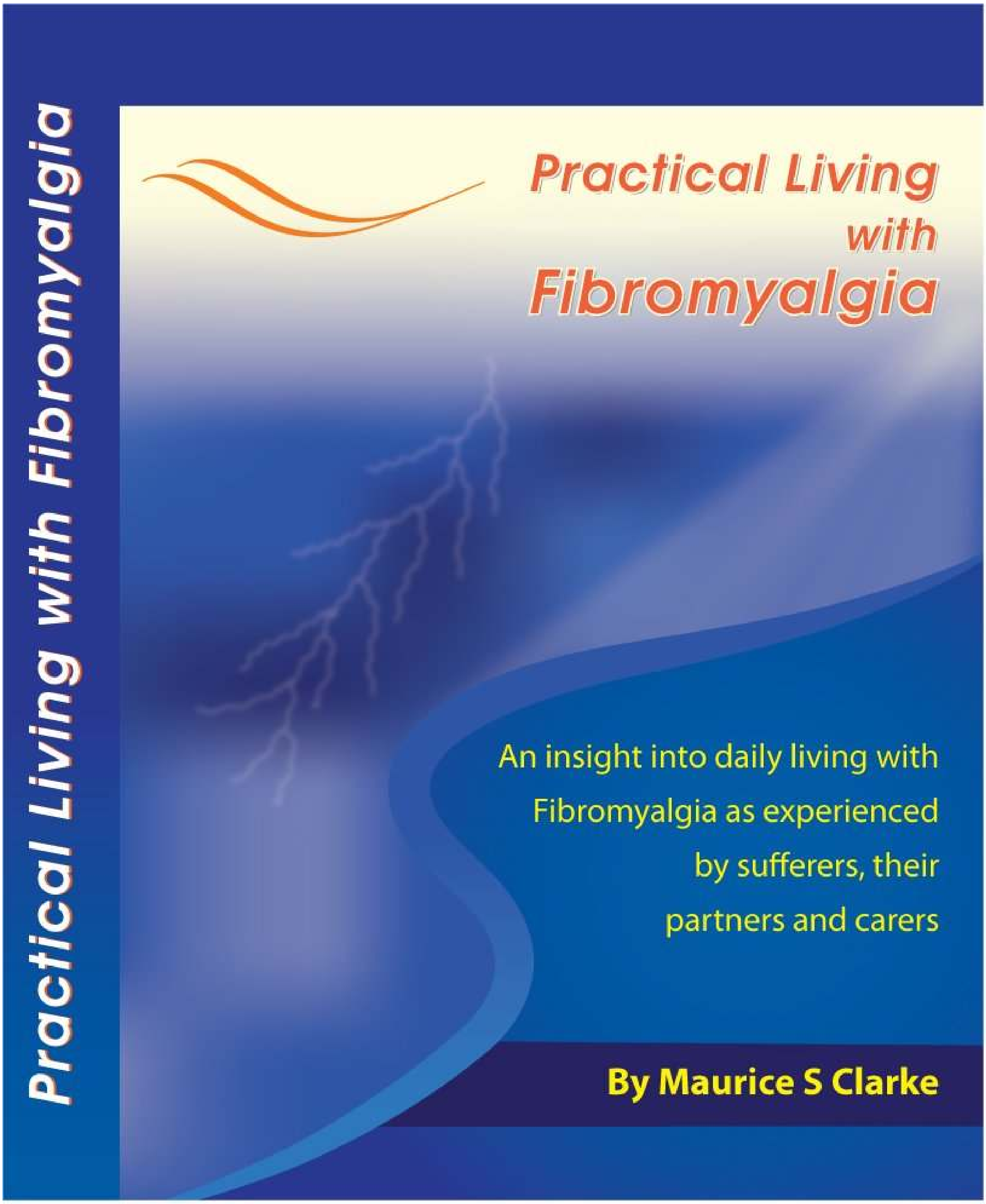

Practical Living with Fibromyalgia

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An insight into daily living with
Fibromyalgia as experienced
by sufferers, their
partners and carers

By Maurice S Clarke

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An insight into day by day living with Fibromyalgia based on the experiences of sufferers, their partners and carers

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Introduction

Fibromyalgia is a painful neuro-muscular condition which affects millions of people worldwide, there is no sign of a reduction in the growth of people being diagnosed with it, thus it has a major and ongoing impact on the daily lives of sufferers and their partners intruding on their personal, social, financial and family life.

Causes of Fibromyalgia remain largely unknown and each person suffering with it has a unique set of circumstances. As a result they approach the problem in different ways, some cope well, others let it engulf their life, leading to much unhappiness.

Whilst women suffer the most from Fibromyalgia (over 90%) there is an increasing trend of more men being diagnosed, so this factor takes on a different perspective in understanding the influence that Fibromyalgia has in households where the women is forced into a caring role rather than more traditionally the man.

Fibromyalgia does not affect just the old and feeble, it can hit young people, even children, and is especially hard for career minded families often with young children who are hit in their 20’s and 30’s by the untimely intrusion of

Fibromyalgia into their lives, changing their ambitions and lifestyle potentially for ever.

An established saying is “Fibromyalgia will not kill you, but can you live with it?” rings true for far too many. This books draws on a variety of experiences, it is not technical or medical but aims to show how people are affected by Fibromyalgia in different ways and how they react to it’s unwelcome and permanent intrusion into their daily lives.

Reading this book can change your awareness and knowledge of Fibromyalgia hopefully enabling you to live a better and happier live despite having Fibromyalgia in it.

