Marfan Trust
Supporting Research into Inherited Aortic and Related Disorders
Loeys Dietz
CONNECTING THE UNCONNECTED AND STRENGTHENING LIVES

Marfan Trust Guide for Schools and Colleges

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.

Medical Emergency

The following emergencies are rare, but it is imperative that all adults in the school or college are aware of them before dealing with young people with MFS/LDS.

There are five rare complications requiring emergency care. If you suspect that a child in your care is experiencing any of these, please call an ambulance. When you speak to the paramedic call handler, it is important to mention that the child suffers from MFS/LDS and that this puts them at increased risk of these rare, but severe problems.

- **Aortic dissection** – the child may present with severe chest or back pain and may become unconscious. This is a **life-threatening medical emergency** and the child should be transferred to a hospital as soon as possible.
- **Collapse of lung (pneumothorax)** – this can occur spontaneously in MFS and may happen during periods of exertion. The child could present with severe breathlessness, may become blue and complain of chest pain which is worse when they try to breathe in. This condition is not always life-threatening but requires **immediate hospitalisation**.
- **Glaucoma** – a dislocated lens may produce a sudden increase of pressure within the eye, causing acute eye pain. This condition requires **urgent medical attention and treatment to avoid blindness.**
- **Detached retina** – this is a separation of the membrane at the back of the eye from its supporting layers and can also cause severe vision loss or blindness if not treated. This requires **urgent medical attention.**
- **Joint dislocations** – loose ligaments do not provide adequate support for joints, and dislocation (knees and shoulders are most frequently affected) may require hospital admission for treatment.

It is important that all staff (teachers/clerical staff/lunchtime supervisors) within the school/college are aware of the procedures to be followed in a medical emergency and that plans are put in place for field trips/school outings as well as routine school days. It is also important to note that these potential complications are rare and children with MFS/LDS should be given the opportunity to participate in all suitable school activities without fear. For most children this will include all school and play activities other than contact sport.

Marfan-associated medical issues: their treatment and impact on school/college life

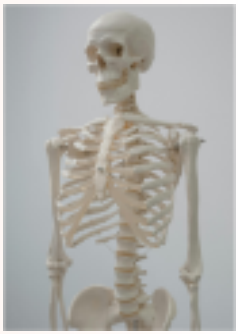
There is no cure for MFS/LDS, but symptoms can be managed. Everyone with this condition needs careful monitoring tailored to their specific situation. Symptoms vary from person to person.

Some pupils with MFS/LDS will be attending regular medical appointments with a whole variety of specialists, often far away, and may miss many days of school as a result.

1.Physical features which may be present:

- Crowded teeth, high arched palate
- Tall and thin body type
- Flat feet
- Sunken or protruding chest
- Flexible joints
- Curved spine
- Long arms, legs, and fingers
- Unexplained stretch marks on the skin

2.Skeleton and nervous system:



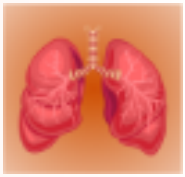
Musculo-skeletal problems are common and troublesome in MFS/LDS. Involvement of the skeleton can include curvature of the spine (scoliosis/kyphosis/lordosis), abnormally shaped chest ("pectus" deformity), tall stature and loose joints (joint hypermobility) that can lead to chronic pain and joint dislocations.

Careful monitoring of the skeleton is important, particularly during the rapid periods of growth in childhood and adolescence. In addition to an Orthopaedic doctor, children may need to see other healthcare professionals such as an Orthotist if aids or shoe inserts are needed to assist with posture and walking. Sometimes actions are taken to inhibit growth in an attempt to prevent excessive height. This can be done with surgery or medication and requires input from an Endocrinologist.

Dural ectasia (widening or ballooning of the dural sac which surrounds the brain and spinal cord) can cause back pain, leg pain, abdominal pain, and headache amongst other symptoms.

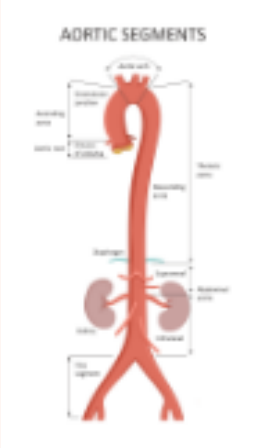
Crowded teeth might require regular Orthodontist visits. The discomfort or pain from skeletal problems may need several adaptations to a child's routine or the equipment they use.

