



National Marfan Foundation

Telephone Support Volunteer

Orientation Manual



Being A Volunteer Means ...



*You will never be bored.
You will always be frustrated.
You will always be surrounded by challenges.
So much to do and so little time.
You will carry immense responsibility and very
little authority.
You will step into people lives and you will make a
difference.
Some will bless you.
Some will curse you.
You will see people at their worst-
And their best.
You will never cease to be amazed at people's
capacity for love, courage and endurance.
You will see life begin and end.
You will experience resounding triumph and
devastating failures.
You will cry a lot.
You will laugh a lot.
You will know what it is to be human and to be
humane.*

-Author Unknown



National Marfan Foundation

TELEPHONE SUPPORT VOLUNTEER ORIENTATION MANUAL

The enclosed materials are provided to assist you with your role as a Telephone Support Volunteer for the NMF.

The items include:

- ♥ NMF Guidelines for Making Medical Referrals
- ♥ Instructions On How To Keep Your Clinic Directory Up To Date
- ♥ Phone Call Guidelines
- ♥ Rules for Helping Peers & Knowing How You Can Help
- ♥ Being Aware of Boundaries
- ♥ Do's and Don'ts
- ♥ A Comparison between a Friend and a Volunteer Peer Relationship
- ♥ Rules for Good Listening
- ♥ Paraphrasing
- ♥ Open-Ended Questions
- ♥ Problem Solving and Decision Making Model
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 - NMF Key Message Statements
 - 2010 Revised Diagnostic Criteria for Marfan Syndrome Key Points
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 - A Resource on Suicide
 - A Resource for Helping People With the Grief Process
 - A Resource For Parent/Child Communication Breakdown
 - List of Resources Available Through the NMF Website /By Request

We request, when someone contacts you, that you ask if they have already received (or requested) an information packet from the NMF. If they have not, that is, if you are their first contact with the NMF, ask them if you can give their name and address to the NMF office. In this way, they can receive our free information packet and updates from the National Marfan Foundation.

- ♥ Explain that being on the national mailing list is an important way to keep informed about new developments in Marfan care.
- ♥ Reassure them that the mailing list is strictly confidential and never shared outside of the NMF.

- ♥ Finally, although they will receive a request for membership dues, the NMF offers complimentary memberships to anyone who asks (by checking the appropriate box on the membership brochure or membership reminder.) We do not want anyone who needs Marfan information to feel they cannot be on our mailing list simply because they cannot afford membership dues.

♥

Sometimes a person will not want to be on the national mailing list.

- ♥ Reassure them that this is fine.
- ♥ Encourage them to contact you again if they have additional questions.
- ♥ Ask if they would like *you* to send them an information packet, thereby avoiding the national mailing list. If this is the case, contact Amy or myself so we can send you the appropriate packet for you to forward.

Also, we in the Resource Center are here to help you. Amy Kaplan, R.N., is the Manager of the Information Resource Center. She is the person with primary responsibility to respond to the requests received by the NMF Resource Center for Marfan information and doctor suggestions.

Please refer persons who contact you to Amy if:

- ♥ They have medical questions and concerns you feel you cannot completely address.
- ♥ They need more help finding medical care including experienced doctors.
- ♥ They need help finding additional non-medical community resources.
- ♥ They have questions about Social Security Disability you cannot answer or they need a letter in support of their Social Security Disability *appeal*.
- ♥ You need an Information Packet (specify if the person is already diagnosed or seeking an evaluation) for you to forward to a person who does not want to contact the National office.

Amy's extension is 26 at the NMF toll free telephone number: 800-862-7326 and her e-mail address is support@marfan.org

If you would like a consultation on what to do next in a particular situation, Jennifer Buffone, LCSW, Director of Support and Volunteer Development, is available to discuss your concerns. You can reach her at ext. 22 or by e-mail at jbuffone@marfan.org.

We thank you for your willingness to be an NMF local contact. We are grateful to all who make themselves available to others who are coping with Marfan syndrome and related disorders in themselves, in their family, or both.

Updated: 1/11/11

National Marfan Foundation **Guidelines for Making Medical Referrals**

We realize that you may be asked for doctors knowledgeable about Marfan syndrome and hope that the following Guidelines and attached Marfan Specialty Clinic Directory will help you with that task.

We request that you take time to read through the Directory to familiarize yourself with the available clinics as we know them. Also we want you to understand the two categories of clinics and the concept of a “Yellow Pages” directory that avoids the notion of a warranted referral from the NMF. If you have any questions about these Guidelines, using the Directory, or suggestions for additional clinics, please call Jennifer Buffone at 1-800-862-7326 ext. 22.

THE NATIONAL MARFAN FOUNDATION DOES NOT RECOMMEND OR ENDORSE ANY PARTICULAR DOCTOR OR MEDICAL FACILITY. We do, however, recognize the need for persons to locate knowledgeable doctors. As a volunteer telephone, support group, or chapter contact you may provide the following information when someone asks you for a doctor to diagnose or manage Marfan syndrome (MFS).

If someone is not yet diagnosed, suggest consultation with a medical geneticist who will evaluate the “total person” in the context of the various body systems affected by MFS. Often people are concerned about the cardiac manifestations. They will ask you for the names of cardiologists and are focused on the echocardiogram, but you should also explain the role of medical genetics for making a diagnosis.

- ♥ First, inform persons of the Medical Centers where members of our Professional Advisory Board practice as indicated on the Clinic Directory attached to this memo. The telephone numbers are for the Marfan Clinic, which may be part of Medical Genetics or Cardiology or Pediatrics etc., depending upon the way the medical center has organized the MFS clinic. No matter where the clinic is located, the MFS specialty clinics should coordinate the various tests and medical specialists, including a geneticist, needed to make a diagnosis.
- ♥ Next, share the additional “institution-designated” MFS specialty clinics also on the Clinic Directory. These clinics should also coordinate the needed specialists.
- ♥ If the person is unable to access a specialty clinic, inform them that the Medical Genetics Department at a large teaching hospital *may* have knowledgeable doctors and is a resource worth trying. If they want more specific information about Medical Genetics clinics close to them, you should tell them to contact Amy Kaplan in the NMF Resource Center at 800-862-7326 ext. 26.
- ♥ You may offer information on the manner in which you or your family members were diagnosed, but you must begin this information with the statement **“THE NMF DOES NOT RECOMMEND OR ENDORSE ANY SPECIFIC DOCTOR OR FACILITY.”** Note that you personally used this doctor or facility and found

If someone is seeking a particular type of specialist for the management of previously diagnosed Marfan syndrome, again provide information on the clinics where members of our PAB practice and the other specialty clinics in the Clinic Directory.

- ♥ The specialty clinic can provide the names of knowledgeable specialists. You should counsel persons to be clear about their MFS diagnosis and the need for a doctor to manage their particular problem when they call the clinic number. This is important because sometimes they will reach a clinic receptionist who will not automatically know what information to provide.
- ♥ You may offer information about local doctors “you have personally used and found to,” as long as you are clear this is not a recommendation from the NMF, but based upon your personal experience. (See disclaimer above.)

Some additional points:

- ♥ From the specialty clinic list, please recommend institutions as opposed to particular physicians
- ♥ Do not say that any particular facility is “The Best,” and try not to get anyone to have you identify “the best” or get you to answer the question, “if it were you, where would you go?” Instead you may note the long-standing experience of a particular institution, or support someone’s selection as “a place where you should expect to find knowledgeable doctors.”
- ♥ You may wish to help persons identify questions they may want to ask their doctor. Your own experience is invaluable in this situation.
- ♥ If *the person* wishes to select a particular medical center where you have been treated, it may be helpful for you to share any tips from your personal experience for negotiating that particular facility. If a particular doctor at a center is mentioned, again use the disclaimer if you have had personal experience with that doctor.
- ♥ It is fine to recognize someone’s frustration in finding knowledgeable doctors. Marfan syndrome is rare enough that many doctors have not had opportunity to manage the condition. Persons have the choice to travel to find knowledgeable care or take NMF literature to their local doctors to educate them.
- ♥ If you sense you have not been able to provide the resources a person may need, suggest they contact the NMF Resource Center (800-862-7326 ext. 26) for additional assistance.