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About the author

Maurice S Clarke married his wife Mary in 1972 and during the ensuring years Mary contracted Fibromyalgia, this book is drawn on their own joint and individual experiences and knowledge of this painful affliction.

In 2006 he created an internet web site about the condition which has served as a useful focal point for many sufferers around the world and is regularly visited by an expanding audience.

In 2008 he and Mary helped form a support group in their home town of Rugby, England to help others cope with the condition. The support group has grown and proven of value to many local people providing a range of support services and social activities.

Through contact with other support groups around the UK, national Fibromyalgia charities and publications, plus enquires from the web site, as well as practical experience with the local support group, the couple have jointly drawn on over 30 years of experience of living with Fibromyalgia and working with and for others with the same problems.

An avid writer he has written many articles about different aspects of Fibromyalgia and has actively used PR to promote the support group issues on a local and national basis.

This book was started in 2011 with the aim of looking at the overall affect on peoples lives who have Fibromyalgia or who live with someone who has.

Dedication

This book is dedicated to my wife Mary without whom this book would not have been possible.

"We both wish this book had no need to be written, nevertheless there in a growing demand for knowledge about Fibromyalgia and how to live with it, we hope this contribution to the battle ahead will be of use to all its readers."

Maurice S Clarke : Rugby UK

This book is written based on the authors personal view of Fibromyalgia as experienced by him in his various roles and situations over many years. Others may have different experiences and opinions, may well disagree to some or many comments and opinions. If you have strong views and experiences please email the author via the publishers web site.

This book is updated from time to time and current readers may be notified if they are registered on the readers mailing list. You may join the list via the "Free Book" link on the web site, and leave the list anytime using the unique sign off link in each notification.

Chapter 1 : From the beginning

Fibromyalgia does not suddenly appear in your life, but creeps up on you slowly and unawares. You may not realise you have a problem, initially it's just a twinge, or stiffness, something a few pills and rest will solve.

When it refuses to stay away and becomes a nuisance you may just learn to live with it, for a while at least, especially if it is just moderately painful and does little to impair your work or lifestyle. You see it as a minor irritation and tell yourself it's only temporary.

Each person has a different level of pain tolerance and some may soon be rushing to their doctor for a diagnosis and be prescribed something to make the problem go away. Such a move may result in all sorts of diagnoses from strain, the weather, injury or any culprits that spring to mind by you or your doctor.

Others may endure the discomfort for years, especially if they feel there are more important duties to take priority. Many people suffering the onset of Fibromyalgia may be young wives perhaps with one or more children. There is little time to feel sorry for yourself, you have a duty to husband, partner and family, so you stay quiet and rely on medicines to keep symptoms at bay.

For many this may be the start of Fibromyalgia and you could be faced with a gradual worsening of symptoms such as;

- Mood changes and irritability
- Tiredness and sleep problems
- Pain becomes more widespread in different parts of the body
- Pain becoming more regular though the day and/or night
- Urinary or vaginal problems
- General mobility worsening
- Depression

The time frame of development of additional symptoms varies, but is usually slow, measured in years rather than months.

It is vital, even at an early stage that you keep in touch with your doctor and discuss your problems and changes with your general health and day to day living.

How do you get Fibromyalgia?

The jury is still out on this one, as there are several schools of thought on this, so one of these may well apply to you;

Hereditary

Certainly the children of sufferers may well exhibit symptoms of Fibromyalgia later in life and it is an easy conclusion to assume “she has the same as her mother” which may be an erroneous diagnosis based on little practical evidence.

It is certainly worth looking at the medical history of your parents, indeed grandparents to see any Fibromyalgia like symptoms they had. Remember diagnosis of illnesses in the past would be less popular or efficient – early versions of modern day Fibromyalgia may well have been “fibrositis ”, “sciatica”, or even “the vapours.”

If your children are showing Fibromyalgia type symptoms then your own experience may well prompt an earlier diagnosis for them than you yourself experienced. Much of the growth of younger people being diagnosed with Fibromyalgia is this family link and interest in causes and treatment.

Accident or physical injury

Since Fibromyalgia is recognised as a neuro muscular condition any life event which may shake up the body could cause some deep rooting injury and “set off” the onset of symptoms which in due course may well be diagnosed as Fibromyalgia.

Proving that little bump you had in the car last year caused your Fibromyalgia may be difficult, however there have been some successful compensation claims succeeding where medical evidence has proved an accident, the fault of a company has lead to a person becoming affected by Fibromyalgia, resulting in substantial financial payouts.

People engaged in high energy contact or endurance sports or other physical pastimes may be in a high risk area for injury which could well cause Fibromyalgia to manifest itself later in life.

Stress and trauma

The complex and stressful lives we all lead nowadays can cause many of us serious mental anguish, and maybe some people go through mental and physical changes to combat this pressure. Often the mind learns to adapt or cause the body to take time out as a warning.

Long term, sustained mental pressure especially if linked to a physical injury may well cause problems which manifest themselves with Fibromyalgia like symptoms.

Does it matter how you got it?

To some degree no, it is potentially negative thinking to try and analysis when, where and how you got Fibromyalgia – what matters is you have it now – assuming your doctor has referred you to a Rheumatologist for a formal diagnosis.

If you have children then having the knowledge they may inherit a great chance of contracting Fibromyalgia, maybe even now showing some potential symptoms, should cause you to monitor their health and seek medical advice.

There are some indications that the diagnosis of Fibromyalgia is being achieved earlier in a persons life as generations progress, suggesting the illness is growing in numbers. This may not be the case, just identifying and diagnosing people earlier who might otherwise go undiagnosed for long periods, potentially life long, can create a false impression of a growth of the illness.