3.Lungs:



Spontaneous collapse of the lung (pneumothorax) with breathlessness and chest pain occurs in about one affected child in 20. This problem requires prompt attention but is usually not life-threatening.

4.Cardiovascular system:



The most serious, life-threatening problems associated with MFS involve the cardiovascular system. Within the heart, the two leaflets of the mitral valve may billow backwards when the heart contracts, a condition called “mitral valve prolapse”. If the mitral valve prolapse becomes severe it can lead to heart failure and/or rhythm disturbances so sometimes an operation will be needed to fix this.

The aorta (the main artery carrying blood away from the heart) is sometimes wider and more fragile in people with MFS. This widening is progressive and may result in leakage of the aortic valve or the development of tears (dissection) in the aorta wall.

Medications (e.g. beta blockers or angiotensin receptor blockers to slow aortic enlargement) may be prescribed to reduce strain on the aorta and regulate the heart rhythm. The medications can lead to tiredness and lethargy. Surgical repair may be required if the aorta continues to widen, and the risk of tears therefore increases.

Children and young people will be seen regularly by a Cardiologist for scans of their heart and aorta. These scans will check for any change to the heart function or size of the aorta and are usually done on at least an annual basis or if there are any changes to the child’s symptoms (e.g. becoming more short of breath during PE or at play).

5.Eyes:

People with MFS are generally short-sighted (myopic). In addition, some have dislocation of the lens known as Ectopia Lentis and/or retinal detachment due to the weakened connective tissues holding the lens in place. This may require surgery. This may affect their ability to see in class or when working.

Regular eye tests will be required; the child will be seen by an Ophthalmologist if there are problems with lens dislocation and if surgery is required. Any difficulty with a young person’s ability to see will need to be accommodated.

6.Bowel:

A proportion of patients with MFS/LDS have gastrointestinal disturbances with abdominal pain, bloating, constipation and diarrhoea. In the general population, IBS (irritable bowel syndrome) commonly first develops in young adults and teenagers. They may need to access a toilet frequently or quickly. Bowel issues requiring GP or Gastroenterologist visits, medication and dietary requirements may also need to be accommodated by school or college. LDS can also increase the likelihood of allergies.

The requirement for appointments with several different specialists means that sometimes absences from school will be unavoidable to ensure the child is getting all the care and input they need to meet their full potential. For some pupils this will mean a significant disruption to their learning at times during their school life.

School/college accessibility and adaptations

Most children and young people with MFS/LDS will cope well in the regular school system but they may need adaptations and adjustments to achieve their full potential within the learning environment.

Legislation including the Equality Act 2010 and the Children and Families Act 2014 protects the right to these equal opportunities in law.

Children with MFS/LDS demonstrate the same range of abilities as all children. However, the variability of symptoms in MFS/LDS requires an Individual Healthcare Plan (not to be confused with the legally binding Education Health and Care Plan (EHCP)). There is useful advice for supporting children with medical conditions at school in this Department for Education document, **https://assets.publishing.service.gov.uk/media/5ce6a72e40f0b620a103bd53/supporting-pupils-at-school-with-medical-conditions.pdf**.

The needs of each child will be different and careful dialogue with the child, parents, school, and healthcare professionals will be needed.

Parents may require a legally binding "Education, Health and Care Plan" if the school requires additional resources to make the necessary adaptations. Age- appropriate focus on a child's strengths and their educational requirements are vital.

Of note, children with MFS can be exceptionally tall and this can have a variety of consequences. They can appear much older than their chronological age and therefore, often be treated as such. It is important to remember this and expect the same of them as their peers.

The child may outgrow small classroom furniture very quickly and need more appropriate chairs or desks to allow them to work comfortably and effectively; as the child moves into senior school, these adaptations need to be in place in all areas the child will visit. These differences can make the child feel "apart" from their peers and it is important to monitor their integration within the class.