KEEPING YOUR CLINIC DIRECTORY UP-TO-DATE

The NMF Clinic Directory is updated and corrected on no particular schedule, but as changes become known to us. Therefore we ask you to check the Directory on our website from time to time to keep your clinic list current and accurate. (The Clinic Directory included with this packet is the current Directory.) Go to www.marfan.org : “Find it Fast”, “Find a Doctor”, “Register Here” and fill out a Registration Form. *On the form under the heading: “Please Check your Reason for Finding a Doctor for Marfan syndrome,” Please check off “Other specify: NVN Volunteer.”* The Directory will immediately arrive as an e-mail. If you do not immediately receive the Directory, check to see if your internet provider has put our message in a spam file for you to review. If this is the case, consider setting up your account to accept e-mails from the NMF without such censoring.

For those of you who do not have internet access or have any difficulty getting the Directory on-line, please call me (Jennifer Buffone) at 1-800-862-7326 ext. 22 and I will send you an updated Clinic Directory.

Once You Have Received Your E-mail:

Click the link for Clinic Directory, which will then open a new window to Clinic Directory, Click link NMF Clinic Directory. Please Note: Adobe is needed to run this directory.

If you have any questions about these guidelines, please contact Jennifer Buffone at 1-800-862-7326 ext. 22

Phone Call Guidelines

1. Ask how the caller got your name.
(through the NMF, a physician, a friend)

2. Introduce yourself; tell them up front that you are a volunteer member of the NMF and that you are not a health care professional.
(your first meeting with a new helpee can often be uncomfortable – this is ok and will decrease overtime.)

3. Try to learn something about the caller.
 - a. Who are they calling on behalf of?
(self, child, friend or other family member)
 - b. Are they in a crisis?
(emotional, physical, or spiritual)
 - c. Have they seen a physician? If so, what did they say?
 - d. Who else have they spoken to?

4. If you are having trouble getting them to open up – share a “little” about yourself whatever seems pertinent to the situation.

5. Try to determine how knowledgeable they are about Marfan Syndrome.
 - a. Are they using words/terms appropriately?
 - b. Are they looking for information, oral or written?
 - c. Are they asking for a health care referral?
 - d. Are they seeking to meet other people with Marfan Syndrome?

6. Wait to be asked about your own experience with Marfan Syndrome and once asked be leery of over doing it.
* Remember to consider the caller’s frame of mind, questions and knowledge of Marfan Syndrome.

7. When closing the phone call review the progress that the helpee has made. Assist the helpee in recognizing where he or she was when the counseling relationship began and what has been accomplished since that time.

Rules for Helping Peers

- ♥ Be non-judgmental
- ♥ Be empathic
- ♥ Do not give advice
- ♥ Do not take responsibility for the other person's problem
- ♥ Stick with the here and now
- ♥ Do not argue, verbally or non verbally
- ♥ Listen between the lines
- ♥ Deal with feelings first
- ♥ Be genuine and sincere
- ♥ Keep confidentiality
- ♥ Be a vital part of a caring network

Knowing How You Can Help

- ♥ Decide what you can offer to a caller.
- ♥ Identify your own special experiences that you are willing to share.
- ♥ Decide whether to use your home phone or a special phone for volunteering.
- ♥ Know how you will cover the costs of phone bills/charges.
- ♥ Research:
 - Local and regional centers and/or names of physicians that specialize in the diagnosis and treatment of people with Marfan Syndrome.
 - Have at least three of these to offer to callers.
 - Encourage the caller to work with their primary physician in obtaining these referrals where possible.
- ♥ Remember you can not make personal referrals. NMF representatives cannot recommend specific physicians. If you feel a local facility is a good one, and/or if you have a specific physician whom you feel is knowledgeable, you might consider using the following: "THE NMF DOES NOT RECOMMEND OR ENDORSE ANY SPECIFIC DOCTOR OR FACILITY. However, I personally have used and gone to (name of doctor or facility) and found that..."
- ♥ Encourage Callers to be in contact with the NMF.
- ♥ Free literature is always available from NMF headquarters.

Being Aware of Boundaries

- ♥ As in any relationship, there are boundaries over which neither party should cross. As peer counselors, you are there to *listen*. You should not intrude into certain areas of the helpee's life unless they have given you permission to do so.
- ♥ You have boundaries also, and it may be necessary to establish these with the helpee. It is important to keep in mind that you are not responsible for the helpee's actions or feelings. Never feel guilty if things do not turn out right for the helpee.
- ♥ Being aware of boundaries may also help to prevent two different kinds of situations which will jeopardize the helper-helpee relationship. One of these situations occurs when the helper becomes the "rescuer." Another difficult situation may occur if the helper and the helpee get attached to each other and become emotionally involved.
 - *Do not Rescue*

As a peer counselor, your role is not to save the helpee. You are there to help the person help him or herself. If you become the rescuer by taking care of something for the helpee, or by enabling him or her not to take risks, you are doing a disservice. You would cause harm to the helpee and his or her personal growth by assuming responsibilities which are not your own or by providing over-protection. In this respect, you would be violating a basic rule of being a telephone support volunteer.
 - *Remember:*
 - If in the helper-helpee relationship stronger feelings become apparent, you must establish how you feel toward the helpee immediately.
 - The helpee may need to work with a different Telephone support volunteer as a result.
 - If you find the helpee is becoming too dependent upon you, reestablish your boundaries and talk with him or her about how you feel.
 - You can always contact the NMF for assistance.

Do's and Don'ts

Do:

- ♥ Follow the rules of confidentiality.
- ♥ Identify yourself as affected or as a family member of someone affected.
- ♥ Listen carefully to questions and statements to avoid giving more information than requested.
- ♥ Be careful not to overwhelm with too much information.
- ♥ When you are uncertain as to what is being asked, request clarification before responding.
- ♥ It is ok to say you don't know and suggest another resource, e.g. the person's own doctor or NMF national office.
- ♥ Use a positive, problem-solving approach to a person's concerns.
- ♥ Answer questions honestly using your own experience.
- ♥ Share how you coped with uncertainty and decision making... (When I had difficult decisions to make I ...talked to my doctor...my family...went with my gut...read everything I could)
- ♥ Share how you gathered information rather than giving information, statistics or advice on management techniques.
- ♥ Assist person with formulating their questions or requests for their doctors.
- ♥ Share information about resources you found helpful.
- ♥ Be aware of your own feelings and responses to different personalities. Know that you do not have to like everyone who contacts you.
- ♥ Avoid getting caught up in the person's conflicts with family or medical personnel.
- ♥ Call NMF if you have concerns about any aspect of your contact or desire a consultation about what to do next.

Don't:

- ♥ Give explicit treatment/management advice or recommend/encourage persons to make specific decisions about treatment choices.
- ♥ Be a cheerleader or critic of any institution or of any health care professional, organization or management technique; or contradict any treatment a person's physician(s) have recommended. If you are concerned that something does not sound right, help formulate questions for the doctor and support concept of a second opinion.
- ♥ Falsely reassure. Instead share how you coped with uncertainty or other difficult situations.
- ♥ Give express advice reflecting your own values, religious beliefs, dietary practices etc. These are personal choices reserved for individuals to make for themselves.
- ♥ Continue conversations with persons who make you feel uncomfortable, e.g. emotionally disturbed or confused persons, those with overwhelming social problems basically unrelated to MFS. Refer them to the NMF.

A Comparison between a Friend and a Volunteer Peer Relationship with an Affected Person or Family Member

Friend Role

The relationship is established through normal life experience entailing a process of social interaction.

The relationship is highly subjective and based on mutual attraction of both parties.

The major goal of the relationship is mutual satisfaction of both parties.

Communication is between equals. Each party has an implicit right to talk about himself/herself.

The relationship does not necessarily have a time frame.

Volunteer Role

The relationship is established through a program designed to facilitate a therapeutic relationship between the volunteer and affected person.

The relationship is objective and based on the willingness of the volunteer to help and the affected person to be helped.

The major goal of the relationship is the provision of emotional support to the affected person.

The communication is not between equals. The affected person is encouraged to talk: the volunteer listens and shares feelings and perspectives only when appropriate.

The duration of the relationship is determined by the program parameters and is limited to a brief intervention.