One of the important issues is for the sufferer to face reality and accept they have Fibromyalgia now and rise to the challenge. Understanding the history of the illness and the affect on others is useful in understanding what you may be facing in the future.

Help and sympathy

You may well become a martyr and endure these initial problems yourself and not seek help or advice from anyone, or indeed get any. It may be becoming more obvious you have a problem which is worsening, yet you persist with the idea nothing is wrong and it is just "passing." So do you make that first move and ask for help, or does someone close to you force such an action on you?

The ones who cope best with the worsening of their Fibromyalgia are the ones who face up to the fact early on and get something done, by seeking help, knowledge and information and obtaining advice and treatment from their doctor.

There is no magic bullet, no instant cure, the future is all about getting relief and changing ones life style to take actions you need to perform each day easier for you. Sympathy is all very well but what you really need is positive aid, so get help and assistance from whoever is on hand to provide it.

Knowledge and Understanding

Often the first you learn about Fibromyalgia is when a doctor suggests it to you as a possible reason for your condition. This may later be confirmed by a consultant rheumatologist, but do not expect to be given much information on or about Fibromyalgia – you have been diagnosed and this helps your normal doctor recommend some treatments to control the symptoms, usually pain control.

People who take an active interest in other options to help control the illness do better in coping with it.

An increasing number of local support groups may, if there are any in your area may make available literature about Fibromyalgia and their support group at clinics where Fibromyalgia is diagnosed. Some support groups have members in attendance enabling you to talk over your problems and this can provide that early stage aid in getting a better understanding and learning about options to improve and make necessary changes to your life style.

Support groups covered in more detail in later chapters can provide friendship and support, even if you cannot make meetings due to distance or your condition they can provide telephone and email support, and some may even provide home visits for those who are housebound.

If no groups exist in your area you may wish to consider advertising for other sufferers in your area and form a simple informal group of a few fellow sufferers and share knowledge and experience. This is how most groups start.

Self Diagnosis

You may have decided you have Fibromyalgia based on some basic facts you know or have collected about the illness, or know someone who has it.

Many people resort to using the internet to look up facts about Fibromyalgia, and draw an early conclusion they "know it all", or create an insatiable appetite for more knowledge and information, both have problems to avoid;

You never know it all, there is always new information, ideas, treatments and people to meet who suffer similarly to you, or worse than you. Many will have tips and hints that worked for them and may help you. Be constantly alert to new opportunities to help yourself.

You are right to seek more information, but it can get confusing – there is much information from suppliers of drugs, machines and other treatments supplied commercially, and whose aim is to sell you their wares. Be wary of claims for cures and treatments, the newly diagnosed is prey to spend money in the hope of a quick or indeed instant cure.

Fibromyalgia plus other conditions

Chances are you do not have Fibromyalgia alone but other conditions or illness as well, making your condition and circumstances unique. As you meet other people you may learn helpful tips and ideas from them which may suit your life style and needs.

Some other conditions may exist first, before you have confirmed Fibromyalgia, others will come along later, maybe even stimulated by Fibromyalgia, typically other issues include;

IBS (Irritable Bowel Syndrome) – is the most common illness affecting people with Fibromyalgia, it is a bowel disorder characterized by chronic abdominal pain, discomfort, bloating, and alteration of bowel habits in the absence of any detectable organic cause. In some cases, the symptoms are relieved by bowel movements. Diarrhea or constipation may predominate, or they may alternate. IBS may begin after an infection, a stressful life event, or onset of maturity without any other medical indicators.

Although there is no cure for IBS, there are treatments that attempt to relieve symptoms, including dietary adjustments and medication Patient education and a good doctor-patient relationship are also important.

Diabetes - is a group of metabolic diseases in which a person has high blood sugar, either because the body does not produce enough insulin, or because cells do not respond to the insulin that is produced. This high blood sugar produces the classical symptoms of polyuria (frequent urination), polydipsia (increased thirst) and polyphagia (increased hunger).

There are three main types of diabetes:

- **Type 1 diabetes**: results from the body's failure to produce insulin, and presently requires the person to inject insulin.
- **Type 2 diabetes**: results from insulin resistance, a condition in which cells fail to use insulin properly, sometimes combined with an absolute insulin deficiency.
- **Gestational diabetes**: is when pregnant women, who have never had diabetes before, have a high blood glucose level during pregnancy. It may precede development of type 2 DM.

Arthritis - is a form of joint disorder that involves inflammation of one or more joints. There are over 100 different forms of arthritis, the most common form of which is osteoarthritis (degenerative joint disease) which is a result of trauma to the joint, infection of the joint, or age.

The major complaint by individuals who have arthritis is joint pain. Pain is often a constant and may be localized to the joint affected. The pain from arthritis occurs due to inflammation that occurs around the joint, damage to the joint from disease, daily wear and tear of joint, muscle strains caused by forceful movements against stiff, painful joints and fatigue.

Whereas Fibomyalgia pain is usually all over in shoulders, arms and legs, arthritis is usally focused on or around joints especially those in active use, wrists, hands, knees and ankles.

Eyes and sight - Vision problems can often accompany Fibromyalgia due to changes in eyesight because it impacts the nervous system, which is the centre of sensitivity in the body.

Common Sight Symptoms

Sufferers can for example develop sensitivity to stimuli such as fluorescent lights or to the light produced by a television set. Contact lenses can cause pain and irritation, while wearing glasses can trigger discomfort in the face and the neck.

