

# Marfan Trust

*Supporting Research into Marfan Syndrome*



## Paediatric Guide

### Marfan syndrome

Find out more today



[www.marfantrust.org](http://www.marfantrust.org)

Registered charity number 328070



## Who is this leaflet for?

We hope this leaflet will help parents, schools and children to better understand the condition so that we can work together to ensure everyone has the best possible start to life.

## What help can this leaflet offer?

We hope it will provide clear guidance on understanding what a young person may be going through pre and post diagnosis, and what small things can be put into place to help them.

## Topics covered:

- What is Marfan syndrome and how does it affect people?
- What are the signs and how is Marfan syndrome diagnosed?
- Understanding your diagnosis and how it impacts on a young person's daily life?
- What I can and can't do?
- As a parent what can I do to help my child understand the changes?
- Guidance for teachers and schools
- Guidance on bullying and Cyber Bullying
- Sharing your diagnosis and creating more awareness
- Disorder related to Marfan syndrome



## What is Marfan syndrome and how does it affect people?

Marfan syndrome is an inherited disorder of the body's connective tissue which predisposes to medical problems affecting the heart, eyes and skeleton, requiring treatment to prevent serious complications. Over 18,000 people are affected by Marfan syndrome in the UK, with many more anticipated to be living with the condition undiagnosed. 1 in 3,000 population worldwide are believed to have Marfan syndrome.

Marfan syndrome is a genetic disorder. This means people are born with Marfan syndrome, however they may not notice any of the signs until much later in life.

**Eyes:** dislocation of lenses, short-sightedness, retinal detachment, glaucoma

**Skeleton:** excessive height with long limbs and fingers, flat feet, protruding or indented chest bone, loose joints, scoliosis, early osteoarthritis

**Lungs:** asthma, pneumothorax (collapsed lung), emphysema, fibrosis (lung stiffness).

**Heart:** ballooning and potentially fatal tearing of the aorta, backward billowing of the heart's valves

Most affected people will not show all the signs and complications of the syndrome.



## What are the signs and how is Marfan syndrome diagnosed?

Marfan syndrome can be difficult to diagnose because signs of the condition vary greatly from one person to the next.

Some signs may include:

- Tall thin physique, long arms, legs and fingers
- Curved spine
- Sunken or protruding chest
- Flexible joints
- Crowded teeth
- Unexplained stretch marks
- Severe near-sightedness, dislocated lens, detached retina
- Heart problems
- Joint hypermobility and dislocations

It is important to remember that these signs may also occur in other overlapping conditions, hence genetic testing is useful in making a clear diagnosis. (Please see related disorders)

Initial diagnosis can usually be made by examining several parts of the body and reviewing family history. Then referral needs to be made to a Marfan syndrome or Regional Genetics clinic for further testing and an echocardiogram. Blood tests demonstrating the abnormal gene are available through referral to a clinical geneticist.



In general, Marfan syndrome is diagnosed after careful physical examination, particularly focusing on the main systems involved: eyes, skeleton, heart and lungs. Major involvement in two out of three systems is required for clinical diagnosis. Certain tests, such as an echocardiogram (a sound wave picture of the heart) are useful in making the diagnosis.

- People with Marfan syndrome should have an initial diagnostic echocardiogram which is repeated at regular intervals.
- An Electrocardiogram (ECG) is not adequate screening.
- Skeletal X-rays (mainly chest and back) may be necessary, and a careful eye examination to detect lens dislocation is recommended.
- Family history also needs to be taken into account.

*“Before we had the diagnosis, I was scared that when I raised my concerns about my son’s health that the doctor was likely to look at me as some kind of overreacting worrier of a mother, but it’s amazing how willing one is to raise issues or ask questions when your own child is involved.” - Ladan*

## Understanding your diagnosis: how does it impact on a young person’s daily life?

Once you are diagnosed with Marfan syndrome it can take some time to adjust. Ensure that you understand what your medical adviser has told you. If you need to take someone with you to ask the appropriate questions, please ask the clinician if this is possible. If you walk away from your appointment and there are medical terms or language you do not understand, please feel free to contact the Marfan Trust [marfantrust@sgul.ac.uk](mailto:marfantrust@sgul.ac.uk) and we will be happy to clarify the terminology and try to answer any questions you may have.