Rules for Good Listening

“Have a desire to listen, there is no such thing as uninteresting people
– only disinterested listeners.” – *Tony Alessandra*

- ♥ **Stop Talking:**
 - If you are talking, you can't be listening. Silence from us often encourages or gives others permission to speak.
- ♥ **Make This A Safe Experience:**
 - Put the individual at ease as much as possible. Accept their point of view and feelings, and try to use your story to validate what they are now experiencing.
 - Don't antagonize the speaker with nasty judgments.
- ♥ **Show Them You Are Listening:**
 - Listen to understand their story. Don't assume their experiences will parallel yours exactly. Concentrate on listening even if you think you have figured out their concerns and where their story is going.
- ♥ **Avoid Distractions:**
 - Don't allow interruptions or distractions that pull you both away from sharing information or support. Help keep the focus on topics of importance, not idle chit-chat.
 - Don't daydream, keep thoughts from wondering.
- ♥ **Use Empathy:**
 - Remember your own experiences to try and understand their points of view. Even when their perceptions are different, accept them as valid for that person. Try to communicate this acceptance and understanding by your attitude and speech.
- ♥ **Don't Hurry:**
 - Don't interrupt and don't seem in a hurry to end the conversation. Make your connection when you have enough time to devote to the contact.
 - Listen to what is being said rather than how tempted you are to respond.
- ♥ **Listen Without Judgment:**
 - Be prepared to hear and feel any and all emotions. REMEMBER: All feelings are worthy of respect, even if you don't understand them, or were expecting a different response.
 - Listen between words for tone, attitude and level of conviction.
- ♥ **Don't Argue or Criticize:**
 - Heightened emotions can cause feelings and words to seem irrational. The responsibility is on you to maintain calm acceptance of all their feelings as matters are discussed.
- ♥ **Ask Good Questions:**
 - Ask open-ended questions to show you are listening and to encourage more self-exploration. Ask for clarification if you do not understand.
 - Take notes if needed

Paraphrasing

How to paraphrase:

Restate in your own words *the central, core content and/or feelings* the person has *explicitly* stated. (Content is the description of the person's situation.)

- ♥ Listen for the message (feelings and content).
- ♥ Restate simply and concisely.
- ♥ Observe the person's response to confirm or disagree with your understanding
- ♥ Allow for correction, clarification.

Purpose:

- ♥ Shows attention and willingness to understand.
- ♥ Increases trust
- ♥ Provides a direct check on your understanding of another's explicit disclosure.
- ♥ Encourages, reassures and increases exploration.
- ♥ Puts a person's experience into a different perspective with new language and greater clarity.

Example: A person says angrily, "That's the way it is. My father is always picking on me."

Paraphrase: "Your dad seems to be on your back all the time."

Guidelines:

- ♥ *Comprehensive summary:* reflect all aspects of the disclosure, including mixed feelings. Avoid focusing on fragments or peripheral information.
- ♥ *Explicit message only:* Address only the feelings and/or content that were directly and explicitly disclosed. Avoid editorializing, assuming too much, reading into the disclosure, or adding to the explicit information.
- ♥ *Personal and appropriate language:* Summarize the statements using your own language. Avoid parroting or using offensive, condescending, or overly complex language.
- ♥ *Tentativeness:* Restate in tentative terms to show you're checking for understanding, (e.g. "Let me see if I have this straight..." Are you saying...?") Avoid paraphrasing that sounds like a pronouncement.
- ♥ *Varied introductory phrases:* Use a wide range of natural-sounding lead-in phrases followed by the concise summary. Try and avoid habitual, stereotypic and stilted lead-ins such as "You said..." or "I heard you say..."
- ♥ *Timing:* Paraphrase at brief summarization points, interspersing dialogue with questions, requests for clarification, minimum encouragers. Avoid paraphrasing after every statement.

Open-Ended Questions

Typical Open-Ended Questions:

1. Could you tell me more about...?
2. Can you tell me something about...?
3. What will that mean to you...?
4. What was the significance of that event for you...?
5. What impact did that have on you...?
6. What do you imagine that will be like for you...?

Examples of Closed & Open-ended Questions in a Conversation:

Conversation 1:

Caller: *“My aorta is at 5.0 and my cardiologist is saying I should start thinking about surgery.”*

Example of a Closed-Ended Response:

Contact: *“Are you scared of having surgery?”*

This is a closed-ended response question because it will limit the caller’s response to a short “yes” or “no.” It may also tend to suggest how the person ought to be feeling and they may respond in a way they think the contact wants them to.

Example of an Open-Ended Response:

Contact: *“Do you have any questions or concerns about having surgery, and if so, what are they?”*

This is an open-ended response question because it makes no particular assumption about what the caller is feeling and doesn’t even require that the person have any questions or concerns.

Conversation 2:

Caller: *“My daughter was just diagnosed with Marfan syndrome and I have never even heard of this before.”*

Example of a Closed-Ended Response:

Contact: *“Are you worried?”*

This is an example of a closed-ended question because this response can be answered with a short “yes” or “no.” It also suggests that the caller should feel worried.

Example of an Open-Ended Response:

Contact: *“How did this diagnosis come about?”*

This is an example of an open-ended response because it asks for some relatively factual information that you may need to accurately assess the caller’s situation. Also telling the story may be very helpful to the caller. You will get to know how they are currently feeling as the call progresses.

Note: That this response does not initially ask about feelings.

Conversation 3:

Caller: *“I saw this show on TV and I think my son may have Marfan syndrome, but I can’t get the doctor to take me seriously.”*

Example of a Closed-Ended Response:

Contact: *“Have you tried taking information to the doctor?”*

This is an example of a closed-ended question because this response can be answered with a short “yes” or “no.” This is a strategy you may ultimately recommend, but it too quickly offers a solution and does not provide opportunity to explore the situation.

Example of an Open-Ended Response:

Contact: *“Tell me about the conversation you have had with your doctor.”*

Problem Solving and Decision Making Model

1. *Clarify feelings.*
 - a. Use active listening to assist helpee sort out feelings.
 - b. Making a list could be helpful.
2. *Gather information.*
 - a. Find out as much as you possibly can about the situation.
3. *Define problem.*
 - a. What does the helpee perceive as the problem?
 - i. Sometimes the first problem presented is not the primary one.
4. *Identify the decision.*
 - a. What does the helpee want to change?
5. *Brainstorm alternatives.*
 - a. Use open-ended questions to explore what the real problem may be.
6. *Evaluate alternatives.*
 - a. List all possible solutions.
 - b. Have helpee prioritize solutions in order of importance.
 - i. Pros and Cons.
7. *Predict consequences.*
 - a. Talk about possible outcome of each possible decision.
8. *Clarify values.*
 - a. Will certain decisions violate helpee's values?
9. *Make an action plan.*
 - a. List things to be done. First, second, third, etc. for helpee to carry out decision.
 - b. Assist the helpee to make a plan for completing each step in a given amount of time.
10. *Follow up.*
 - a. Make an appointment for the helpee to contact you again and report how it is working out.

Feedback

Feedback Defined: Corrective information given by one person to someone else who is thought to be using inappropriate behavior, when the person receiving feedback feels the information is provided in a context of caring and concern. Feedback must come from a trusted source.

The probability that corrective information will be heard as feedback, rather than as criticism, is the greatest when as many as possible of the following conditions are met.

- ♥ When the information is descriptive rather than judgmental. This is essential.
 - *Information is judgmental when it associates the worth of the person with the value of his or her behavior.*
- ♥ When the information comes from a trusted source. This too, is essential.
- ♥ When it is about behavior and not attitudes, values, character etc.
- ♥ When it is asked for, not imposed.
- ♥ When it is specific, not general.
- ♥ When it is only about behavior that can be changed.
- ♥ When it is given at an appropriate time and place.
- ♥ When it is checked by the giver to see if it has been understood.
- ♥ When it can be validated by others when necessary.
- ♥ When it results from a situation both giver and receiver have shared.

Effective feedback involves what or now, not why. Asking why is asking people about motivation and that can provoke defensiveness.

After Conversation Check List

REMBER TO ASK YOURSELF:

♥ *For Active Listening*

- Did I focus solely on the helpee?
- How was my tone of voice?
- Did I refrain from giving advice?
- Did I refrain from passing judgment?
- Did I allow the helpee time to completely express his or her thoughts and feelings?
- Was I empathetic?
- Did I refrain from arguing with the helpee?
- Was I supportive?
- Did I express caring and love?
- Did I restate the helpee's feelings?