The following are just a few examples of adaptations that might be required: (taken from the Disability Rights UK website, 2022):

- **https://www.disabilityrightsuk.org/adjustments-disabled-students-and-apprentices**
- **https://www.gov.uk/topic/schools-colleges-childrens-services/special-educational-needs-disabilities**

Permission to stand or move around to avoid discomfort

Arrangements to ameliorate impact of frequent medical appointments

Tailored examination arrangements such as extra time or supervised rest breaks as detailed in Exam Access Arrangements **https://www.jcq.org.uk/exams-office/access-arrangements-and-special-consideration/**

Provision of work that can be done at home if the child is fatigued or in pain

Physically accessible classrooms, exam rooms, toilets, catering, and leisure facilities

Specialist or adapted furniture or computer equipment

Regular dialogue with staff/teachers if the condition is hidden/fluctuating

These tables break down some of the issues that a child with MFS/LDS may experience, the impacts on their learning, and potential adaptations to minimise this.

Heart issues

Issue	Impact	Possible adaptations
Aortic dissection (rare in school-aged children but a medical emergency if does occur)	Fatigue Restrictions on lifting	Take medical complaints seriously Easy access to school nurse and place to rest
Aortic root dilatation/aortic aneurysm	Restriction on physical activities	Adapt schedule or deadlines to allow for rest if necessary
Mitral valve prolapse	Medication regime	Provide additional time to get to classes
Irregular/erratic heartbeat		Modify (PE) curriculum or offer alternative

Nervous system

Issue	Impact	Possible adaptations
Dural ectasia	Pain (often chronic) which can affect ability to sit and focus for prolonged periods of time	Easy access to the school nurse Access to pain medication as required
	Difficulty participating in PE	Adjust school timetable to give opportunities for rest/ lying down
	Difficulty completing homework/assessments on time	Allow extra time for homework/ exams if needed
Gut discomfort	Pain	Arrangement to go home if necessary
	Need for easy toilet access Lack of sleep	Allow for rapid access to toilet
	Need to eat smaller/ more frequent snacks	More frequent eating arrangements

Eyes

Issue	Impact	Possible adaptations
Severe short-sightedness Dislocated lens Risk of detached retina	Vision may fluctuate	Provide large print books/texts
	Difficulty reading for prolonged periods	Provide seating at the front of the class
	Difficulty reading small/ light-coloured fonts	Use dark/clear font on school materials
	Difficulty seeing whiteboard	Provide IT equipment with settings to accommodate visual impairment

Bones and joints

Issue	Impact	Possible adaptations
Tall stature with long arms, fingers, and legs Loose and flexible joints Underdeveloped muscles Pain (often chronic) Pectus excavatum or Pectus carinatum (chest bone that dips inwards or protrudes outwards) Curved spine (scoliosis) Flat feet Muscle fatigue Fatigue	Difficulty sitting in standard desks and chairs	Provide desks/chairs at a suitable height for classrooms, home study and exams
	Difficulty sitting for extended periods of time Difficulty sitting on the floor	Allow student to stand/move around if uncomfortable and provide a bed in a rest area if necessary Possible adaptations – allow time for rest and changing position during class. Ideally, rest should be allowed outside of breaktimes. Having a break time to move and play can help with pain and fatigue and should be encouraged.
	Difficulty walking long distances Inability to carry heavy books long distances Some students may require a wheelchair (rare)	Provide extra time to get to class Schedule classes in rooms closer together Assisted mobility for longer distances Use of a lift if necessary
	Difficulty writing may lead to lack of engagement, deterioration in behaviour, worsening handwriting	Use aids for handwriting and consider scribe/laptop use in lessons and adapted exam conditions such as additional time for tests/exams
	Prone to joint injuries	Allow access to nurse for pain medication if necessary
	Body image issues	Modify PE curriculum or offer alternative

MFS/LDS affects all individuals differently and it is therefore vital to plan safe access to PE and sports for children, considering their specific needs. **This will require close liaison with parents and advice from the child's medical practitioners so that children can maximise their participation whilst remaining safe.**

Recent research within the Marfan community has demonstrated that regular, moderate physical activity is beneficial in improving an individual's health-related quality of life and in early studies there has been evidence to show slowing of aortic dilatation in groups undertaking tailored exercise plans. This is an area that is constantly evolving.

A useful first step can be to provide parents with information about the PE/ sporting curriculum for the coming academic year so they can obtain specific, tailored advice from the doctors.

