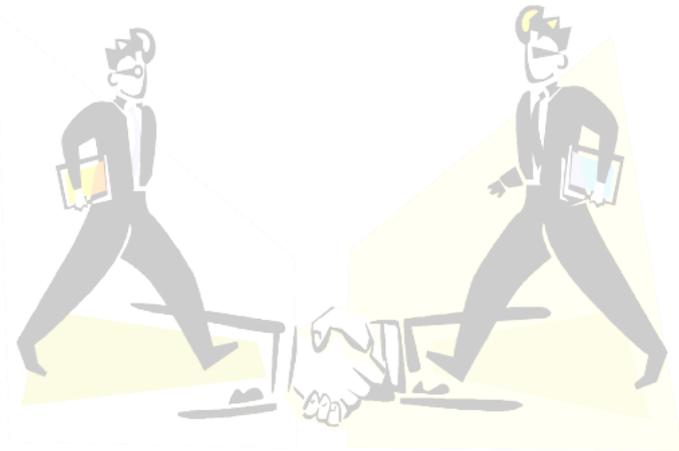


Coping with Relationships Day by Day



Fibromyalgia Regional Coordinators' Consortium UK
working with local support groups throughout the UK.



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The Fibromyalgia Regional Coordinators' Consortium



In Conclusion

Try to ensure that all of your team of supporters meet the following criteria for you:

- ◆ You enjoy being with them.
- ◆ You choose to be with them when you want to relax and have a good time.
- ◆ You turn to them when you need to talk to someone.
- ◆ You turn to them for help in making decisions.
- ◆ You depend on them for help with tasks in daily living that have become too difficult.

At the same time, don't forget to hold up your end of the relationship. Although relationships must be fifty-fifty, your half of the bargain will need to be made up of activities your fibromyalgia allows you to do. So offer a listening ear or a helping hand whenever you can. **And most important, express your gratitude. A simple thank you will let your supporters know that you appreciate them.**

Whatever You Do—Live Your Life to the Full

Do not be afraid to talk –it is good to talk!!

Live! Know yourself and live each day,

enjoying the moment.



Live Life to the Full

Try not to Cancel Plans

The last thing you want to do during a Fibro Flare is go to lunch with your friends. However, cancelling on them all the time isn't a great idea either. Try your hardest not to cancel plans too often.



People who Love you Won't Stop because of Fibromyalgia

This is the most important thing to remember. If your best friend was diagnosed with cancer would you suddenly stop talking to her? Of course not! The people who truly love you won't stop.



Forgive yourself. Get rid of the statements, "If I only..."

Listen to your body. Fibromyalgia is a unique condition. The medical profession can assist you in managing your health and medical specialists also rely on you to pay attention to the signals and messages your body gives.

Be proactive, not reactive.

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INTRODUCTION

FIBROMYALGIA (FM) doesn't exist in a vacuum.

Fibromyalgia can force profound adjustments, both for people who have it and for those around them.

FIBROMYALGIA:

- ◆ can cause profound changes in the life of the person diagnosed
- ◆ the lives of family and friends

The changes may include:

- ◆ loss of income
- ◆ loss of independence
- ◆ loss of good health
- ◆ loss of future plans

Changes in lifestyle often makes some of those affected by fibromyalgia:

- ◆ feel isolated
- ◆ feel unable to express their emotions, needs, and experiences with others -not feeling understood or accepted
- ◆ feel pressurised to do more than is healthy
- ◆ feel rejected and abandoned
- ◆ feel that they are a burden for others
- ◆ feel guilty

Live Life to the Full

Find an Online Fibromyalgia Forum

It's good to talk about how you're feeling and bounce ideas off other people who know what you're going through. Find an online health forum that focuses on Fibromyalgia. Being able to express how you feel with an audience who understands will give you the support you need. It also keeps you from talking to your friends and family about it all the time. While you need to talk to your loved ones about Fibromyalgia, doing so all the time can be overwhelming.