It is important to focus on the fact that early diagnosis is a very important step as this ensures that you receive the best possible care; ongoing advances in medicine ensure that people with Marfan syndrome are living longer and have a better quality of life with appropriate treatment and care.

Take time to explain the condition to your child and that he/she may have to visit the doctors and hospitals more. One parent has suggested depending on



the age of the child, first focus on the tangible and easy to explain features, such as the need for glasses or having pictures of your heart and taking medicine.

To receive the right treatment, you may need to be monitored. This could include an annual echocardiogram (a sound wave picture of the heart). You will then meet with your clinician who will explain the results of this test.

Having Marfan syndrome does mean you need to take things like exercise into consideration. The Marfan Trust and most doctors will advise against competitive and strenuous sports and exercise, as well as lifting heavy objects and sudden extreme bursts of energy. Please see our 'Exercise Guide' for Marfan syndrome for more detail.

There is currently no evidence base for how exercise affects people with Marfan syndrome and therefore the advice given should be based on the guidelines issued by the Marfan Trust. Please remember that each individual with Marfan syndrome is affected differently and therefore we would recommend that discussions about exercise are held with the medical professional involved in your child's wellbeing. Young people should be allowed to stop when tired.

*"I realised early on that for the majority of my son's life he will have to understand and advocate for himself. It made little to no sense to shield him from it, particularly as he got older and began to see the physical changes first hand." - Ladan*





James Allen, aged 11

### Further advice with regards to exercise:

**Heavy lifting** is NOT advised. \*

**Basketball** should be discussed with your doctor. If played as a contact sport, it can lead to repeated falls.

**Horse riding** on a quiet horse is best; jumping is not advised as this may result in falling off the horse.

**Squash** can be played wearing goggles to protect the eyes for those who do NOT have heart problems.\*

Participating in **Aerobics** and **Abseiling** should be judged by the young person's limitations, for example aerobics may not be suitable for those with heart and lung troubles. If you are unsure please consult your doctor.

#### Recommended (NOT high level competition):

<i>Archery</i>	<i>Cycling (on the level)</i>	<i>Hockey</i>
<i>Shot-put</i>	<i>Badminton</i>	<i>Discus</i>
<i>Javelin</i>	<i>Skating</i>	<i>Bowls</i>
<i>Canoeing</i>	<i>Tennis</i>	<i>Swimming</i>
<i>Fencing</i>	<i>Netball</i>	<i>Racquetball</i>
<i>Table Tennis</i>	<i>Football (no heading)</i>	<i>Golf</i>
<i>Sailing</i>	<i>Cricket</i>	<i>Yoga</i>
<i>Walking / Jog-walking</i>	<i>Dancing</i>	<i>Light weight-lifting</i>



**Prolonged activity** is generally not advised, and in the gym only short stints in a number of activities are recommended. We highly recommend you speak to your doctor about what activities your child can take part in and perhaps ensure the doctor writes a letter confirming, to take to your child’s school.

<b>Not advised:</b>	<b>To prevent damage to:</b>
<i>Boxing</i>	<i>Eyes</i>
<i>Rugby</i>	<i>Heart and Joints</i>
<i>Deep Sea Diving</i>	<i>Lungs</i>
<i>Rowing</i>	<i>Heart and Joints</i>
<i>Distance Running</i>	<i>Heart and Joints</i>
<i>Sky-Diving</i>	<i>Lungs</i>
<i>Hang Gliding</i>	<i>Lungs</i>
<i>Squash*</i>	<i>Eyes and Heart</i>
<i>High Altitude Mountaineering</i>	<i>Lungs</i>
<i>Trampolining</i>	<i>Joints</i>
<i>High Diving</i>	<i>Eyes</i>
<i>Weight-Lifting*</i>	<i>Heart and Joints</i>
<i>Karate / Judo</i>	<i>Heart and Joints</i>
<i>Wrestling</i>	<i>Heart and Joints</i>

**More information by the Marfan Trust available on our website:**

- |                |                          |                       |
|----------------|--------------------------|-----------------------|
| Dental Guide   | Pregnancy Guide          | Musculoskeletal Guide |
| Exercise Guide | Guide to Marfan syndrome | Bowel symptoms Guide  |





## What can I do and what can't I do?

Complications can be prevented if young people are seen on a regular basis by their various specialists.