Night driving can be dangerous for those with Fibromyalgia, as they often have trouble seeing the lights of oncoming cars. Seasonal Affective Disorder (SAD) can be a another complication associated with Fibromyalgia. People with SAD need light to ward off depression, which is another common symptom of FMS.

Memory (“Fibro Fog”) - Fibrofog is a term given to the variety of cognitive problems that many fibromyalgia sufferers face during their illness. Fibrofog encompasses memory loss, difficulties using language, and difficulties with learning. These symptoms tend to descend in a haze or "fog," around the sufferer. Fibrofogs can occur at any time and can vary in level of intensity when they occur.

Fibrofog affects women sufferers more often. Episodes of fibrofog typically are often brief, although sometimes can last for weeks or even months.

Symptoms of Fibrofog

Fibrofog is one of the most common yet unrecognized symptoms of fibromyalgia. If you have fibromyalgia signs and symptoms it is important to be aware of fibrofog so that you can seek appropriate treatment and manage your illness more effectively. Some symptoms of fibrofog include:

- short term memory loss
- difficulty remembering where you put things
- difficulty remembering plans
- difficulty with language, including trouble holding conversations, understanding conversations, and expressing thoughts
- difficulty finding the "right" word to use in conversation
- trouble remembering simple numbers
- transposing letters and numbers
- trouble concentrating and focusing
- trouble retaining new information

CFS (Chronic Fatigue Syndrome) - causes long-term tiredness (fatigue) that affects everyday life. It does not go away with sleep or rest.

CFS is also known as ME, (which stands for myalgic encephalomyelitis.) “Myalgia” means muscle pain and “encephalomyelitis” means inflammation of the brain and spinal cord. Both terms are commonly used.

There is no cure for CFS, so treatment tends to focus on easing the symptoms which can include muscle pain and headaches.

Anyone can get CFS, although it is more common in women than in men. It usually develops in the early 20s to mid-40s. Children can also be affected, usually between the ages of 13 and 15.

How serious is it?

Most cases are mild or moderate, but up to one in four people with CFS have severe or very severe symptoms. These are defined as follows:

- Mild: you are able to care for yourself, but may need days off work to rest.

- Moderate: you may have reduced mobility, and your symptoms can vary. You may also have disturbed sleep patterns, and sleep in the afternoon.

- Severe: you are able to carry out minimal daily tasks, such as brushing your teeth, but occasionally you may need to use a wheelchair. You may also have difficulty concentrating.
- Very severe: you are unable to carry out any daily tasks for yourself and need bed rest for most of the day. Often, in severe cases, you may experience an intolerance to noise and become very sensitive to bright lights.

Outlook

CFS may last for years. Most people improve over time and some people recover and are able to resume work and normal activities. However, others will continue having symptoms or may relapse, and some remain housebound.

And this is just the beginning?

At this point you can become very worried about what the future may hold for you if you have Fibromyalgia, but take time to reflect at this stage and consider these key issues;

1. People who contract Fibromyalgia are affected in different ways, their condition does not always advance to encompass all the symptoms and scenarios mentioned above.

2. You can learn to live with the condition provided you continue to consult with your doctor AND take an active interest in your Fibromyalgia.
3. Ask for and seek help and information which can help you, especially via a partner or close friend who can help you day to day when and if needed.

4. Read each chapter of this book and learn about the PRACTICAL ways people like you can and do cope with having Fibromyalgia.

5. Make sure your partner, close friends and family members read this book too, all of it not just parts!!. They need to understand about

Fibromyalgia just as much as you do, if they are to be there to give support and guidance you need over the coming years.

6. Be aware of change – in your condition and the availability of new techniques in coping, and in treatments, being pro-active and seek knowledge and information which may help you now or in the future.
7. Focus on the practical issues, the real world, worry less about "what if" and focus on the "what is", deal with each issue if and when changes occur which are causing you concern.

Chapter 2 : Family and Fibromyalgia

The family of a person with Fibromyalgia can have a major impact on the way a sufferer copes with the illness.

The term family will vary with each person, it may refer to a few people, or in some cases a vast number of people all leading busy and different lives, possibly in different parts of the country or indeed the world.

Often close family will have little understanding of Fibromyalgia and have no real need to get to know about the illness, mainly due to it's slow intrusion into family life. There is no need of any urgency or need to respond to an emergency.

The sufferer may complain little and their worsening condition may be seen as fairly "normal" just a twinge, or ache, something we all get, so why should they need any special treatment?

If and when the pain and other symptoms increase a visit to the doctor is a must and this may lead to the suggestion that the cause of your problem may well be Fibromyalgia. At this stage some family discussions will be useful for you collectively to talk about what Fibromyalgia is and what to expect.

Attitudes here will start to become apparent, and support may be limited and replaced with indifference or even ignorance of the issue. You may feel isolated and ignored and that no one cares.

Some people may not seem to care as they are busy with THEIR lives and could potentially seem selfish. Some may be genuinely caring and interested and might be willing to provide limited help and care if asked.

You may find caring people are not necessarily your immediate family but friends or more remote family members. Many husbands and male partners of female sufferers are traditionally backward in taking an interest and helping the sufferer to cope.

The important issue here is one of communication, sharing knowledge and getting Fibromyalgia discussed and talked about openly.

It may be early days and Fibromyalgia just a new "buzz" word in the family, perhaps just a fleeting idea which many will feel will pass by. Later with more frequent visits to the doctor may result in a greater chance of a confirmed diagnosis of Fibromyalgia as the cause of pain and discomfort and other related symptoms.