Be Prepared to Educate

Fibromyalgia awareness has grown but most people aren't going to really know what it is. Prepare what you're going to say ahead of time. Give a short explanation such as:

“Fibromyalgia is a chronic pain condition that affects all parts of my body. Doctors believe it is a nervous system disorder and there isn't currently a cure. Luckily, it isn't deadly, just painful”

then allow them to ask questions if they want to know more about it.

SURVIVAL STRATEGIES

Don't Make Plans too Far in Advance

Try not to commit to anything that is more than a week away.



Be Prepared to Lose Some Friends

Inevitably there will be some people who won't be ok with the "new you." You have to accept it and move on. Stress makes Fibromyalgia worse, and dealing with the loss of friends can be very stressful. Keep in mind that they probably weren't a great friend to begin with. Spend your energy focusing on friends and loved ones who care enough about you to stick around.



You Don't have to Talk about Fibromyalgia

All The Time

Try to remember what you and your friends talked about before your Fibromyalgia? Make sure to touch on those subjects too. Fibromyalgia is a chronic condition that we deal with every day. It's present in our minds and seeps into our conversations. Sometimes it's good to be distracted and talk about other things. Have fun. Laugh! Don't let Fibromyalgia ruin your time with friends.

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Household tasks may need to be juggled, finances are often strained, and all family members may wonder what the future will bring. There can be a lot of strain on relationships between people with fibromyalgia and those who undertake a caring role. In addition, some people with FM are less likely to take the initiative to meet new people or maintain current relationships.

Every family's circumstances are different. Families need to develop a response to dealing with fibromyalgia that fits their individual circumstances. The severity of medical issues will set the limits on the amount of adjustment required. The actions of those around the person who has fibromyalgia will have a major effect on the quality of life of the person with fibromyalgia .

Some people with Fibromyalgia feel an on-going need to talk about their illness and its impact on their lives. At the same time, many people become more distant or reclusive; this is especially true during periods of severe symptoms, because being around others requires energy that is in such short supply. These alternating needs for distance and closeness can be difficult and confusing.

Family and friends may become exasperated because they don't know how to respond to the fibromyalgia. In order to prevent relationships from deteriorating, you need to express your emotions, needs, and your limits, while being sensitive to the listener.

Illness can put families under great stress, making good

INTRODUCTION

communication more difficult. Working to improve communication can help increase understanding, uncover unrealistic expectations, strengthen relationships and aid cooperative problem solving

Any form of chronic illness changes relationships, both for the person who is ill and for others as well, creating new strains and frustrations. Relations with family, friends, co-workers and bosses, and even doctors are altered. Fibromyalgia is certainly not a life threatening illness but is surely life changing. Learning to live with fibromyalgia can be like taking a journey into unknown territory for both the person who has it and their family members and friends.

Although living with this chronic condition can be challenging, it is important to focus on the positive. People with fibromyalgia and their family members need to be reassured by their medical professionals that it does not kill, cripple or become life threatening despite what the pain in their bodies might be telling them. Also to understand that it is clinically possible to look good on the outside but be hurting on the inside.

People with fibromyalgia always need to remain positive, focused and remember that they can and will have improvement in their fibromyalgia symptoms by implementing their own personalised self-management plan. All members of the family should try to be as open with each other as possible. They should try to continue to learn all that they can about fibromyalgia and aim to keep all lines of communication open.



Live Life to the Full

3. Live Life to the Full

Can people with Fibromyalgia sustain relationships and live life to the full?

Yes! Some of your relationships will suffer but by following a few simple suggestions you can keep your relationships alive and take care of yourself at the same time.

Always Be Honest

Don't hide your Fibromyalgia from the people who matter. They'll know something is wrong. People can sense when you're hiding something and they'll probably start imagining scenarios worse than the actual truth.



Start Calling your Friends on the Phone

People maintain great friendships when they live across the country from one another through phone calls, emails and occasional visits. Just because your friends live close by doesn't mean all the contact you have with them has to be in person. You can stay connected through a great conversation over the phone while lying on your heating pad.

Seek Professional Help

2. Seek Professional Support

Some people with fibromyalgia report being helped by counselling. A sympathetic therapist can provide a confidant's level of caring and offer an outsider's view as well.