♥ *Checking Your Responses*

- Did I validate the helpee's feelings?
- Was I able to ask questions which facilitated the helpee further express his or her feelings?
- Did I do anything which caused the helpee to put up barriers?
- Did I avoid over-analyzing?
- Did I refrain from expressing personal opinions?
- Did I use open-ended questions?
- Was I able to summarize/restate the helpee's thoughts and feelings?

Strategies for Self Care

- ♥ Cultivate these feelings about yourself in relationship to your volunteer role:
 - I am a good person for this job
 - Being “good” does not mean I am “perfect.”
 - I am open to new learning and greater understanding.
 - I believe in what I am doing.
 - The persons I contact are free to accept or not accept what I say

- ♥ Be clear in your own mind, from the beginning of any contact, about the limits and restrictions of your involvement.

- ♥ Allow yourself to return feelings of the past without panicking
 - Reassure yourself that you know your coping skills are in place.

- ♥ Know that listening is helpful even in the face of overwhelming difficulties.

- ♥ Know that you are not responsible for fixing all of the caller’s problems.

- ♥ Talk with a spouse or other close relative or friend, but give care to keep caller’s identity confidential.

- ♥ It is ok to end a relationship, but do so with planning and care.

- ♥ Remember that it is ok to ask to NMF for a break or resign from being a volunteer contact.

- ♥ Call Jennifer Buffone at 1(800)862-7326 ext. 22 if you are upset by a contact or have questions about what to do next.

Being Self Aware

Self-awareness is a vital part of being a peer counselor. Being in touch with how you are feeling, or something you are experiencing, greatly affects how you can help someone else. Peer counselors by no means are without problems. Everyone experiences things on a daily basis in his or her life. Be aware of what you are feeling and why. Be as honest as you can about your feelings – this will help you from releasing your feelings inappropriately, not only with a helpee, but with others as well.

How to Check Your Self Awareness

- ♥ Be honest with yourself and others. You may want to internalize your feelings and act as if everything is ok, when really, it is not. This can be very dangerous and lead to emotional instability.
- ♥ Recognize your feelings. Focus on those feelings.
- ♥ Don't run away from whatever you may discover. Talk to someone about what you are feeling and what is happening in your life.
- ♥ Listen to others and their input
- ♥ Do not discount or minimize your feelings – any feeling is important and deserve validation.
- ♥ Once you have recognized those feelings deal with them in a healthy way.

Remember, you can always contact the NMF, Jennifer Buffone is a Social Worker and Director of Support Services at 1-800-862-7326 ext.22

Questions to Ask Yourself

- ♥ *General Questions*
 - Am I feeling guilty about something involving the helpee?
 - Am I comfortable with the problem the helpee needs to work on?
 - Do my values get in the way of my objectivity on this particular issue?
 - Does this problem require a referral?
 - Do I have any irritating habits I need to change? (interrupting, daydreaming, etc.)
 - What can I do differently next time to better support and listen to the helpee?



Resources For Telephone Support Volunteers



National Marfan Foundation

Key Message Statements

NATIONAL MARFAN FOUNDATION

The National Marfan Foundation is the only nonprofit health organization in the U.S devoted to Marfan syndrome and related disorders. Its mission includes research, support, education and advocacy.

MARFAN SYNDROME

Marfan syndrome is a genetic disorder that weakens multiple body systems, including the heart, blood vessels, bones and joints, lungs and eyes. The life-threatening part of Marfan syndrome is the weakening of the aorta, the large blood vessel from the heart. Early diagnosis and treatment are essential for maximizing life expectancy.

RESEARCH PROGRAM

The NMF supports and promotes research to identify ways to improve diagnosis and treatment and to find a cure.

EDUCATION AND AWARENESS

The NMF educates patients, provides resources to medical professionals and raises awareness in the general public to increase early diagnosis, assure proper treatment and reduce preventable deaths through coordinated program initiatives and media outreach.

SUPPORT SERVICES

The NMF's Informational Resource Center (IRC) provides individualized information, counseling and support about diagnosis and management, and facilitates peer to peer connections within the Marfan community. The IRC also serves as a valuable resource to medical professionals seeking information on diagnosing and treating their patients

NATIONAL VOLUNTEER NETWORK

The NMF's National Volunteer Network (NVN) is made up of chapters, local groups, and individuals. Chapters and groups provide the opportunity for volunteers to strengthen the Marfan community and support the NMF mission in their local areas.

ADVOCACY

The NMF advocates to federal, state and local governmental agencies for policies and funding that supports research, healthcare and quality of life needs of the Marfan Community.

GOVERNANCE

The NMF is governed by an independent Board of Directors that consists of people affected by Marfan syndrome and other leaders in the business, professional and healthcare communities. A professional Advisory Board provides medical expertise and a Scientific Advisory Board evaluates research grant proposals.

FUNDING

The NMF is a member supported non-profit organization that raises funds through grants and donations from individuals, corporations, foundations and government agencies.

2010 Revised Diagnostic Criteria for Marfan Syndrome Key Points

Purpose:

- ♥ Simplify the evaluation process for physicians.
- ♥ Provide patients with a more accurate diagnosis and better medical management

New: Systemic Score

- ♥ Assigns various features of Marfan syndrome a numeric value (no more “major” or “minor” criteria)

Changes in Marfan Syndrome Diagnosis:

- ♥ The two cardinal features of Marfan syndrome – aortic root dilatation/dissection and ectopia lentis (dislocated lens of the eye) – are weighted more heavily than other characteristics.
- ♥ There is a more precise role for molecular testing.
- ♥ Less specific manifestations of Marfan syndrome are either removed or given much less weight in the evaluation process.

Other Considerations:

- ♥ Diagnostic criteria have been defined for those with a family history of the condition and for those who may be a sporadic case
- ♥ There are specific guidelines for children (under 20) – with and without family history.
- ♥ New category of “non-specific connective tissue disorder” for those who do not meet the diagnostic threshold for Marfan syndrome or a related condition; emphasizes continued follow-up, especially of the aorta.
- ♥ Additional diagnostic considerations and recommends more testing if a patient has sufficient findings of Marfan syndrome but, additionally, shows other unexpected features.
- ♥ Outlines differential diagnosis and management for alternative diagnoses, such as Loeys Dietz syndrome, vascular Ehlers Danlos, mitral valve prolapse syndrome, familial aortic aneurysm and more.

Hal Dietz, MD. Response to New Diagnostic Criteria

The revisions to the diagnostic criteria focus on improving the efficiency of the diagnostic process, assuring accurate diagnosis, and suggesting follow-up procedures for people who do not meet diagnostic criteria. Importantly, the diagnostic criteria largely formalize existing diagnostic philosophies and practices. We do not anticipate that the diagnosis will change for the majority of individuals, and we anticipate that most diagnostic changes will not alter management. On this basis, we do not believe that individuals with an established diagnosis of Marfan syndrome should schedule an immediate appointment for consideration of these revisions. Rather, this should be a topic for discussion at the time of the next routine follow-up visit.

Marfan Syndrome Facts

What is Marfan syndrome?

Marfan syndrome (MFS) is a disorder of connective tissue. Connective tissue holds all parts of the body together and helps control how the body grows. Because connective tissue is found throughout the body, MFS features can occur in many different parts of the body.

MFS features are most often found in the heart, blood vessels, bones, joints, and eyes. Sometimes, the lungs and skin are also affected. MFS does not affect intelligence.

What causes Marfan syndrome?

MFS is caused by a defect (mutation) in the gene that tells the body how to make fibrillin-1 -- a protein that is an important part of connective tissue. This mutation creates different MFS features and causes medical problems for people with MFS.

Who has Marfan syndrome?

About 1 in 5,000 people have MFS. This includes men and women of all races and ethnic groups. People can inherit MFS, meaning that they get the mutation from a parent who has MFS. This happens to about 3 out of 4 people with MFS. Other people have a spontaneous mutation, meaning that they are the first in their family to have MFS. People with MFS have a 1 out of 2 chance of passing the mutation on each time they have a child.

People are born with MFS but may not notice any features until later in life. However, MFS features can appear at any age, including in infants and young children. MFS features and medical problems can get worse as people age.

What are Marfan syndrome Features?

MFS features occur in many different parts of the body. Always, a person with MFS has at least 3 features in different parts of the body. Rarely, a person has every feature. Some MFS features are easy to see. Other features, such as heart problems, are hidden and need special tests to find them. It is important that a person with 3 or more features see a doctor who knows about MFS.