Family may well assume a stance of DENIAL if and when a formal diagnosis is made and Fibromyalgia is confirmed. Again talking with the family to explain more about what Fibromyalgia is and the potential scenarios expected in the future is important lest the illness is ignored.

In many cases Fibromyalgia may continue to ravage family life as it continues to cause the sufferer to have worsening symptoms which increase is quantity and severity. The result is a reduction in ones ability to live normally, typical outcomes may have differing impacts which then affects family life;

- Tiredness and lack of energy – family life can be busy, cooking meals, looking after baby or young children, schooling, housekeeping and more…….. a sufferer may find themselves having to rest more, some tasks becoming more difficult, even no longer possible. Often this means extra pressure as some routines tasks are late getting completed, or cannot be done at all, or to a lower standard.
- Increased frequency and need for pain relief and visits to the doctor.
- Sleeping patterns may become irregular, falling asleep in the day, waking early, or cannot sleep properly at night. Often this is a result of pain/and or fatigue.
- Increased discussions about the symptoms and the various forms they can take and the impact they have on general family life. The sufferer may have to stop being the leader and "doer" and become more reliant on family members to take on tasks for which they ill equipped, and accept grudgingly. Others will do tasks differently to higher or lower standards, or not at all.
- Increased mental pressure making people more irritable, short tempered and angry.
- Not talking enough – family discussions come easier to some people, others are surprisingly reluctant to talk about health issues and how they feel – open chats on a regular basis is a vital key to coping and adjusting to living with Fibromyalgia.

The family can become irritated and selfish with the sufferer's changes in health, rather than supportive - "you forgot to iron my shorts" or "where are my sandwiches?" are examples of ongoing complaints about your failings without any sympathy.

Family may be notoriously lacking as volunteers, and fail to get on with jobs and help with tasks that they know, or should know, need doing. As a consequence family tasks start to get missed and late and everyone becomes irritated. At this stage discussions need to be held to explain why and look at ways of sharing the work load or modifying needs.

By sharing the work load and reorganising family needs and schedules can make it easier for everyone, even if family is just a husband and wife or a couple with 6 children.

The close proximity of other family members may help a sufferer to solicit aid from close relatives, parents, siblings or older children who can pop in regularly and help with a few chores that are proving difficult.

Communication is the key to a family successful integrating a sufferer's Fibromyalgia into their lives, look out for this time tried phrases used by partners or other family members.

- "I did not realise it was that bad!"
- "You never mentioned you had a problem!"
- "You should have asked for help"

You can see that such comments almost blame the sufferer for not informing family members enough or indeed at all. This may be the case, if things are kept quiet and not discussed you cannot blame other people for nor caring or being prepared to help.

Family members may be slow to react, and several attempts over a period of time to "get through to them" may be needed, even then constant reminders to keep the needs firmly in focus.

Regular reviews are needed too, especially if the illness worsens, it may mean family members taking on more tasks and adjusting their own lives to compensate.

Going out may become a problem, so social life can become restricted, an outgoing socially active couple may find they can no longer go out as much, or for long. Sometimes the partner may go out alone reluctantly (I do not like leaving you!) to a more selfish approach (I am just going down the pub!)

Living with Fibromyalgia is all about adjusting, about change, not just the sufferer modifying their life style due to the illness, but each member of their family too, as they learn (or are taught) to help them cope with a painful and distressing illness which has limited opportunities to be cured or improved on.

Chapter 3 : Working and career changes

Fibromyalgia affects an increasing number of people, mainly women, a lot of whom are in their 20s and 30s and leading busy work and business lives, often alongside of bringing up a family.

No longer are wives stay at home mums whilst husband earns all the family’s income. Family life is already pressurised so both partners may often work, either just to survive and meet the increasing costs of living, or to afford holidays and other luxuries they would otherwise do without.

In some households the career woman may earn more than her male partner so the impact on family finances and life style can be serious when she suffers with Fibromyalgia which starts to take a firm hold of her life.

Over a period of time a typical young family unit may find the workload becoming increasingly harder due to Fibromyalgia taking a stronger grasp. Eventually this may mean the sufferer reducing the number of working hours in the week, which, if the condition worsens she becomes unable to hold down a full or even part time job.

There is a further potential knock on effect when the partner of the sufferer has to take an increasing care role and also undertake more household and possibly child care duties.

It is especially hard on the couple and any young family if there are no close family or friends living locally who can provide help and support. Such help is likely to be ongoing, unlike a sudden temporary crisis, Fibromyalgia permanently changes lives and puts new demands on the life style and commitment to family life.

Men as breadwinners

More traditionally the man is the “hunter gatherer” and the family’s main income provider, although they suffer less than women (1:9) the impact on family life where a man is stricken with Fibromyalgia, reducing income dramatically and increases pressure on the partner can be substantial and far reaching.

Non career or working women in childless families may then find the need to work to supplement or replace reduced or lost income due to the Fibromyalgia of their male partner, as it gradually restricts the mobility and life style of that partner.

In families with children the extra burden placed on the partner may be considerable and cause crucial issues within the family unit, making help and support more vital to both cope with and re-structure life style to make Fibromyalgia as bearable as possible.

Business owners

Where a sufferer owns, or has a share in a business the effect on that business will be ruled by its size and value;

- If the business is run solely by the sufferer then it may be difficult to carry it on, so unless the business can be reduced or modified to be run easier with less hours, or sold off it may have to close down.
- Many small businesses are run by a few people in partnership so if this is the case other partners may "fill the gap" in the short term, but long term plans may have to be considered as Fibromyalgia takes a firmer hold. This may mean the other partners buying out the sufferer, or them taking a "back seat" as investor with a lower share of profits.
- If husband and wife are running a busy together and raising a family, as well as the need to care for the sufferer may serious impact on the business. Decisions to close the business, sell it off, bring in paid staff etc may all have to be considered.
- In successful, established businesses making good profits the ability to "step back" from the business on a practical daily basis may be easier to afford and justify, a privilege not available to small proprietor owned and run business organisations.