If you're interested, you might look for one who specializes in working with people who have chronic illness.



A local support group is often a good source of leads.



Therapy can also be helpful for couples, offering a place in which the strains created by living with long-term illness can be addressed.



A counsellor can facilitate a solution to particular problems and also help you practice good problem solving skills

Fibromyalgia can cause a Strain on Relationships

Financial strains: The family's financial situation can be a crucial issue which in some circumstances can put undue strain on the relationship between man and wife or partners. Some families can afford to let the ill person stop working or have them take an early retirement, while others are stretched financially and may be forced to make financial adjustments of various kinds. The presence or absence of children and, if present, their ages is significant. Couples with school-age children have to juggle work and child care. Those with adult children may get help from their kids.

Health related issues: The health of the spouse is another important factor. In some families, if both husband and wife are ill or if a normally-healthy spouse has a health emergency like a heart attack or surgery this can increase the strain on what had been a normal healthy relationship.

Marital relationships: Some marriages are made stronger by illness, while others become frayed and others break. The response of the well spouse to illness may vary from strong support, on the one hand, to disbelief, abuse and abandonment on the other. Some people who have had multiple marriages report that they have experienced the full range of possible responses, most commonly a lack of support in an initial relationship and understanding in a later one.

Strategies to help you deal with Frustration in Relationships.

Assess Your Relationships

Having a chronic illness means less energy for relationships, so you may have to accept that some relationships will die. You may decide others are not worth maintaining.



Acknowledge Your Part

A healing approach to relationships can begin with our acknowledging to ourselves and then to others how our illness and behaviour affects those around us. Serious illness changes the lives of all who are touched by it. It alters dramatically the financial circumstances of most families, forces radical changes in how household tasks are divided up, and drastically reduces the number and scope of activities the family can do together .



Educate Others, but Accept That Some May Never Understand

You can do this either by sitting down to talk with relatives and friends or by giving them something to read. It is important to accept that some people may never understand the illness or be sympathetic.

Join a Support Group

A support group offers the opportunity to gather together with people who share similar situations, problems and symptoms. It provides an opportunity to talk about your fears; you may find that many of them are unrealistic.



A support group offers the opportunity to share information that provides support and education as well as providing emotional support. It allows participants to validate their common experiences through sharing information whilst getting feedback and support.



A support group adds an element of social interaction and encourages you to get out of the house and become less isolated. Contact with fellow fibromites can counteract isolation and provide an experience of being acknowledged and supported. Such contact can be a way to experience feeling understood, comforted and inspired.



Also, groups offer a way to be helpful, thus counteracting the loss of self-esteem that often results from illness. Volunteering to help with the running of the group is an excellent way to stop thinking about your own problems and feel good about helping others deal with theirs. It feels good to feel useful again.

Your Support Network



In thinking about how to meet your practical and emotional needs, consider putting together a network of people who can help. Such a network could contain at least five people. Some may offer practical help, such as grocery shopping, housecleaning or driving. Others may be companions for outings such as a visit to the coffee shop or a night at the cinema. Still others may offer emotional support by listening and offering reassurance. In any case, it's wise to have several people to fill these various needs, so that one person does not feel overburdened and burn-out.

1. Join a Support Group

A support group can provide support and education for carers, family members and co-workers. It helps them understand the condition and therefore enables them to provide support and encouragement for the person with fibromyalgia as well as receiving support themselves from fellow carers.

A support group promotes problem solving and encourages members to help one another. It is an excellent way to develop new relationships—it is a wonderful place to make new and understanding friends. A support group focuses on the positive, where you learn to deal with your illness—rather than on the negative issues.

Set Limits

Learn to set limits with yourself and then with others. Make clear to yourself and to others the consequences of your trying to meet old expectations. Be as specific as possible in asking for help if others offer assistance.



Make New Friends and Develop New Interests

Creating new relationships, especially with fellow fibromyalgics or others who are empathetic, can be a powerful antidote to frustration in relationships. It is very healing to feel understood. Also, having friends with the same illness as yours may give you the opportunity to help others, which can boost your self-esteem.