### Exercise and fitness

In general it is important to keep as fit as possible. This improves muscle tone and is good for overall function of the heart and blood vessels, but any exercise should be appropriate to each individual's physical condition. Some activities are best avoided, such as long distance running, heavy lifting and competitive sports. If played as contact sports, basketball and rugby are best avoided but walking, swimming and cycling can have a very positive effect on some patients. (Please ask for a copy of our Exercise guide)

The child should stay with his or her peer group, perhaps given a related task, such as keeping score, refereeing or managing equipment.

### Easy Fatigability

Fatigue, due to Marfan syndrome, can be a problem, especially when long periods of concentration are required. Learn to "pace yourself", working within your own comfortable time scales.

Teachers should take account of the level of fatigue that may affect their pupil, in their lesson plans, perhaps allowing frequent breaks. They should consider the impact of emotional and physical stress involved in certain activities, on a young person with Marfan syndrome.



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## Young people with Marfan syndrome

Young people with Marfan syndrome feel different and may look different and restrictions are often imposed on them because of their poor eyesight, lax and painful joints and cardiac problems. It has been reported in some cases that young people may display some behavioural and emotional problems and low self-esteem. They may internalise their worries, resulting in withdrawal, physical complaints, anxiety and depression. Teachers and parents should be sensitive to these issues and ensure they have strategies to address these areas, such as learning to be comfortable with the diagnosis, identifying a young person's areas of strength. Are they musical, academic or creative? Can these skills be encouraged and developed to help improve confidence and social interaction? Parents and Teachers may identify when professional psychological counselling may help improve a young person's self-image.

## As a parent what can I do to help my child understand the changes?

The Marfan Trust approached a few parents to get their perspective on helping their children with understanding their diagnosis.

### Jo MacKinnon:

Don't read too much on the internet. There is a lot of information out there that can be very distressing and it is important to remember that each person diagnosed with Marfan syndrome is unique. What may affect one person severely may not affect another as badly.

It is important not only to understand that your child with Marfan syndrome is unique in how they may be affected, but that your child may meet other young

*“When my daughter was first diagnosed I read and read and read and thought the world was over! Yes, there are things that she can’t do but there are still an awful lot that she can do.” -Jo*

people with Marfan syndrome who may look and be affected in completely different ways.

The older your child will get the more they will want to know and may even research themselves and approach you with questions. It is best to be honest with your child. If you don't know the answer, explain this and then put together a series of questions you can ask the clinician on your next visit, or contact the Marfan Trust who may be able to answer any medical questions puzzling you.

It is important to know that your clinician may not know the answer to particular developments your child is going through as research is ongoing.

### **Ladan Cockshut:**

Never shield your child from their own medical condition, but tell them what makes sense at their age. The younger they are, the more you may want to focus on discussing the most tangible impacts of Marfan syndrome such as taking medicine or wearing glasses. As they get older it can be helpful to start talking about limits such as high impact sports or knowing when to slow down doing strenuous activity.

*“In recent years, as my son has become a teenager, I’ve noticed that the medical staff have begun to speak directly with him a lot more. This has not been easy for him (as he’s used to being the passive participant) but it’s really important for him to develop his own voice. He and I speak about this process and even during the last cardiology visit the cardiologist asked him what exactly was ‘wrong’ with his heart and he did me proud by accurately explaining what mitral valve prolapse is.” - Ladan*

As they begin to feel different from everyone else (this seemed to happen most noticeably for my son once he moved up to secondary school) try and find ways to discuss those changes openly. If it helps, arrange for talking therapy. It's hard enough to become a teenager but can be doubly hard when you have a condition that makes you look and feel different!

Use as many resources as humanly possible to provide you suggestions of way to discuss the condition. The Marfan Trust and the Marfan Foundation can provide a lot of great tools and supportive resources.

- Talk to the child and teach them to live within their limitations
- Answer questions as they appear
- Initiate care plans with your local council and your child's school
- Suggest suitable sports and hobbies
- Help them find friends
- Involve the school in teaching about disabilities and tolerance
- Meet other families with Marfan syndrome

## Guidance for Teachers and schools

Young people are able to attend a mainstream school; they may need special help in the classroom.