Here are the most common MFS features:

Heart and blood vessels (Cardiovascular system)

- ♥ Enlarged or bulging aorta, the main blood vessel that carries blood from the heart (aortic dilation or aneurysm)
- ♥ Separation of the layers of the aorta that can cause it to tear (aortic dissection)
- ♥ “Floppy” mitral valve (mitral valve prolapse – MVP)

Bones and Joints (Skeletal system)

- ♥ Long arms and legs
- ♥ Tall and thin body type
- ♥ Curvature of the spine (scoliosis or kyphosis)
- ♥ Chest sinks in (pectus excavatum) or sticks out/pigeon breast (pectus carinatum)
- ♥ Long, thin fingers
- ♥ Flexible joints

- ♥ Flat feet
- ♥ Teeth that are too crowded

Eyes (Ocular system)

- ♥ Severe nearsightedness (myopia)
- ♥ Dislocated lens of the eye
- ♥ Detached retina
- ♥ Early glaucoma
- ♥ Early cataracts

Other body systems

- ♥ Stretch marks on the skin, not explained by pregnancy or weight gain
- ♥ Sudden collapse of the lung (spontaneous pneumothorax)

What is life like for a person with Marfan Syndrome?

While there is no cure for MFS, advances in medical care are helping people live longer and enjoy a good quality of life. Research is also finding new ways to treat people with MFS. Most people with MFS can work, go to school, and enjoy active hobbies.

It is very important that people with MFS get treatment and follow medical advice. One reason is that heart problems can cause sudden death if they are not treated. Early diagnosis means helpful treatment can begin early in life. People with MFS should not play active team sports such as football, soccer, or basketball. They should not lift heavy objects when at work, home or the gym.

What should you do if you suspect Marfan Syndrome?

Look for a doctor who knows about MFS so you can be checked for this disorder. Keep in mind that you can have MFS features but not have the disorder. The only way to know for sure is to be checked by a doctor who understands MFS.

How can you learn more about Marfan Syndrome?

MFS is a complex disorder, with many features that affect different parts of the body. Here are some ways to learn more about MFS:

- ♥ Call the National Marfan Foundation (NMF) Resource Center at 1-800-862-7326 ext. 26. When you call, you will speak with a nurse who can answer questions and mail you information. The nurse can also suggest ways to find a doctor who knows about MFS.
- ♥ Go to the NMF website at <http://www.marfan.org> You can find more information on the “About Marfan Syndrome” and “Living with Marfan Syndrome” pages. You can also ask questions online at “Support Services: Ask a Question.”
- ♥ Talk with a doctor. Sometimes it helps to take MFS information with you when you visit the doctor. Your doctor can go to the special section for doctors on the NMF website by clicking on “Medical Professionals.”

How to Find Out if You Have Marfan Syndrome

People sometimes ask, “Do I or a loved one have Marfan syndrome?” Here are some ways you and your doctor can find out the answer to this question.

What You Can Do

Find a doctor who knows about Marfan syndrome (MFS)

Marfan syndrome (MFS) is rare and not all doctors know about it. You need to find a doctor who knows about MFS and how to tell the difference between MFS and the other medical conditions that look like it.

The first choice of doctor to look for is a medical geneticist (a doctor who specializes in genetic conditions such as Marfan syndrome).

A second choice is a cardiologist (heart doctor). Make sure the cardiologist has treated people who have MFS.

You can find a doctor by:

- ♥ asking your primary doctor for a referral
- ♥ calling the doctor referral service at your local hospital
- ♥ calling the National Marfan Foundation Resource Center at 800-862-7326, ext. 26

Learn the health history of you and your family. You might want to write this down in a health history notebook with lists of:

- ♥ your past illnesses, operations, and hospitalizations
- ♥ medications you are taking
- ♥ reasons why you think you might have MFS
- ♥ family members who have, or might have, MFS
- ♥ family members who died of a heart problem

What Your Doctor Can Do

Talk with you about your health history.

This is the time when you can talk about the information in your health history notebook and why you think you might have MFS.

Do a thorough physical exam.

This includes looking for MFS features in your bones, joints, skin, and lungs.

Ask you to have medical tests. These common, painless tests include:

- ♥ Echocardiogram. This test looks at the heart, its valves, and the aorta (vessel that carries blood from the heart).
- ♥ Electrocardiogram (EKG). This test checks your heart rate and heart rhythm. Your doctor may do both an EKG and an echocardiogram.
- ♥ Slit lamp eye exam. This test, a part of most eye exams, helps your doctor see if the lenses in your eyes are dislocated (out of place).
- ♥ Other tests, such as a MRI or CT scan of the lower back. These tests can help your doctor see if you have dural ectasia, a back problem that is very common in people who have MFS.

What You and Your Doctor Can Do

You asked, “Do I have MFS?” There are three possible answers to this question. Each answer has actions you and your doctor should take.

- ♥ **No, you do not have MFS.** Ask your doctor if you have any other medical condition that needs medical care. You should also ask how you can get this needed care.
- ♥ **Maybe, you have MFS.** Ask your doctor if you should repeat the echocardiogram in 1 to 2 years to find out if the valves of your heart and aorta have changed.
- ♥ **Yes, you have MFS.** Ask your doctor how to take care of yourself. It is very important to follow these instructions. Find out if other people in your family also have MFS. You may feel overwhelmed and have a lot of questions. Below are some ways to learn more about MFS.

Ways to Learn More about MFS

- ♥ Call the National Marfan Foundation (NMF) Resource Center at 1-800-862-7326 ext. 26. You will speak with a nurse who can answer your questions and mail you information. She can also suggest articles your doctor can read about MFS.
- ♥ Talk with your doctor. Sometimes it helps to use the information you have from the NMF when you speak with your doctor.
- ♥ Visit the NMF website at <http://www.marfan.org> You can print out information from the “About Marfan Syndrome” and “Living with Marfan Syndrome” pages. You can also ask questions online by clicking: “Support Services: Ask a Question.”

(February 2006)

Related Disorders

Although we do not expect volunteers to be knowledgeable about all related disorders, we would like for you to be familiar with them

Sometimes a person may have one or more features of Marfan syndrome, but not have enough features to meet the diagnostic criteria for Marfan syndrome.

“Differential diagnosis” is the process of weighing the probability of one disease or disorder versus that of other diseases or disorders possibly accounting for a patient's illness or symptoms.

People may have disorders related to Marfan syndrome, such as other connective tissue disorders or metabolic disorders that closely resemble Marfan syndrome. A doctor will likely consider several conditions in the differential diagnosis to determine the actual diagnosis.

Regardless of the diagnosis, it is important to follow recommended treatments for the particular symptoms that do exist to make sure further problems do not result. For example, a person may not have enough features to be diagnosed with Marfan syndrome, but can still have an enlarged aorta. In this case, the aorta should still be monitored at regular intervals even though there is no Marfan diagnosis.

If the condition is hereditary, ensure proper evaluation of other family members who may be at risk.

Following is a list of some related disorders and their relation to Marfan syndrome:

| Marfan Related Disorders | | |
|---|---|--------------------------------------|
| Condition | Symptom Overlap with Marfan Syndrome | Mutation in Fibrillin-1 Gene? |
| Loeys-Dietz Syndrome | Aortic enlargement and dissection. Variable skeletal findings | No (TGFBR 1/2 mutation) |
| Familial Aortic Aneurysm | Aortic enlargement and dissection. Variable skeletal findings | Generally not |
| Bicuspid Aortic Valve with Aortic Dilation | Aortic enlargement and/or dissection | Unknown |
| Familial Ectopia Lentis (Dislocated Lens) | Eye lens dislocation Common skeletal findings | Yes |
| MASS phenotype, Mitral Valve Prolapse, Myopia | Borderline aortic enlargement Skin and skeletal findings | At least sometimes |
| Marfanoid Habitus (Marfan Body Type) | Skeletal findings | At least sometimes |
| Mitral Valve Prolapse | Mitral valve prolapse | At least |

| Syndrome | Variable skeletal findings | sometimes |
|--|---|------------------------------|
| Congenital Contractural Arachnodactyly (CCA or Beals syndrome) | Mitral valve prolapse Variable skeletal findings | No (FBN-2 mutation) |
| Stickler Syndrome | Myopia Retinal detachment Joint hypermobility or contracture Scoliosis Mitral Valve Prolapse | No (Collagen genes mutation) |
| Shprintzen-Goldberg Syndrome | Aortic enlargement Skin and skeletal findings | Rare |
| Ehlers-Danlos Syndrome | Skin and skeletal findings Aortic enlargement/dissection in selected types only | No (Collagen gene mutation) |
| Homocystinuria | Mitral Valve Prolapse Eye lens dislocation Skin and skeletal findings | No (metabolic disorder) |

Additional information can be found on the National Marfan Foundation website.