Chronic illness can be isolating and demoralising. Stay connected to family and friends to the extent possible, but be realistic in your expectations. Seek support from others in your situation. There is great strength in knowing you are not alone. Be spontaneous and have fun together with your partner, family, and friends.



Try to Be Honest with Yourself.

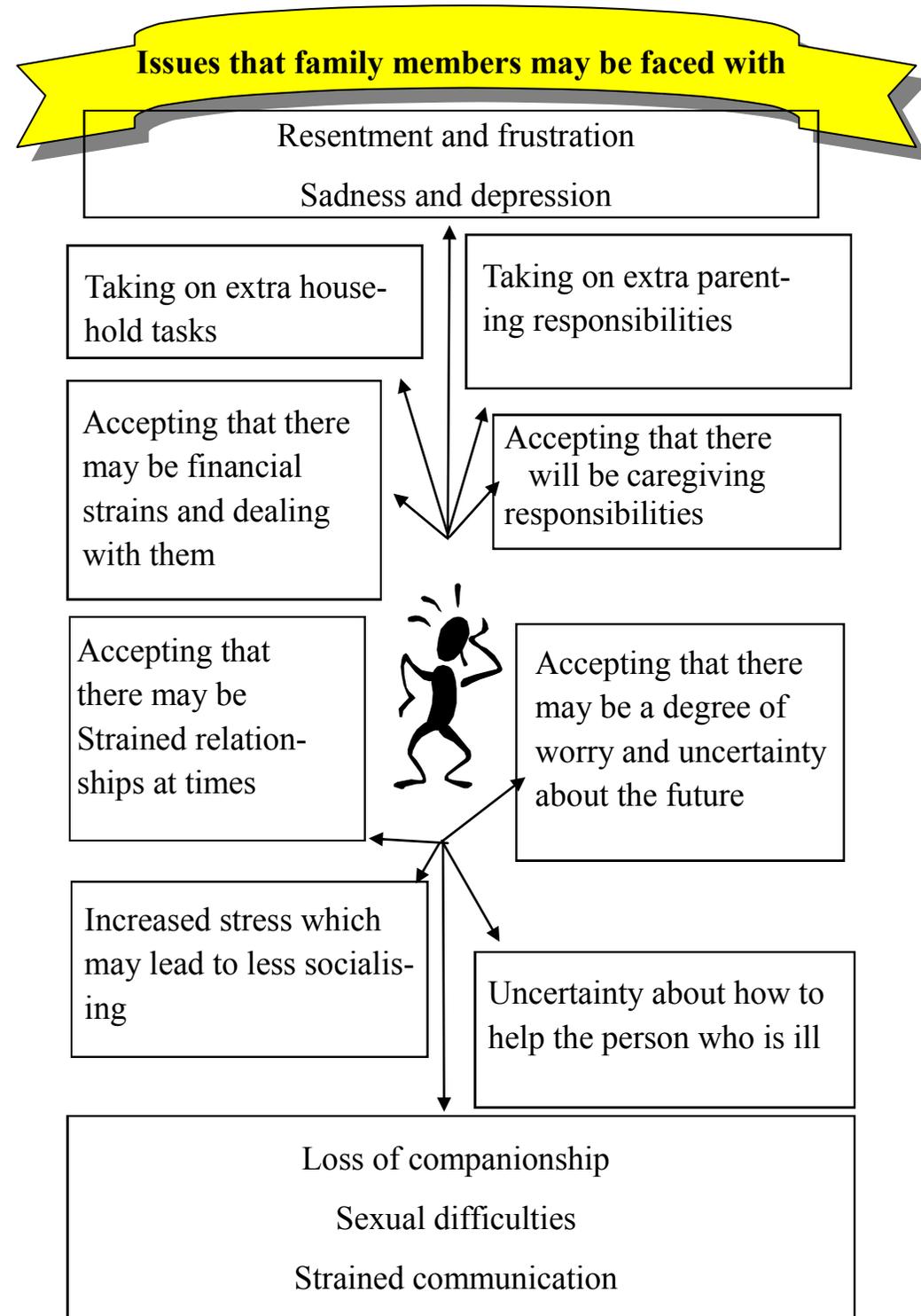
When faced with FM, you need to take care of yourself physically, mentally, and spiritually. If you don't, you won't be prepared to contribute to the lives of others. The following are ideas to help ensure your life is filled with joy, satisfaction, and fulfilment