Every Marfan syndrome patient is unique; therefore an **assessment** with child and parent may be necessary to understand what requirements may be needed by each child; a plan made for one child with Marfan syndrome may not be applicable to another. For example, one child may have poor eyesight, and therefore there should be careful consideration about where the child may sit so that they are not disadvantaged. Another child may need to have their desk adjusted so that they may sit more comfortably, due to tall stature and hypermobility, rather than being placed for visual purposes.

*"The school always needed to understand what having Marfan syndrome was like for my son and this also required that he felt empowered to talk about it with me and his teachers." - Ladan*

### Areas for consideration for teachers, parents and young persons are:

As a parent make sure you engage with the school. Take time to meet with the teacher, head teacher and explain your child's condition. Provide materials about Marfan syndrome and even official letters from your GP, the more information the school knows the more they can work with you to ensure that your child is sitting comfortably and taking regular breaks.

Is the student's **eyesight** poor? What classroom adjustments can be made to ensure the student is not disadvantaged. Large print written material could supplement lessons.

Does the student suffer from **fatigue**? Perhaps short breaks may need to be taken.



**Physical problems:** Back and joint pain may impact on a child's ability to concentrate. Dexterity and fine motor skills may affect practical classes such as home economics, and design and technology. This may be more challenging for a young person with Marfan syndrome and may require assistance. **Wheelchair use:** it may be that some young people with Marfan syndrome may need to use a wheelchair, therefore schools should cater for wheel chair access in accordance with the Special Educational Needs and Disability Regulations 2014.

**Physical education.** This should be discussed with the young person, parents and teacher. It should be clearly outlined from your doctor what activities a young person with Marfan syndrome is allowed to do. The Marfan Trust have an Exercise guide for Marfan syndrome which clearly outlines what form of exercise individuals are allowed to undertake. Competitive sports and heavy weight lifting are not recommended. It may be that the young person may need to be offered an alternative lesson.

**School absence** may be frequent because of hospital appointments and corrective surgery for skeletal, eye and cardiac problems. However, time off school should be minimised by asking for hospital appointments and operations to be arranged whenever possible during holidays to ensure children do not miss out on too much.

### Educational support:

When parents and young people meet with the school to outline an education plan to support the young person, we would advise that a brief health care plan is also outlined. This could just be a brief discussion about what health issues the young person is facing, and how many hospital appointments the young



person may need to attend. Health care professionals' guidance should ensure the school is prepared if the young person's health requires attention while at school.

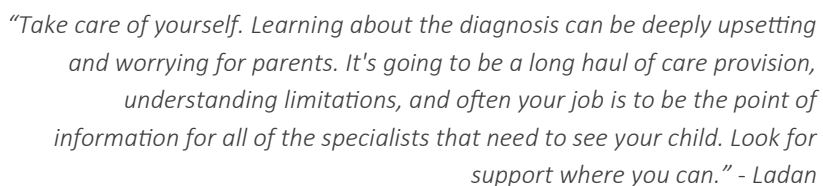
As previously stated each person diagnosed with Marfan syndrome is affected in different ways and levels of severity. In some cases young people may need extra care. It is therefore important to contact your local authority to speak about establishing an '**Education, Health and Care (EHC) plan**'. EHC plans are for young people from the age of 0 to 25 years old. They assess a young person's needs around education, health and social care. For more information about EHC plans please visit [www.gov.uk/children-with-special-educational-needs/extra-SEN-help](http://www.gov.uk/children-with-special-educational-needs/extra-SEN-help) website or contact your local authority. EHC plans have been in place since September 2014 and are replacing what was known previously as 'statements of special education needs'.

We can also recommend the charity **Contact a Family**, which you can find online [www.cafamily.org.uk](http://www.cafamily.org.uk) or you can call their free helpline on 0808 808 3555. They offer a wealth of information about how to support young people and their educational needs; they also have a page explaining EHC plans as well.