Is it Loeys-Dietz Syndrome or Marfan Syndrome?

Why a Correct Diagnosis Is Important

Doctors who know about Loeys-Dietz syndrome (LDS) believe there are many people diagnosed with Marfan syndrome (MFS) or “atypical” Marfan syndrome who actually have Loeys-Dietz syndrome. Because medical care for LDS is different from care for MFS, it is very important that people have the correct diagnosis. Here are some facts to help you decide if you need to talk with your doctor about LDS.

How are features of Loeys-Dietz and Marfan Syndrome alike?

LDS and MFS are both genetic disorders of connective tissue. People with either disorder share many features including:

- ♥ Long, thin fingers
- ♥ Chest that sinks in (pectus excavatum) or sticks out/pigeon breast (pectus carinatum)
- ♥ Curvature of the spine (scoliosis)
- ♥ Flexible joints
- ♥ Flat feet
- ♥ Stretch marks on the skin, not explained by pregnancy or weight gain
- ♥ Enlarged or bulging base of the aorta (aortic dissection)
- ♥ “Floppy” mitral valve (mitral valve prolapse – MVP)
- ♥ Swelling, bulging, or widening of the spinal save (dural ectasia)

How are features of Loeys-Dietz and Marfan Syndrome Different?

People with LDS usually do not have long arms and legs so often seen in people with MFS. Also, people with LDS do not have dislocated lenses in their eyes, whereas, about six out of ten people with MFS have dislocated lenses.

In addition there are several LDS features that set it apart from MFS. These include:

- ♥ Arteries that twist and wind (arterial tortuosity)
- ♥ Frequent aneurysms and dissections in other parts of the aorta or in arteries other than the aorta
- ♥ Heart defects at birth such as atrial septal defect, patent ductus arteriosus, bicuspid aortic valve
- ♥ Widely-spaced eyes (hypertelorism)
- ♥ White of the eye looks blue
- ♥ Wide or split uvula (the tissue that hangs down in the back of the throat)
- ♥ Cleft palate (when the roof of the mouth is split at birth)
- ♥ Club foot (when the foot is turned inward and upward at birth)
- ♥ Premature fusion of the bones of the skull (craniosynotosis)
- ♥ Malformation or instability of the spine in the neck
- ♥ Collection of fluid in the brain (hydrocephalus)
- ♥ Part of the brain (cerebellum) with an abnormal shape (Chiari I malformation)
- ♥ Skin issues other than stretch marks including easy bruising, abnormal scars, and a translucent (see-through) quality of the skin that makes it easy to see the veins under the skin
- ♥ Gastrointestinal problems (stomach and intestine problems) such as difficulty absorbing food and chronic (comes and goes but never really goes away) diarrhea, abdominal pain, and or gastrointestinal bleeding and inflammation.
- ♥ Allergies to both food and things in the environment

- ♥ Fragile organs that can cause rupture of the spleen or bowel and rupture of the uterus during pregnancy
- ♥ Poor mineralization of the bones (osteoporosis) that can make the bones more likely to break

Who should be checked for Loeys-Dietz Syndrome?

People who are in any group listed below should talk with their doctor about the possibility of LDS. Those with a diagnosis of MFS or “atypical” MFS who also have any LDS feature (any feature from the second list above).

Those who have several MFS features but no clear diagnosis, and who have any LDS feature.

Those with MFS features who have family members who have LDS features.

How is Loeys-Dietz Syndrome Diagnosed?

Because LDS was only identified and named in 2005, not all doctors know about LDS and how to tell LDS from MFS. A medical geneticist (a doctor who specializes in genetic disorders) is the kind of doctor most likely to know how to recognize and diagnose LDS. There is genetic testing that can tell if a person has LDS. The genetic testing is looking for mutations in either of the two genes that tell the body how to make proteins called transforming growth factor beta receptor 1 (TGFB1) and transforming growth factor beta receptor 2 (TGFB2.) This testing is most helpful when used as part of a complete examination that includes:

The health history of you and your family

Your physical exam

The results of special imaging tests including studies of the head, skeleton and blood vessels

Why is it important to have a correct diagnosis?

Medical care for LDS is not the same as for MFS. The most important difference is the care of the aorta and other blood vessels. The care is different because life-threatening aneurysms in LDS are more likely to tear and rupture at smaller sizes than in people who have MFS. For these reasons, surgery to repair aneurysms is often done earlier in LDS. In addition, imaging tests must look at blood vessels throughout the body using either CT or MR scans from the top of the head to the top of the legs.

There are other LDS medical problems not seen in MFS that need special care. These include cervical spine instability (slipping of the upper part of the spine), congenital heart problems (heart defects at birth), allergies, chronic gastrointestinal problems, rupture of the spleen and bowel, and rupture of the uterus during pregnancy.

LDS medical problems can be managed, but a person needs a correct diagnosis to find the right LDS medical care and counseling.

How can you learn more about Loeys-Dietz Syndrome?

Call the National Marfan Foundation (NMF) Resource Center at 1-800-862-7326 ext. 26. When you call, you will speak to a nurse who can answer questions and suggest ways to find a doctor who knows about LDS.

Read other NMF fact sheets on LDS. They have more information on how LDS is different from other disorders, how LDS is diagnosed and LDS management. They are available on-line at www.marfan.org or from the NMF resource center.

For laboratories that do LDS genetic testing go to the website of Gene Tests at www.genetests.org and select Laboratory Directory.

Go to the Loeys-Dietz Foundation website at www.loeysdietz.org

How to Find Out if You Have Loeys-Dietz Syndrome

In 2005 doctors identified and named a newly defined genetic connective tissue disorder called Loeys-Dietz syndrome (LDS). For some people, a diagnosis of LDS can now explain why they have certain features and medical problems. Here is what you need to do to find out if LDS is the correct diagnosis for you or a family member.

Find A Doctor Who Knows About Loeys-Dietz (LDS)

Because Loeys-Dietz syndrome (LDS) is newly identified, not all doctors know about it. You need to find a doctor who knows about LDS and how to tell the difference between LDS and the other connective tissue disorders.

The kind of doctor most likely to know about LDS is a medical geneticist (a doctor who specializes in genetic disorders including Marfan Syndrome (MFS), Ehlers-Danlos Syndrome (EDS) and LDS).

You can find a medical geneticist by:

Asking your primary doctor for a referral

Calling the doctor referral service at your local hospital

Calling the National Marfan Foundation Resource Center at 1-800-862-7326, ext .26

Go Over The List of LDS Features That Are Not Usually Seen in Other Connective Tissue Disorders.

Write down any of these features you or your family members have. They include:

- ♥ Arteries that twist and wind (arterial tortuosity)
- ♥ Frequent aneurysms and dissections in other parts of the aorta or in arteries other than the aorta
- ♥ Heart defects at birth such as atrial septal defect, patent ductus arteriosus, bicuspid aortic valve
- ♥ Widely-spaced eyes (hypertelorism)
- ♥ White of the eye looks blue
- ♥ Wide or split uvula (the tissue that hangs down in the back of the throat)
- ♥ Cleft palate (when the roof of the mouth is split at birth)
- ♥ Club foot (when the foot is turned inward and upward at birth)
- ♥ Premature fusion of the bones of the skull (craniosynotosis)
- ♥ Malformation or instability of the spine in the neck
- ♥ Collection of fluid in the brain (hydrocephalus)
- ♥ Part of the brain (cerebellum) with an abnormal shape (Chiari I malformation)
- ♥ Skin issues other than stretch marks including easy bruising, abnormal scars, and a translucent (see-through) quality of the skin that makes it easy to see the veins under the skin
- ♥ Gastrointestinal problems (stomach and intestine problems) such as difficulty absorbing food and chronic (comes and goes but never really goes away) diarrhea, abdominal pain, and or gastrointestinal bleeding and inflammation.
- ♥ Allergies to both food and things in the environment
- ♥ Fragile organs that can cause rupture of the spleen or bowel and rupture of the uterus during pregnancy
- ♥ Poor mineralization of the bones (osteoporosis) that can make the bones more likely to break

Go Over The List of Features of LDS That Are Also Found in Other Connective Tissue Disorders.