- Grieve for your losses, and then allow yourself to dream new dreams.
- Deal with the past, and let it go. Make a tape, or write a letter to people you have grievances with and then throw it away. If that doesn't help, speak with a professional therapist.
- Make goals for yourself, and don't let fibromyalgia always dominate your life.
- Love, honour and value yourself. Living with fibromyalgia is often challenging. Remember to treat yourself well and take some quality time, just for you.
- Educate yourself about fibromyalgia. Information is empowering.
- Watch out for signs of depression, and don't delay in getting professional help when you need it.
- When people offer to help, accept the offer and suggest specific things that they can do.

USEFUL WEBSITES

Fibromyalgia Association UK:	www.fmauk.org
How Does Fibromyalgia Affect a Relationship?	www.ehow.com
NHS Direct:	www.nhsdirect.nhs.uk
Stress Management	www.patient.co.uk
Fibromyalgia & Sleep	www.prohealth.com www.fibromyalgiasupport.com
Fibromyalgia Support Diet & Nutrition	www.fibromyalgiasupport.com www.prohealth.com
General FM information, letter to relatives explaining how people with fibromyalgia feels	www.fibrohugs.com
Information from Dr Devin J. Starlanyl—what your medical team should know	www.sover.net
Irritable Bowel Syndrome Network	www.ibsnetwork
Digestive Problems	www.corecharity.org.uk
Information for Carers	www.carersuk.org www.direct.gov.uk/caringforsomeone
Myopain Society	www.myopain.org

- Be wary about giving advice. Don't attempt to "fix" the person with FM or provide a solution.
- Realise that your loved one may seem "okay" while you're together but then pay an enormous price later for the over-exertion.
- Ask questions about things you don't understand.
- Enjoy low-energy activities together; such as watching movies, sitting outdoors, and eating meals together.
- Express gratitude for what the person with FM still gives to you, even though they may not be able to do some of the things they could before.
- Reassure them about how important they are in your life.
- When you are not sure about how to be helpful, just ask.
- Be aware of unpredictable mood swings. Try not to take reactions personally that might seem illogical or over-emotional.
- Learn to be perceptive. You don't have to be a mind-reader, but you can watch for signs of how your loved one is feeling, or when they may need extra help and support.
- Stay in touch and extend invitations, even when the person with FM may not be able to accept.



Hints for Keeping Lines of Communications Open

Good communication is based on speaking clearly and on good listening. Good communication depends on each person's understanding the other's views. The idea is to be able to discuss problems in a constructive rather than a confrontational way.

Try to avoid making accusatory remarks.

When preparing to discuss issues in your relationship, pick a time when you can give each other full attention.

Inform them that the severity of your pain varies, even if it is never completely gone.

Do not have an important discussion or make important decisions when your pain is at its worst. It is only when things have settled down that you will be able to make clear what you can and cannot do, and in which ways you want to be helped.

Tell them in a friendly way what kind of help you expect and why.

Tell others what you can and cannot do, but emphasise on what you can do rather than what you cannot.

Tell them when they are doing something well!



Maintaining Friendships is Important

Your relationship with friends does matter, now more than ever. There are many things a friend can do to support a person with fibromyalgia.

You *can* do:

- Educate yourself about Fibromyalgia.
- Read articles about personal experiences and coping. Be patient and caring. Reassure your friend of your love and support.
- Acknowledge the seriousness of the illness. Validate feelings of loss, sadness, anger, and hope.
- Offer to help in practical and specific ways; such as grocery shopping, managing finances, running errands, or household chores.
- Attend doctor's appointments with your friend. Show interest in their medical care and be there to provide moral support.
- Most people with Fibromyalgia both love and hate hearing "you look good." It's okay to say it, but understand that looking good doesn't necessarily mean your loved one feels good!
- Spend time together, enjoying activities that can be modified if necessary.
- Make plans flexible to accommodate unpredictable symptoms and fluctuating energy levels. Be understanding when they must be changed or cancelled at the last minute.

