan syndrome in the United Kingdom and we estimate that half remain dangerously undiagnosed.

The Marfan Trust's three main objectives are to:

- provide personalised support and medical guidance through its helpline;
- conduct cutting-edge medical research through its self-funded Sonalee Laboratory, named after a young doctor who tragically died of complications from MFS during her ward round;
- continue to provide educational information and raise awareness of the condition.

Marfan Trust
Supporting Research into Inherited Aortic and Related Disorders

Loeys Dietz

CONNECTING THE UNCONNECTED AND STRENGTHENING LIVES

How you can help

The Marfan Trust relies solely on the goodwill of its unstoppable supporters who tirelessly raise funds and awareness, allowing the charity to continue its good work and lift the shadow from this condition.

Marfan Trust
Supporting Research into Inherited Aortic and Related Disorders

Loeys Dietz

You can help to secure the Marfan Trust's future by becoming a member today for just £3 per month:

www.marfantrust.org/pages/10-membership

JustGiving®

Just Giving – **http://bit.ly/3Scj51w**

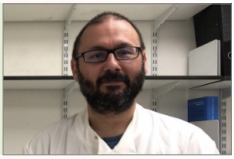
PayPal

PayPal Giving – **https://bit.ly/45NCuwQ**

- BANK: Charities Aid Foundation (CAF) ACCOUNT NAME: Marfan Trust
- SORT CODE: 40-52-40
- ACCOUNT NUMBER: 00017677
- REFERENCE: Your Name (plus campaign name if relevant)

By donating to the Marfan Trust, you are contributing to an ever-growing body of knowledge on the condition, allowing more doctors and medical specialists to deliver the best possible treatment to patients affected by Marfan syndrome.

You can also help to fund a piece of equipment in Dr José Aragon-Martin's Sonalee Laboratory. Email **info@marfantrust.org** to find out more.



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