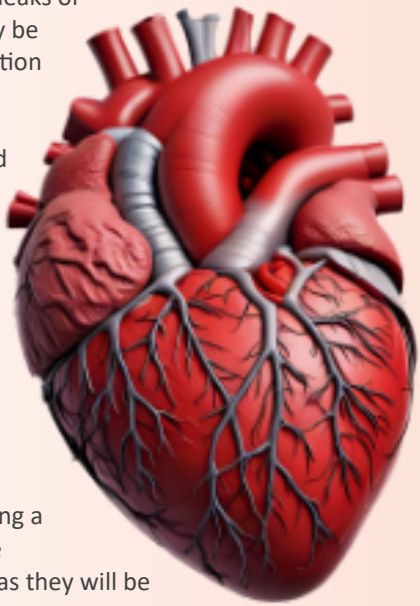
The key issues listed previously – heart, bones and joints, eyes, nervous system – are the same things that will need to be considered here. The aim is to help the child develop a healthy lifestyle incorporating physical activity whilst not putting them at increased risk of complications.

As a rule, children with MFS/LDS should be encouraged to choose low-impact, low- intensity activities and their expectations need to be managed: participating in sports at an elite or competitive level will not be possible and this can be difficult to hear, particularly if their diagnosis is made at a later age and they are already playing or competing at a high level.

Regular exercise, important for the maintenance of good physical and mental health, is equally important for children with MFS/LDS

Considerations during physical activities

1. Heart



Children may have a dilated aorta, a heart valve that leaks or may have already undergone heart surgery. They may be taking medications. The dilated aorta requires protection and contact sports should be avoided.

Heavy weightlifting or other isometric exercise should also be avoided due to the spikes in blood pressure which stress the heart and aorta.

Beta blockers will slow the heart rate and reduce the blood pressure; the pulse rate becomes less responsive to exercise, so it is harder for children to make rapid changes to their activity level and pulse rate is a less reliable way to assess their level of exertion.

If a child has had heart surgery, they may also be taking a blood-thinning medication and in these instances the avoidance of contact sports is particularly important as they will be at increased risk of bleeding.

2. Eyes

Short-sightedness can affect co-ordination and may increase their risk of collisions. Appropriate glasses that can be worn during exercise will be an important consideration.

There is the risk of retinal detachment and lens dislocation, so appropriate eye protection should be used and contact sports should be avoided. It is important to listen to the child during physical activity and provide ready access to the school nurse if they report new symptoms that need assessment.

3. Bones and joints

The child may have joint hypermobility or loose joints which put them at increased risk of injury. Their height and long limbs may also affect their hand-eye co-ordination. Lack of muscle bulk can lead to fatigue at an earlier stage than that of their peers. These children will need the option of resting during PE and taking part for short periods of time and to be given extra support to find sports and activities that they enjoy.

4. Guidelines for activity

Each individual is affected differently, and these general recommendations need to be discussed with the child and parents, alongside advice from their own medical professionals.

- Take regular low/moderate recreational aerobic activities.
- Avoid contact sports, high-level competitive sports and static/isometric exercise in which the muscles and blood vessels contract, causing spikes in blood pressure.

The age of diagnosis will impact the child's response to restrictions on their physical activity. If they have a pre-school diagnosis, their activities can be tailored from an early age and other activities can be incorporated, e.g. hobbies such as art, music and photography can foster a community and a social circle that is common within sport. If a child is diagnosed at an older age, they may already be participating in sports at a high level and be a valued member of a team that is an important part of their identity and social circle. This is challenging and can lead to them feeling excluded, angry and depressed if they can no longer be a part of this team. This requires careful management and can be incredibly difficult for a teenager.

As a rule, the ESC (2024) recommend that most children with MFS under the age of 10 can carry on physical activity without specific limitations but once they get older their aortic size needs to be taken into account.

Final advice should always come from the child's own doctor.