If traditional paid employment becomes more difficult, starting a home based, easy to run business may be an option as it offers flexible working hours and can be low cost to start. Perhaps turn a part time interest or hobby into an income maker.

Such a business can have the advantage of securing income for the future but also provide interesting challenges which can help divert you from the trauma of having Fibromyalgia.

Be wary of financing such a new venture and take no risks. Take advice and use redundancy money, or look into available grants. Borrow only based on a small part of assets such as free equity in a property. Increasing or restructuring an existing mortgage may provide useful funding.

Other age groups

Fibromyalgia hits all age groups but modern diagnosis is catching more younger people and men, thus the impact is more serious on these young people in work where finances, and the bearing and rearing of children are major factors in people's lives.

Older people may well have less financial pressures, and any family will have left home and be leading independent lives. The onset of grandchildren may well mean getting involved with helping especially "baby sitting" and this, if coupled with Fibromyalgia may well be an unnecessary pressure on the sufferer and/or their partner.

Ill health may be more likely for people as they age, but any illness is never welcomed especially Fibromyalgia.

Older people perhaps may have had aches and pains for years but only now are having it identified and diagnosed as Fibromyalgia.

Early retirement may have to be considered to cope with the extra demands where Fibromyalgia strikes, and careful study made of any redundancy payments which may be obtained, as well as pension levels. Part time work may have to be considered to supplement income in a enforced early retirement scenario.

Adjusting to reduced income

If the ability to work is reduced, more so if a partner has to reduce or give up work to care for their Fibromyalgia sufferer partner, then family finances can be serious hit.

Careful budgeting is vital as income is eroded, reducing or cutting out non vital costs. Sell of old surplus things to create income or a cash reserve.

Avoid credit which is a short term fix for what is rapidly becoming a long term problem. Seek methods of controlling work and finances which are capable of being maintained and practical long term.

The knock on effect of Fibromyalgia is usually permanent so do not fool yourself the problem is just temporary, it may stay like this, or get worse in the future.

Adjusting to changed live style and social status

With reduced income as well as the rigours of Fibromyalgia often means a reduction is being able to take holidays, nights out and other pleasurable social pursuits.

Whilst reduced income may make socialising financially more difficult, other issues may restrict an otherwise busy social life, usually a result of Fibromyalgia – tiredness and pain.

You may see less of friends especially those you have made through work, which is now potentially proving more difficult and you may have less time, money or energy to mix socially with work colleagues.

Much of this type of readjustment is best approached with a good strong and positive mental attitude. Try and be systematic and logical in planning the necessary changes that are needed now, and in the near future. Look at alternatives and options and avoid fixed ideas. Flexibility is a big asset to nurture.

Benefits and State Aid

There may well be some reluctance to apply or receive any state aid, and the reality is that applying for any benefit is not an easy road to travel along. Forms are complex and rejection of even the most deserving cases seemingly easy to achieve.

Assistance with housing costs in a major expense which can be funding via Housing Benefit for rented proper by people on lower income, even if working part time. Or help with mortgage interest. Council or other local authority taxes may be reduced or eliminated for lower earners and offer a large saving.

For health linked benefits even if one succeeds in qualifying the actual income is not over generous and needs additional income sources to maintain even a modest life style.

Whilst the sufferer is still working it tends to suggest disability type benefits are unlikely to be granted, To avoid the traumas of making an application and being rejected talking over your condition with an advisor may put an application into perspective.

In most cases you would expect to have endured the new qualifying disability for at least 3 months or more before qualifying to even apply. Check with advisors or see resources page later in this book for contacts.

The future in perspective

One thing is clear, or should be, Fibromyalgia if it is diagnosed settles in for the long haul, and becomes a partner in your life style, forcing changes with work, income and ambitions.

Learning to accept the future, means change, slowly and well thought out plans and adjustments. Made after much discussion and some trial and error.

Try and see Fibromyalgia as an irritation, with limited options to make it go away and at best control it. Changes forced on you may open up new interests and opportunities, many people’s lives have been devastated by being told they have Fibromyalgia. Others have risen to the challenge and adjusted their lives in a positive way, if you suffer from Fibromyalgia or know someone who does, look at the bright side – Fibromyalgia is not fatal – and YOU can learn to live with it better than you think you can.

Practical living with Fibromyalgia is all about you and your “team” of husband, wife, partner, children, siblings, parents, grandparents, neighbours, friends, your doctor, consultant, social and health workers ……… all pulling together for YOUR benefit.

Chapter 4 : Medical matters over the years

Fibromyalgia is a modern illness about which there is much confusion and misunderstanding, and there remains a great need for further education of sufferers, their partners and family as well as the medical profession.

It is easy to confuse the symptoms of Fibromyalgia with those of other illnesses and a formal mis-diagnosis may still be possible despite the considerable increase in knowledge and awareness of this painful illness.

There are several ways Fibromyalgia is described which may confuse many people, these are the most common terms used to describe what Fibromyalgia is:

- Fibromyalgia is an **ILLNESS**, which is often described as;

  a. Poor health resulting from disease of body or mind;
  b. A disease.