Write down any of these features you or your family members have. They include:

Enlarged or bulging aorta, the main blood vessel that carries blood from the heart (aortic dilation or aneurysm)

Tear of the wall of the aorta (aortic dissection)

“Floppy” mitral valve (mitral valve prolapse – MVP)

Chest that sinks in (pectus excavatum) or sinks out (pectus carinatum)

Spine curves to the side (scoliosis) or from front to back (kyphosis)

Flexible joints

Flat feet

Premature fusion of the bones in the skull (craniosynostosis)

Swelling, bulging or widening of the spinal sac (dural ectasia)

Features in the skin such as: easy bruising, wide scars, soft skin texture, and translucent skin (when it looks almost see-through)

Rupture (tearing) of the spleen or bowel

Rupture (tearing) of the uterus during pregnancy

Take Your Lists to Your Doctor.

Explain your reasons why you think you might have LDS. Also take lists of:

Your past illnesses, operations, and hospitalizations

Medications you are taking

Family members who have, or might have LDS

Have your doctor do a thorough physical exam. This includes looking for LDS features in your bones, joints, skin and face.

Talk to Your Doctor About Ordering Medical Tests. These Tests Include:

Echocardiogram. This test looks at the heart, its valves, and the aorta (vessel that carries blood from the heart) close to the heart.

Either a computerized tomography (CT) or magnetic resonance (MR) angiogram (study of the blood vessels) with 3-D reconstruction, from the top of the head to the top of the legs. The CT or MR can find twisted blood vessels and aneurysms in the other blood vessels in the body. These features are common in LDS and help doctors both make the diagnosis and plan the right medical care.

Genetic testing that can find the TGFBR1 or TGFBR2 mutation; the person most likely has LDS and testing is most helpful when used in people who have LDS features not usually seen in other connective tissue disorders. Your doctor must order this testing. To find laboratories that do LDS genetic testing go to the website of Gene Tests at www.genetests.org and select Laboratory Directory.

When genetic testing finds a either a TGFBR1 or TGFBR2 mutation, the person most likely has LDS and needs special medical care and counseling. Ask your doctor how to take care of yourself. It is very important to follow these instructions. You also need to find out if there are other people in your family who also have LDS.

When genetic testing does not find a mutation it is still possible a person has LDS or a different connective tissue disorder. Ask your doctor if you have any other condition that needs medical care. Also ask how you can get this care.

Here Are Some Ways to Find Out More About Loeys-Dietz Syndrome.

Call the National Marfan Foundation (NMF) Resource Center at 1-800-862-7326 ext. 26. When you call, you will speak to a nurse who can answer questions and suggest ways to find a doctor who knows about LDS.

Read the other NMF fact sheets on LDS. They include more information how LDS is different from Marfan syndrome and LDS management. They are available on-line at www.marfan.org or from the NMF Resource Center.

Go to the Loeys-Dietz Foundation website at www.loeysdietz.org

A Resource on Suicide

- ♥ Suicide is the voluntary act of taking one's own life.
- ♥ Suicide is an act of depression. It truly is a "dropout" from life which is permanent.
- ♥ Suicide is a permanent solution to a temporary problem.
- ♥ Suicide can represent a failure in communication between the individual and his or her meaningful relationships, together with an inability to cope with the stresses of life.

As a peer helper, you need to take every mention of suicide seriously.

- ♥ Adolescent suicide and suicide attempts constitute a major problem in the United States today. The present suicide rate for young people has doubled in the last decade and tripled in the last twenty years, while the nation's overall suicide rate has not varied much in the past half-century.
- ♥ Usually suicidal adolescents are looking at their world through a very narrow perspective. They will say things like, "I've tried everything and nothing works" or "I can't handle it anymore." In reality, they have probably tried very few alternatives.

Stressful Situations That Can Trigger Suicidal Feelings

- ♥ Depression which has not been recognized or treated.
- ♥ Major life changes, such as death of a parent or friend, school failure, divorce, or breakup with a boyfriend or girlfriend.
- ♥ Illness which may be prolonged or terminal.
- ♥ Use or abuse of drugs and alcohol.

Facts about Suicide Attempts

- ♥ More women than men attempt suicide.
- ♥ Men often use more violent methods.
- ♥ Women tend to use barbiturates, other drugs or poisons
- ♥ More men than women kill themselves.
- ♥ *Anyone* may commit suicide, at *any* age.

Danger Signs to Look for in the Potentially Suicidal Person

- ♥ **Previous Attempts:**
 - If the person has attempted suicide before, he or she may be at high risk to try again. The person may talk about previous suicide attempts without saying he or she is considering it at the present time.
- ♥ **Threats:**
 - *If the helpee is threatening to commit suicide, the peer helper must always take such threats seriously.*
 - Experts in the field of suicide estimate that threats are followed by suicide attempts at least seventy percent of the time.
 - The helpee may not say he or she is going to kill him or herself, but the words may be something like, "I'm not planning to be around much longer."
- ♥ **Extreme Depression:**
 - If the helpee appears to be extremely depressed or has had changes in personality or behavior, the peer helper will want to look into this further.
 - The helpee's depression may be exhibited by a loss of weight, inability to sleep, or a tendency to withdraw.
 - Loneliness is a major factor in suicide.
- ♥ **Changes in Personality or Behavior:**
 - If the person had been depressed previously, then all of a sudden seems to be happy and appears to have had a burden lifted, the peer helper should probe into what has happened. Sometimes a sudden shift in moods may mean that he or she is relieved because a plan for suicide has been made. The helpee may believe the pain of living will soon come to an end.

♥ **Preparation for Death:**

- If the helpee is preparing for death, this is a signal which should alert the peer helper to possible danger ahead. The helpee may start talking about giving away favorite possessions, making a will, or buying a gun.

What You Can Do to Help

♥ **Be Alert to What the Real Problem is:**

- Listen to what the helpee is not saying, as well as to what he or she is saying.

♥ *Let the Person Know You Take Him or Her Seriously.*

♥ **Listen to the Person and Follow up with Appropriate Questions:**

- If the signs are apparent, you may ask the person if he or she is thinking about suicide. You may ask if the person has a plan, how that plan would be carried out, and if pills or guns are available. Remember, mentioning suicide does not give the idea. A suicidal person already has the idea, and talking about it openly may help to prevent the helpee from acting out the suicide.

♥ **Do Not Argue or Try to Reason:**

- Never tell the helpee, “You can’t kill yourself because...”

♥ **Explore Other Options with the Helpee:**

- He or she may not realize that other options are available.

♥ *Tell the Person Help is Available.*

♥ **Refer the Helpee to a Professional or A Suicide Prevention Service:**

- Many people have had extensive training in suicide prevention and are experts in the field.

Remember, you can always contact the NMF, Jennifer Buffone is a Social Worker and director of support services at 1-800-862-7326 ext. 22

Common Misconceptions about Suicide

FALSE:

If someone wants to kill him or herself, you can’t stop it from happening.

TRUE:

Most suicidal gestures or attempts are a cry for help, which the person cannot communicate by other means.

FALSE:

People who talk about killing themselves seldom do.

TRUE:

The majority of persons attempting suicide have talked about it. Suicide threats and attempts must be taken seriously.

FALSE:

The tendency toward suicide is inherited and passed on from one generation to another.

TRUE:

Suicide does not “run in families.” It has no genetic quality.

FALSE:

The suicidal person wants to die and feels there is no turning back.

TRUE:

Suicidal persons most often reveal ambivalence about living versus dying and frequently call for help immediately following the suicide attempt.

FALSE:

Only a certain type of person commits suicide.

TRUE:

Suicide occurs in all social classes, races, religions, in all personality types and all levels of intelligence.

FALSE:

Everyone who commits suicide is depressed.

TRUE:

Although depression is often associated with suicidal feelings, not all people who kill themselves are obviously depressed. Some of these people are anxious, agitated, psychotic, or simply feel they can not deal with their life situation and want to escape

FALSE:

Suicidal persons rarely seek medical help.