### Peer to peer support:

Young people with Marfan syndrome may look different, such as being very tall, slender, with flat feet and stretch marks, wearing thick glasses, having a protruding or indented chest. They may require braces for their back, they may have to have dental work and they may rarely be in a wheelchair. Sometimes talking about Marfan syndrome in class or as a school may help dispel any misconceptions people may have about the syndrome. Perhaps holding an event where young people can learn more about genetic disorders in general may be an informative and useful exercise.

The Marfan Trust tries to organise an annual event for families to meet each other and perhaps make friends. It is important to keep all channels of communication open with young people, teachers, family members and friends.



*"Take care of yourself. Learning about the diagnosis can be deeply upsetting and worrying for parents. It's going to be a long haul of care provision, understanding limitations, and often your job is to be the point of information for all of the specialists that need to see your child. Look for support where you can." - Ladan*



Marfan Trust charity: staff, Trustees and Friends of the Marfan Trust.

## Suggested resources:

### Treehouse At Number Nine – found on iTunes store under Books

Is a book that reads aloud with music, colourful, bright and fun characters, it is designed to keep young people engaged and to teach them about young people who have rare genetic disorders. It was funded by Jeans for Genes / Genetic Disorders UK and all money raised through book purchase goes towards genetic disorders charities. **Website:** [www.treehouseatnumbernine.org](http://www.treehouseatnumbernine.org)

### Genetic Disorders UK (Registered charity number 1141583)

Is a large charity that covers a variety of genetic disorders and has a lot of resources that you may find very useful. They have pages with information for parents whose children have been diagnosed with a genetic disorder.

[www.geneticdisordersuk.org/parentsofaffectedchildren](http://www.geneticdisordersuk.org/parentsofaffectedchildren) has information about education, management, support and living with genetic diagnosis. Genetic Disorders UK have a document called GDUK patient passport you may find useful and you can download from their website. *“By filling out the GDUK patient passport for your child, this should help you to describe their healthcare needs in an easy-to-read and person-centred way to help both you and hospital staff.”* **Telephone:** 0800 987 8987

### Genetic Alliance UK (Registered charity numbers: 1114195 & SC039299)

Produce a lot of information leaflets which you can download from their website for free. They work towards improving the lives of people affected by genetic disorders through making information available to “all who need them”.

**Website:** [www.geneticalliance.org.uk/publications\\_patients.htm](http://www.geneticalliance.org.uk/publications_patients.htm)

**Telephone:** 020 7704 3141

**Email:** [contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)

## The Council for Disabled Children

(National Children's Bureau - Registered charity No. 258825)

The Council for Disabled Children (CDC) works to make a difference in the lives of children with disabilities and children with special education needs. *"We do this by influencing Government policy, working with local agencies to translate policy into practice and producing guidance on issues affecting the lives of disabled children."*

**Website:** [www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk)

**Telephone:** 0207 843 1900

**Email:** [cdc@ncb.org.uk](mailto:cdc@ncb.org.uk)

## Guidance on bullying

Unfortunately bullying has increased over the last few years, to now include cyber-bullying. Young people with Marfan syndrome, especially those who display clear physical features, may experience these difficult situations. The Marfan Trust has contacted a number of anti-bullying charities to help write a small piece on the guidance of a parent or teacher to deal with some key issues. If you are a parent, teacher or young person struggling with bullying we strongly advise you to seek help. Asking for help to deal with bullying can be simple, anonymous and help you feel less alone. Anti-bullying charities can help teach you techniques on how to cope when faced with a bully/bullies that can really change a potentially difficult situation around.

Teenage years can be very difficult for any young person. However, Marfan syndrome teenagers may be acutely affected by the change in their bodies, as they may begin to display Marfan syndrome features.

## Anti-Bullying Charities

The Marfan Trust has contacted a few Anti-Bullying charities that may help you further when struggling with bullying, whether you are a young person experiencing the bullying, or a parent of a young person being bullied or a teacher who has noticed bullying at school. The charities below will be able to offer you advice and guidance. We spoke to two charities **Kidscape UK** and **The Cybersmile Foundation** who have kindly given us the following information as guidance. We strongly recommend you visit these charities' websites or contact them for more information.