Hints for Keeping Lines of Communications Open

- Reading a book to children before bedtime does not require a lot of exertion on your part and goes a long way to improving your relationship.
- Watching a film together may be nice to do.
- Activities in which you interact with your children on a more personal level will bring you closer together.
- It is extremely important that you do not lean on your children as emotional crutches. This can lead to problems for them in the future. Although it is appropriate to ask them to help you with physical activities you cannot perform, do not overdo it or ask for more than they can handle.
- Be mindful of their age and capabilities.
- A five year old can perform tasks such as emptying the dishwasher, setting the table, or emptying small rubbish bins. Older children can handle more. Younger ones can pick up their own toys.

Ultimately, you want to reassure children that you love them. Spending quality time with your children and having fun together can help strengthen your relationship with each other. Showing your children ways they can express and let go their emotions will help them become happier, healthier individuals

If you treat your partner with love, respect, and courtesy when you communicate, your relationship will better withstand the challenges fibromyalgia places on it. Talk regularly, not just when your pain is most intense. Make your problems, fears, and uncertainties clear to trusted people.

Tell loved ones that you might sometimes take your angry feelings out on them. Ask for their understanding.

Make it clear that you can and will be positive, despite the pain. Do not be scared to report if things are going a little better.

Even if the outcomes of your conversations are not what you desire, do not give up—but rather try again, possibly approaching the issue in a different way.

Give a short answer to the question, "How are you feeling?" Then inquire how the other person is doing. Show interest in others.

Do not make the pain or discomfort obvious by groaning, sighing, or grimacing. This makes others scared and insecure, brings up guilt and inferiority feelings, and spoils the atmosphere. Be direct in telling people how you are feeling.

How Families Can Help

Family members and friends can help people with FM in many ways. Some help is practical, such as providing transportation to medical visits or taking on tasks the person with FM is no longer able to do. Some help is emotional, offering support and understanding.

Try to maintain an orderly, clean and cheerful physical environment. Divide up the chores differently among members of the family, be open to hiring occasional or regular assistance.

Help to improve and maintain an environment conducive to sleep, this includes a good mattress and control of light, noise and temperature.

Use problem solving to find solutions and achieve goals. Try to schedule family activity for “good hours” of the day.

If at all possible try to avoid causing stressful situations.

Encourage the person with FM to focus on one activity at a time, do not expect multi-tasking.

The biggest aid family and friends can give is to support the person with FM in their efforts to adapt their life to what is best for them.

Family and friends can help the person adapt to FM by accepting that the person can do less than before and by acknowledging that the person will need to spend more time in rest and do things in new ways (such as alternating activity and rest) and encourage them to pace themselves.

SEEK SUPPORT FROM FAMILY & FRIENDS



Communicating with Children

Children can't be fooled. They know when adults are in pain, stressed out, or are unhappy. If you don't explain to them what is wrong, they may imagine the worst. Let your children know what is happening and encourage them to ask questions. Children and adolescents do need to be educated about your fibromyalgia. If they are not told, they may worry more. Sometimes children believe they have caused the illness by some act they did that the person with fibromyalgia may not even be aware of. Their imaginations are very active. If you do not ask them how they are feeling or thinking they may not tell you. Children are often concerned that an illness may cause death to a parent. Letting them know how fibromyalgia affects you at a level they can understand can alleviate many of their fears and concerns.

Try to find ways to let your children spend quality time with you and help you at home

- Your fatigue and pain may keep you from being able to enjoy physical activities together, but there are many other fun things to do with children that do not require much exertion on your part.
- Most young children and even adolescents love to play games, such as draughts, monopoly or snakes and ladders. This is also an activity the whole family can enjoy.