Try to maintain an aerobic level of activity (the child should be able to continue to hold a conversation whilst exercising)

Incorporate adequate time for warm-up and cool-down

Light weights can be used with higher numbers of repetitions rather than heavy weights with fewer repetitions

Wear protective equipment e.g. bike helmet

Avoid 'fitness tests' that pit children against other children; try to focus on personal achievements and achieving a 'personal best'

Activities such as football, basketball, cycling and dance can all be done at high, strenuous levels, but they can also be enjoyed at a more leisurely, low-impact level and children need to be taught that they can enjoy these pastimes but at a lower intensity

Regular physical activity is important and children with MFS should be encouraged to find a sport or activity that they enjoy

Absence from school due to ill health

Some children will require surgery or prolonged periods of time off school due to ill health. School can help minimise the disruption to their education by being understanding of the importance of these absences, planning appropriate work for the child to do whilst not at school and liaising with other caregivers, e.g. parents, hospital teachers/play specialists who can support learning in a different environment.

Planning for surgery

Planned surgery for any individual will be anxiety-provoking, but this can be particularly difficult for teenagers to deal with and careful liaison between parents and teachers is vital to smooth the path. Teenagers may have a range of worries and concerns:

- Missing friends and family
- Fear of the operation itself and pain afterwards
- Fear of the unknown
- Loss of control
- A change in their appearance due to scars
- Missing a large period of time at school or clubs and wondering what people will think

Teachers can be an important piece of the puzzle in the build-up to surgery; they can watch out for mood swings and behaviour changes.

In addition, they can modify work assignments and put together a plan for phased return to school so that the young person has a clear plan for the post-op period.

A teacher or pastoral head at school may be the trusted person that a teen wants to speak to about their worries and concerns; it is important that the school are aware of the plans for surgery so they can provide appropriate support.

Psychological wellbeing

Attention needs to be paid to the psychosocial and mental health of a child with MFS. There is limited research in this area, but it suggests that children and adolescents with MFS generally have poorer Health-Related Quality of Life (HRQoL) and mental health than their peers

They may perceive themselves as 'different', perhaps feeling ostracised or bullied. They may understandably feel left out of exciting things due to absence or illness, missing peer group enjoyments.

Limitations to daily life due to fatigue and physical symptoms or different bodily appearance can increase social stigma and have an impact on psychological wellbeing and quality of life (Gritti et al, 2015).

The World Health Organisation defines HRQoL as the perceived (subjective) health-related physical, mental, and social functioning of children and adolescents.

Mental health is defined as a state of wellbeing in which children and adolescents realise their own abilities, can cope with the normal stresses of life, can study/work productively, and are able to contribute to community (World Health Organisation, 2007).

Handisides et al (2019) found that children and adolescents with MFS up to the age of 18 reported lower quality of life when considering physical, psychological, emotional, social, and school functioning than their peers.

Interestingly, young adults aged 19-25 in this study still had lower physical scores but their scores for emotional, social, and school/work functioning were higher than those of their peers.

It is possible to speculate that children with a chronic condition such as MFS can develop effective coping strategies, and this should be supported during their childhood years.

Support of a child's mental health requires close liaison between school and home: information needs to be shared between parents, teachers and pastoral staff, medical professionals, and the child in an age-appropriate way.

Clothing and shoes

Excessive height, curved back (scoliosis), protrusion of the chest, long thin arms, legs, hands, and feet cause great difficulty in finding clothes and shoes (including school uniform) which fit. This often results in a poor self-image and the school may need to be flexible with minor non-compliance.

Families may find it challenging to find all pieces of the school uniform that fit children and children may need to wear specially adapted shoes, for example to support lax ankles, flat feet, and unequal foot sizes.

Many online retailers now have ranges that cater for very tall individuals so appropriate clothes should be available, but costs of extra/different items may be difficult for families to meet if they are having to buy adult-sized shoes and clothes for their child.

Bullying

The NSPCC (2022) defines bullying as 'behaviour that hurts someone else. It includes name calling, hitting, pushing, spreading rumours, threatening, or undermining someone. It can happen anywhere – at school, at home or online. It is usually repeated over a prolonged period of time and can hurt a child both physically and emotionally.'

Children with MFS/LDS may appear physically different to some of their peers; they may frequently miss school due to medical tests or appointments and this can put them at risk of bullying which needs to be monitored.

Children should be encouraged to talk to a trusted adult if they are experiencing bullying and careful attention should be paid to their behaviour by teachers/ parents and other care givers to look for any changes that may signify bullying. This needs to be dealt with swiftly and effectively with ongoing review.