- Fibromyalgia is a **DISEASE**, described as;

  "A disease is an abnormal condition affecting the body of an organism. It is often construed to be a medical condition associated with specific symptoms and signs. It may be caused by external factors, such as infectious disease, or it may be caused by internal dysfunctions, such as autoimmune diseases.

- Fibromyalgia is a **CONDITION**, described as;

  "A disease is an abnormal condition affecting the body of an organism. It is often construed to be a medical condition associated with specific symptoms and signs."

- Fibromyalgia is a **SYNDROME**, described as;

  "In medicine and psychology, a syndrome is the association of several clinically recognizable features, signs (observed by a physician), symptoms (reported by the patient), phenomena or characteristics that often occur together, so that the presence of one or more features alerts the physician to the possible presence of the others."

Each description seems to be accurate and fit a typical person who is affected by Fibromyalgia.

Or as many sufferers simply say "I have Fibromyalgia"

An Initial Diagnosis

Identifying and diagnosing Fibromyalgia is not always immediate and anyone suffering from an onset of pain and discomfort may react in several ways;

Some rush to the doctor as a matter of course, seeking to be made better with a few pills.

Others suffer the pain and discomfort and may well self diagnose, either option may seem to be positive ways, with the sufferer telling themselves the problem is only temporary and they will be better soon.

The more pessimistic person may jump to horrible conclusions as to the truth of their ill heath which often is nothing like the reality.

Modern day illness is best dealt with as a partnership between patient and medical advisor on whom one can both trust and rely.

Gone are the days when the "poor patient" knew nothing about illness and disease and had to rely solely on a doctor to tell them what they were suffering from and offer a treatment or more ideally a cure.

Thanks to modern technology and a wealth of knowledge in books, internet web sites and computer programs the modern person can be provided with a range of options from which to choose as suiting their symptoms.

Education can be good, but can also get confusing unless you are guided by others through the maze to enable you to reach a sensible and logical conclusion.

One immediate problem is that the medical profession sees patients as "lay people" this means they are non-experts or non-professionals, suggesting they know nothing, or very little about their own symptoms or illness.

This may be true but not everyone is an amateur and knows nothing, many have become serious experts at their own specific illness, and certainly many sufferers can become very knowledgeable about Fibromyalgia specifically.

Clearly it would be wrong, indeed potentially dangerous for a patient to consider they know more than a trained professional who has seen a large number of people with Fibromyalgia.

Living successfully with Fibromyalgia is all about understanding the illness and consulting regularly with your normal doctor.

You have the right to see a different doctor than your normal one, especially if you know another doctor is more knowledgeable and experienced about Fibromyalgia.

You also have the right to change to a different doctors practice if you feel the current practice lacks any doctors with sufficient knowledge and experience of Fibromyalgia.

It is logical to assume that no doctor has the time or need to be an absolute expert on Fibromyalgia as they deal daily with a large number of patients with a wide range of illnesses and conditions.

This may be true in the UK, however in the US specialist clinics and hospitals have been established staffed by professionals whose sole task is dealing with Fibromyalgia sufferers on a regular basis.

As a consequence many sufferers may be attracted to the US for treatment, which few can afford as all treatment normally needs to be self funded. The average Fibromyalgia stricken family are usually having to adjust to living on reduced income and can rarely afford such an investment which may still be unable to guarantee success of a permanent cure, or even lasting relief.

So where does your normal doctor fit in and what should you expect of them?

- In early stages when you are getting mild twinges most people “self medicate” using over the counter pain control tablets, which can provide short term relief.

- If the pain and any other symptoms persist then a visit to your doctor is both sensible and vital, as at this stage the cause of your ill heath is a mystery. You need to seek a diagnosis and find a cure.

- After a while you may find symptoms persist and pain returns perhaps increasing in intensity, as a consequence visits to a doctor who is experienced and knowledgeable of Fibromyalgia become more frequent.

- If the symptoms appear to identify Fibromyalgia as a serious “suspect” as to the real cause the concept should be discussed with the doctor, who may personally rule out Fibromyalgia. This may later prove to be true, or the possible link continue to pour doubts on the doctors denial of the existence of Fibromyalgia.

- If a sufferer is confident enough about their own symptoms and knowledge of Fibromyalgia then they may be wise to ask the doctor to refer them to a consultant rheumatologist for a proper diagnosis. It matters not who takes the lead or initiative in arranging a referral, simply that this logical step is taken.

- The role of the consultant rheumatologist is in essence simple, it is just to confirm or otherwise the fact the person referred to them has Fibromyalgia, nothing more. Their role is not to suggest treatment or provide information about what Fibromyalgia is.

A formerly diagnosed patient may then enter a period of confusion based on several factors:

- The diagnosis may be the final stage in a process which has already identified as fairly certain that Fibromyalgia is the culprit.

- It seems unlikely that a Fibromyalgia diagnosis should come as a surprise since it will have been suggested as a "possible" cause of the patients problems and the referral is being made to rule out or confirm Fibromyalgia as the guilty party.

Fibromyalgia clinics, where the diagnosis is made may well have literature about Fibromyalgia and details of any local support group. In some areas the local support group may have one or more people in attendance to provide information about the illness and the support group. Otherwise many can leave the clinic diagnosed but not knowing much about what Fibromyalgia is and what to expect in the future.

Once formerly diagnosed returning to the doctor is the next step to discuss treatment options, usually pain control.

Changes in life style may be recommended by the doctor, but generally the newly diagnosed patient should be looking at what to do best to suit themselves, looked at as various bullet points to be focused on;

- Discuss and invoke recommendations from the doctor, these have to be practical to introduce into normal daily life and maintainable for the foreseeable future.