**Marfan Trust**  
*Supporting Research into Marfan Syndrome*

## Kidscape UK

Registered Charity (326864)

Telephone: 020 7730 3300

Website: [www.kidscape.org.uk](http://www.kidscape.org.uk)

Email: [info@kidscape.org.uk](mailto:info@kidscape.org.uk)



**Mission:** is to ensure children live in a safe and nurturing environment. By providing training, support and advice to children, parents, schools and those in professional contact with young people, they enable them to gain knowledge and develop the confidence and skills to challenge abuse and bullying in all its forms.

### Kidscape's Top 5 tips for parents tackling bullying

1. **Speak to your child.** Find a quiet time when you won't be interrupted to talk to your child about bullying. Be patient, calm and understanding, and do not make assumptions or interrupt. Put your feelings aside and really listen to what your child is telling you so you can fully understand the situation.
2. **Give reassurance.** Make it clear that the bullying is not their fault and praise them for being brave enough to confide in you. Assure them that now you know what is happening, the issues can be resolved.
3. **Report to the school.** Schedule a meeting with the school immediately. For primary schools this is likely to be with your child's classroom teacher, and for secondary schools, the head of year. Give specific examples of bullying incidents and how your child has been affected. Keep a log of incidents to facilitate this. Ensure a course of action is agreed upon regarding how the school will work to resolve the situation.
4. **Stay informed.** Continue having open conversations with your child about their experiences with bullying, and report each incident to the school. If you are unhappy with how your child's bullying is being dealt with, schedule a meeting with the school's head teacher. If appropriate action is still not taken, it is within your rights to make a complaint to the school governors.
5. **Build confidence.** Bullies often 'test' potential targets to see how they respond, and while the target is never to blame, those who appear the most vulnerable usually continue to be bullied. It is for this reason that alongside reporting incidents to the school, building your child's confidence and self-esteem can be one of the most effective ways to help them. Kidscape runs free ZAP anti-bullying and assertiveness training workshops for young people and their parents/carers, which teach practical and effective skills. Please visit Kidscape's website for more details about ZAP.



## Kidscape's Top 5 tips for Young people tackling bullying

1. **Report it.** Unless you report bullying to an adult, it's very unlikely that it will stop. Talk to someone you trust about what has been happening. This could be a parent, a family friend or a teacher.
2. **Protect yourself online.** If you have been experiencing cyber bullying, as well as telling a trusted adult, you should also report abusive messages or phone calls to website administrators and/or service providers. It's also important to use privacy settings on social media, and to block bullies from being able to contact you. You should not respond to bullying remarks, as this will only make the situation worse.
3. **Remember that you are not to blame.** Bullies will often target others based on 'difference', which can sometimes make their targets feel like they are the ones to blame. But you are not. Bullies will use any difference, even tiny ones, as an excuse. Never try to change for a bully, as they will often just find something else to pick on.
4. **Build up your confidence.** Bullies will often pick on people who they think won't stand up for themselves, as it means they can get away with it. Learning how to say 'no' and hold assertive body language with confidence is a really effective way to tackle bullying. Visit the Kidscape website for practical examples of how you can do this.
5. **Choose friends wisely.** Bullying can be very subtle, and can even come from the people who are meant to be your friends. This type of bullying can be hard to spot, as it often happens little by little over a long period of time. Good friends support you, make you feel good about yourself and encourage you to behave in positive ways. If you think your friends don't have your best interest at heart, you may wish to consider making new ones.

For more information about how to protect yourself from bullying and cyber bullying, make new friends and build confidence, visit the young people's advice section on our **website**: [www.kidscape.org.uk/advice](http://www.kidscape.org.uk/advice)

*"I am not stuck in a body with Marfan syndrome; Marfan syndrome is stuck with me."*

*- Austin Carlile, lead singer, Of Mice & Men.*





**Respect Me (Scotland)**  
Scottish Charity No SC-008897

Telephone: 0844 800 8600.