As a result of being aware of being different, a child may have fragile self-esteem and can interpret innocuous comments as bullying which may benefit from discussion.

The fostering of an inclusive school ethos, valuing diversity, with an emphasis on kindness is crucial for all children's emotional development and wellbeing. Some children and parents will be keen to share the diagnosis of MFS. This should be encouraged, and the school can assist by giving them a platform to educate and inform teachers and peers. Others may wish to maintain their privacy and confidentiality, and this should also be respected as long as the child understands that some information needs to be shared with their teachers and other caregivers in order to keep them safe at school.

- **https://www.youngminds.org.uk/young-person/coping-with-life/bullying/**
- **https://www.kidscape.org.uk/**
- **https://www.nspcc.org.uk/what-is-child-abuse/types-of-abuse/bullying-and-cyberbullying/**

School trips

School trips of long or short duration are an important part of school life, both socially and academically. Children with MFS/LDS should be included as far as possible, and this may require some advance planning to ensure that necessary adaptations can be put in place.

PLEASE ENSURE ALL ADULTS INVOLVED IN A TRIP ARE AWARE OF THE RARE POSSIBILITY OF MEDICAL EMERGENCIES DESCRIBED ON PAGE 2 OF THIS DOCUMENT.

Liaison with parents and students to discuss the trip and the activities on offer is important. As MFS/LDS has such a range of symptoms and severity, this will need to be done on an individual basis to meet the specific needs of each child. Further information or advice might be needed from the child's healthcare providers and the school nurse is a useful resource who will be able to help with this.

NOTE: parents will need to consent to any medical information being shared. Once a child reaches their teenage years, they will naturally begin to take more responsibility for their own health and should be involved in decisions. It is vitally important to include teenagers in these discussions so they feel empowered and start learning to weigh up the risks and benefits of different actions.

Further Education and Career Guidance

As with sport and physical activity, there may be restrictions on career pathways for a child with MFS/LDS. Physical issues such as poor eyesight, joint hypermobility, heart murmur or aortic dilatation can mean that pursuing careers that are physically demanding, e.g. armed forces, police service, building, nursing, elite sport may not be an option. Again, this will all depend on the child's individual needs and symptoms, and guidance from their medical practitioners is key.

Teenagers reaching the point of exam options and career choices need careful, tailored guidance. Suitable work experience placements need to be found along with tailored advice about career pathways. Transition from childhood to adulthood is a challenging time in any teenager's life, but with the added complication of a chronic condition this can be particularly difficult.

Many young people aspire to attend university and if this is something you would like to do, your diagnosis should not hold you back. There is a plethora of advice and support available that can help you make a decision about studying at undergraduate level. Universities are obliged to abide by the Equality Act 2010 and must therefore make reasonable adjustments to help you reach your full potential.

The best advice is to start early and do lots of research! Your school will be able to help with your application. The UCAS website is a trove of useful information for students with additional needs. The link below will take you to these pages. There is advice on everything, from the questions to ask at open days, to the financial support that might be available and how to apply for it.

https://www.ucas.com/applying/applying-university/individual-needs

Any young person considering university has much to think about, but living with a chronic condition can make these decisions more complex, the Complete University Guide have a really useful article that helps you think about everything you might need to consider:

https://www.thecompleteuniversityguide.co.uk/student-advice/applying-to-uni/disabled-students-university-guide

Finally, every individual university website will include a section for students with additional needs so you can explore these too. Most universities will be happy to put prospective students with additional needs in touch with a Student Support advisor who can talk through your specific concerns.

At the Marfan Trust, we want to help you reach your full potential and are happy to help support you in this process. We can provide letters of support, talk through your concerns and help advocate for you. Get in touch!

Conclusion

With support and understanding, children with MFS/LDS can all lead a successful and fulfilled educational life. Young people with Marfan syndrome will experience this success and fulfilment more readily if the accommodations and understanding described in this document are in place. Such understanding and arrangements should greatly ease the path to adulthood and an appropriate future career. For further specific advice, please contact the Marfan Trust who should be able to direct you to the appropriate information.

With special thanks to the Pothecary family for their help and assistance with the creation of this information.

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
CONNECTING THE UNCONNECTED AND STRENGTHENING LIVES

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.

Supported by The Hospital Saturday Fund