TRUE:

In retrospective studies of people who had committed suicide, more than half had sought medical help within the six months preceding the suicide.

FALSE:

If you ask a helpee directly, “Do you feel like killing yourself?” that will lead him or her to make a suicide attempt.

TRUE:

Asking a helpee directly about suicidal intent will often minimize the anxiety surrounding the feeling and act as a deterrent to the suicidal behavior.

FALSE:

A suicide attempt means that person will always think of attempting it again.

TRUE:

Often a suicide attempt is made during a particularly stressful period. If the remainder of that period is appropriately managed, the person will go on with his or her life.

FALSE:

It takes courage for a person to commit suicide.

TRUE:

Suicide is often considered the only way to relieve the pain. It is not an act of courage, but an act of desperation.

REMEMBER:

Be Alert and listen. Someone may be talking about suicide and you could possibly be the only one who will hear the cry for help.

You can always contact the NMF if you need assistance working with a helpee. Jennifer Buffone is a Social Worker and the Director of Support Services. She can be reached at 1-800-862-7326 ext. 22 or jbuffone@marfan.org

A Resource for Assisting People with the Grief Process

Dealing with Death and Dying

Death touches every person at some time or another, and in your role as a peer helper, you may be called upon to be available for a helpee who has experienced such a loss. If the death is in the family, the helpee may not want to talk to other family members, thinking he or she might put an added burden on them. A peer helper can play an important role for the helpee at this time.

Facts about Grief

- ♥ The experience of grief is felt by every person at some point during a lifetime.
- ♥ Grief is an experience of anxiety and deprivation which can manifest itself physically, emotionally, socially, and spiritually.
- ♥ Any loss can bring about grief: death of another person, divorce, death of a pet, retirement from ones job, selling a home, or moving away from friends and neighbors.
- ♥ Whenever a part of life is removed, there is grief.

Stages of Grief

Granger Westburg, the author of Good Grief, has identified several stages of grief. These stages may overlap and merge with each other:

- ♥ Shock
- ♥ Emotional release
- ♥ Depression/loneliness
- ♥ Physical distress
- ♥ Panic
- ♥ Guilt
- ♥ Hostility/resentment
- ♥ Inability to return to usual activities
- ♥ Gradual hope
- ♥ Struggles to affirm reality

Ways You Can Help A Person who is Grieving

- ♥ Encourage discussion about death before it occurs.
- ♥ Be available after the person returns from the funeral and after everyone else has gone. Oftentimes many people are available at the funeral and for the next week thereafter. Usually by the second week friends are back to their normal routines, and the person who is grieving is alone. This is when the peer helper may be most needed.
- ♥ Make it known that expressing feelings is good and acceptable. However, do not pressure the griever to show feelings.
- ♥ Expect the griever to be emotionally upset and let him or her know you are still available.
- ♥ Be a receptive listener.
- ♥ Provide practical help in the beginning. Free the person, allowing him or her to have time to grieve.

Fears People May Have of Dying

- ♥ **The fear of the unknown.**

The helpee may wonder if “this is all there is” or if there is a life beyond this one.

- ♥ **The fear of losing opportunities and goals of a lifetime.**

When young people find out they will not be able to live their life out fully, they often feel a loss and sometimes feel cheated out of what might have been.

- ♥ **The fear that after they are dead everyone will get along fine without them.**

A young girl may want to talk about her sister moving into her room after she is gone; a boy may want to talk about his younger brother taking his place on a team. Feeling that someone will take their place and they will not be missed is a real fear for many people.

- ♥ **The fear of pain.**

The helpee may be wondering how much pain will come before death. His or her own ability to withstand pain also may be a concern.

- ♥ **The fear of being left alone.**

The helpee wonder if the family will have time to make frequent hospital visits. Will death come when no else is there?

What Can You Do To Ease These Fears?

- ♥ **Listen Patiently.**

The helpee may want to talk through many different issues.

- ♥ **Avoid reacting negatively to the helpee.**

Some days the helpee may appear to be angry and may direct the feeling toward the peer helper. By realizing anger is a normal feeling for a dying person, the peer helper should not take the words personally.

- ♥ **Explore options with the helpee.**

Sometimes the person may feel there are no options available in the months ahead. When he or she has realized options do exist in the life that is left, the death acceptance will be easier.

- ♥ **Let the helpee know you care.**

Having the knowledge that someone cares and is there for him or her will make a difference to most people.

***Remember: You can always contact the NMF if you need assistance working with a helpee. Jennifer Buffone is a Social Worker and the Director of Support Services. She can be reached at 1-800-862-7326 ext. 22 or jbuffone@marfan.org**

A Resource for Parent/Child Communication Breakdown

“My Parents just don’t understand...”
“You’re just a kid; you aren’t mature enough yet.”

These expressions are classic examples symptomatic of communication breakdown between teens and their parents. When communication is not open and free in a family setting, when yelling or just not talking is the norm, the result is an extremely unhealthy environment. This environment may be the reason why a teen experiencing school problems, feeling angry or depressed, abusing alcohol and other drugs, or acting out rebelliously. Once these problems have surfaced, the lack of healthy communication in a family will serve as a catalyst, making problems worse.

Usually a helpee will not approach you for help specifically because of a communication problem with his or her parents. Many teenagers may not recognize there is a communication problem in their family because this is what they have lived with their entire life. You will discover that communication breakdown in the family is often an underlying symptom of another issue. Unfortunately, lack of good communication is almost an epidemic when it comes to teens and parents. Neither the teen nor the parent is to blame, although each is responsible for his or her own behavior.

Support You May Offer About a Communication Breakdown

- ♥ Listen.
- ♥ Help the helpee explore the option of learning how to send effective messages.
- ♥ Role Play.
 - Role play a family situation, allowing the helpee to be both the teen and the parent. This allows the helpee to view his or her behavior from a new perspective, and see how he or she contributes to the family dynamics. The helpee will also be able to better understand where his or her parents/child is coming from. Role playing will help prepare the helpee for communication situations and hopefully for confronting the parents/child about how he or she is feeling.
- ♥ Assist the helpee in understanding the importance of taking care of him or herself. The helpee needs to see what changes need to be made in his or her own communication skills and behavior.
- ♥ Check in with the helpee on a regular basis to talk about any progress being made. Help the helpee examine what he or she could have done differently and provide positive reinforcement. It is important for the helpee to receive affirmation for what he or she is doing and encouragement for the risks being taken.
- ♥ Problems which coincide with the communication breakdown also need to be addressed. Often it is too unclear to know which problem caused the other to exist. Many times these problems overlap; you and the helpee will need to decide which one to work on.

RESOURCES ALSO AVAILABLE FROM THE NATIONAL MARFAN FOUNDATION

♥ AVAILABLE ON THE INTERNET AT <http://www.marfan.org>

- Under Living with Marfan syndrome
 - Patient Took Kit
 - [Family Health History Template](#)
 - [Emergency Information Packet Template](#)
 - [Hospital Interview Form](#)
 - [Heart of the Matter Fact Sheet Series](#)
 - ♥ Marfan Syndrome
 - Skeletal Information
 - Cardiovascular Information
 - Ocular Information
 - ♥ Clinical Trial Information
 - ♥ Loeys-Dietz Information
- About Marfan Syndrome
- Related Disorders Information

♥ ITEMS AVAILABLE FROM THE NMF UPON REQUEST

- Marfan Syndrome: The Heart of the Matter - DVD
- Marfan Syndrome: Need-to-know Information for the School Nurse - CD-ROM
- Marfan Syndrome A-Z (a children's story book) - BOOK
- Marfan Syndrome: A Guide for Teens – BOOK
- Marfan Syndrome: Obstetric Issues - BOOKLET

TO REQUEST ITEMS:

Contact - Jennifer Buffone, LCSW, Director of Support Services and Volunteer Development, jbuffone@marfan.org or 800-8-MARFAN ext. 22



**TELEPHONE SUPPORT VOLUNTEER ORIENTATION MANUAL
RECOGNITION FORM**

I, _____, acknowledge that I have received a copy of the National Marfan Foundation Telephone Support Volunteer Orientation Manual. I understand that it is my responsibility as a Telephone Support Volunteer for the National Marfan Foundation to read the manual and ask National Marfan Foundation staff any questions I have about information provided in the manual.

SIGNATURE: _____ **DATE:** _____