Website: [www.respectme.org.uk](http://www.respectme.org.uk)

Email: [enquire@respectme.org.uk](mailto:enquire@respectme.org.uk)



*“They work with all adults involved in the lives of children and young people to give them the practical skills and confidence to deal with children who are bullied and those who bully others. The service is fully funded by the Scottish Government and is managed by SAMH (Scottish Association for Mental Health) in partnership with LGBT Youth Scotland.*

*Their vision is of a respecting, just, equal and inclusive Scotland in which all children and young people can live free from bullying and harassment and are encouraged to reach their full potential. Their work is driven by a focus on children’s rights.*

*They aim to build the capacity of these adults to effect change and challenge bullying and stigma, at an individual, school, family, community and societal level. They also campaign at a national level to raise awareness of the service, and the impact that bullying can have.”*

**Respect Me** charity has a great deal of information on their website, including practical advice and guidance ‘Bullying – A guide for parents and carers’ and ‘Bullying...What can I do’. The charity has also suggested taking a look at and reading the blog <http://briandrespectme.blogspot.co.uk>

## Cyber Bullying Guidance

**The Cybersmile Foundation**  
UK Registered Charity No 1147576

Telephone: 020 7241 6472

Website: [www.cybersmile.org](http://www.cybersmile.org)

Email : [help@cybersmile.org](mailto:help@cybersmile.org)

They also have a help centre on their website which can provide various kinds of help for parents, teenagers, pre-teens, adults. The Cybersmile Foundation have provided us with some suggested guidance.

## The Cybersmile Foundation: Guidance for Cyberbullying.

Being bullied online can have devastating effects and it is important that parents are aware of the dangers and what they can do to protect those in their care.

The following guidelines will help you to understand more about the risks and how you can manage them effectively.

**Awareness** – be aware of what sites your child is using and what security measures and privacy settings are available. Look at these with your child and make sure they also know how to block other users and report any abuse.

**Look for the signs** – changes in behaviour, hiding the screen from you, becoming less sociable, mood swings, aggressive language and depression are all signs that there could be a problem online.

**Talk openly** - open dialogue on the issue of digital abuse is going to be needed to build trust. Letting your child know that you care about their wellbeing and that you will help them if they have problems online will develop this trust.

**Don't Panic** – If an incident occurs, do not panic. Take time out and get away from the computer to gain some perspective. Acting out of anger or fear will not help so take the time to calm down and assess the situation.

**Get help** – If you or your child receives threats or explicit content then you should contact the Police immediately.

**Do not retaliate** – Responding in kind will only make things worse and you could end up being accused of bullying yourself! It is better to record/screenshot any abusive content and store it in a file as evidence, should you need it.

**Community Support** - See what resources are available to you in your local area. Schools, local authorities or community groups may offer meetings/talks or training for parents.

For a more comprehensive guide you can find more information at their web site [www.cybersmile.org/advice-help](http://www.cybersmile.org/advice-help).

### Anti-Bullying Alliance

UK Register Charity 258825

Website: [www.anti-bullyingalliance.org.uk](http://www.anti-bullyingalliance.org.uk)

*“The Anti-Bullying Alliance (a partnership body based at the National Children's Bureau) is a coalition of organisations and individuals working together to stop*

*bullying and create safe environments in which children and young people can live, grow, play and learn. ABA also supports a growing network of almost 1000 schools and colleges across the country. The ABA coordinates Anti-Bullying Week each November and is the national voice for evidence-based practice in relation to the prevention of bullying between children and young people. They can provide expertise in relation to all forms of bullying in this age group. They have experience in working with a vast range of clients including the government, youth charities, journalists, documentary makers, public services, schools and colleges, children's homes, young offender institutes, and businesses. If an expert member of their team is unable to assist - they can put you in touch with someone who can."*

The Anti-Bullying Alliance cannot offer an individual service, but may be a useful service for schools and teachers. For individual advice they suggested the following contacts:

If you are a child or young person and you are worried about bullying you can call **ChildLine** (Registered charity numbers for ChildLine are 216401 and SC037717) on **0800 1111**, for free and confidential advice 24 hours a day.

ABA and Red Balloon Learning Centres have worked together to produce a document for **Parents and Carers** that you can download :  
[www.anti-bullyingalliance.org.uk/advice/parents-carers/](http://www.anti-bullyingalliance.org.uk/advice/parents-carers/)

*"Be open about the condition with your friends, family, and the parents of your child's friends. If they understand Marfan syndrome, they can be more supportive and understanding. Sometimes they'll need to keep an eye open to notice any medical issues or to support your child. As an anecdote, I had a lot of discussions with my well-meaning mum about how thin my son is, particularly right after the diagnosis. She just thought he needed to 'eat more'. After taking time to educate her about the condition and my son's body type she understands now that it's not just about needing to eat more and has shifted her support toward healthy eating and his ongoing well-being." - Ladan*

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## Sharing your diagnosis and creating more awareness

Once you have a diagnosis, choosing to share it with others is a very personal decision and each person approaches this differently. When you share this with friends and family, make sure you are open and honest about your situation and be prepared to answer questions. Sometimes this can be liberating to disclose more about what you have been through and also a good way to share what you have learnt. You may like to bring information leaflets with you and give them to friends and family so they can read through them later.



Some people may not ask questions or may ask you later once they have digested what you have told them. It is suggested that the best way to share a diagnosis with friends and family is face to face, however this may not always be possible, and some people may find writing a letter easier.

It is always best to consider broaching the subject of sharing your child's diagnosis within your child's best interest. Sharing their diagnosis can teach your child to not be afraid of being open about having Marfan syndrome and may help your child adjust as he/she gets older and begins to understand what living with Marfan syndrome includes.

**Genetic Disorders UK** has more information about sharing news of genetic disorders on their website [www.geneticdisordersuk.org/](http://www.geneticdisordersuk.org/)

### Disorders related to Marfan syndrome

Several disorders produce features similar to those found in Marfan syndrome. These include:

- **Loeys-Dietz syndrome:** more information can be found at The Loeys-Dietz Syndrome Foundation [www.loeysdietz.org/en](http://www.loeysdietz.org/en)
- **Ehlers-Danlos syndrome :** more information can be found on the NHS website and support can be found at The Ehlers-Danlos Support UK [www.ehlers-danlos.org/](http://www.ehlers-danlos.org/) Telephone: 0208 736 5604 or helpline: 0800 907 8518

- Familial Thoracic Aortic Aneurysm and Dissection
- MASS Phenotype
- Beals syndrome
- Bicuspid aortic valve: more information can be found on Congenital Heart Defects UK [www.chd-uk.co.uk/types-of-chd-and-operations/bicuspid-aortic-valve/](http://www.chd-uk.co.uk/types-of-chd-and-operations/bicuspid-aortic-valve/)
- Ectopia lentis syndrome
- Stickler syndrome: more information can be found on The Stickler Syndrome Support Group (SSSG) UK [www.stickler.org.uk/info.htm](http://www.stickler.org.uk/info.htm)

## Make a donation to our work:

All of our leaflets are distributed for free. In order to continue to provide this much needed information we rely on donations. Please consider making a donation to The Marfan Trust charity. Visit our website: [www.marfantrust.org](http://www.marfantrust.org)



*Director of Sonalee Laboratory: Dr Jose Antonio Aragon-Martin, BSc (Hons), PhD.*

There are **many ways you can help** towards the work we do here at the Marfan Trust. Please visit our website to find out more:

- ◆ Monthly Donations
- ◆ One off donation
- ◆ Sonalee Wish List purchase
- ◆ Marfan Trust Shop
- ◆ Fundraise for us
- ◆ In memory donation
- ◆ Legacy donation
- ◆ Volunteer

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# Marfan Trust

*Supporting Research into Marfan Syndrome*

## The Marfan Trust charity

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W: [www.marfantrust.org](http://www.marfantrust.org)

E: [info@marfantrust.org](mailto:info@marfantrust.org)

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**Our Mission:** The Marfan Trust is the only Marfan charity in the UK that funds its own laboratory undertaking medical and analytical research so that more is known about Marfan syndrome and its management. The results of our internationally recognised research enable doctors and surgeons to provide better treatment for patients in the short and long term. Over 18,000 people are affected by Marfan syndrome in the UK, with many more anticipated to be living with the condition undiagnosed. Our important work hopes to improve the treatment of patients and increase awareness of this condition.

### The Marfan Trust's three main objectives are:

- To fund **medical research** projects that aim to aid the diagnosis and treatment of Marfan syndrome patients.
- To provide **educational literature** on Marfan syndrome and all its aspects to the medical profession and the general public, thus **raising awareness** of the condition.
- To provide **peer-to-peer support** and **medical guidance** to those affected and their families.

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