- Develop and expand one's own knowledge of Fibromyalgia so the condition is fully understood and suggestions of changes in life style can be arrived at with some confidence they are workable options.

- Seek out, make contact with, and draw on the knowledge and experience of a local support group, usually founded and run by sufferers. Take time to discuss options and the experiences of other sufferers in similar circumstances.

- Review how Fibromyalgia develops and changes – does it get worse, or is there relief. This stage is all about managing change, and adapting your daily life to cope with the pain, changes in energy levels and mood swings.

- Typical changes which sufferers and their partners may experience include;

    - Having to reduce work load due to increased pain, energy and stress levels.

    - Changed diet especially to control weight as reduced mobility can often lead to an increase in weight. Experiment with different foods and consult a dietician recommended by your normal doctor.

- Taking up mild exercise – the sufferer may already be an active sports person so may be cutting down on their normal levels of physical activity. Others may find exercise difficult and hard to maintain.
- Changes in walking, sitting and sleeping patterns. Ask your doctor to refer you to an occupational therapist who may be able to recommend changes and additions to make movement easier on a daily basis. Some mobility aids may be available on loan, otherwise devices and equipment can be bought from a local mobility shop or online. Second hand equipment can be bought to save money.

This book is not about Fibromyalgia as such but about how to live with it, not just the sufferer but all those who come in contact with the person with it, especially their partner who may well be taking on an increasing caring role. They must be seen as a united team to face the future together as a knowledgeable unit, ready to fight Fibromyalgia with a variety of tools and techniques.

Chapter 5 : The invisible illness – "you do not look ill"

In the early stages of Fibromyalgia the sufferer rarely looks ill as symptoms are usually mild and just simple twinges and aches.

To others nothing appears wrong with you, to them you seem quite normal and average. They probably have aches and pains too, the difference is theirs usually goes away.

Perhaps some of your relatives or friends have Fibromyalgia too, but they do not know it yet, nor do you. After all over 2% of the population are reported as having it, so chances are you know one or more people with Fibromyalgia, or soon will.

If and when Fibromyalgia advances more into your life you may find symptoms worsening, yet you still have this outward sign of health and normality, when the truth is slowly becoming more obvious you have a problem with is affecting your life.

Typical early stage issues which can hit you without changing outward physical signs which may include;

- Memory issues – confusion, mixing words and so called "Fibrofog".
- Tiredness – lack of energy and enthusiasm.
- Frustration and anxiety – being on edge, shorter temper, even anger.
- Pain – mild or sudden twinges, increased sensitivity.

Peoples attitudes

Some people you meet in your locality or whom you work with may be amazing cruel and say things to you directly or to others when they do not understand you have a potential advancing illness. Such people are thankfully in the minority, but their words and actions can be extremely hurtful and humiliating, and distress and depress you.

Often cruel words can be, if repeated to others be believed and you get "marked" as lazy and/or inefficient – as a worker, mother, wife, husband – you have no chance to defend yourself and can begin to believe it as true.

The way forward to combat rumours and misunderstanding is the EDUCUATION of friends, relatives, work colleagues and employers who do not understand about Fibromyalgia, and worse may not want to.

Building your own knowledge of Fibromyalgia may enable you to talk confidentially to critics of you and your condition, and hopefully convert them to a better level of understanding.

Locating any local support group may help improve your own knowledge about Fibromyalgia and get a broader understanding of how other sufferers have coped with the problems you now face.

Online discussion groups can also provide a useful springboard to air your questions and concerns and get feedback from other sufferers who know and care.

Staying Invisible

There is often a reluctance to not show any signs of a disability, but Fibromyalgia may be forcing you to begin to display the fact you are now no longer well.

Pain can often make you shout out suddenly or even scream if that pain is acute and you have a lowered tolerance to it.

Your face may show you are in pain, and you may loose colour or look hot, this can start to indicate to others you have pain and discomfort, even though you yourself just say "Oh it's nothing, just a passing twinge."

So you are actually fighting to stay invisible and maintain those visible symptoms as secret as possible and even then defend them lightly and brush them off as "temporary" when you know they are not.

Becoming more visible

If and when Fibromyalgia deepens your mobility may become more of a problem and often the first sign is for you to be forced to use a stick for support, at least some of the time.

Some may resist using a stick, at least for a while, or use one for as little a time as they can.

Later the stick becomes a critical accessory whenever you go out, although most people can cope indoors without one.

Once you become dependent upon a stick its as well to get one or two spares, as "fibro fog" may cause you to leave yours behind somewhere, and unless you have someone with you, you could be susceptible to misplacing stick, bag and other items.

For the few sufferers whose condition advances even more a second stick may be necessary for greater support. Later still even a walking frame, four wheeled walker or wheelchair may be needed, ideally one that can fold and be put in a motor vehicle.

For those with limited mobility, yet have the need to travel independently a mobility scooter may be useful to consider. Again some people find them a nuisance on pavements and shopping areas. Verbal insults and abuse against mobility scooter users, although rare, and is experienced in some areas, is illegal and cannot and should not be tolerated.

Mobility scooters which come in various types, sizes and prices, and you can buy new and second hand, even hire short term as a preamble to buying. These can be a useful aid if you need to travel short distances but find walking difficult except over very short distances.

Mobility scooter users take time to adjust, using the machine sparingly initially and increasing their use of it as you become more confident with its use, and have a great need for mobility assistance.

You may not feel normal and do not see yourself blending in with the public at large – but ask a few people how you look to them.

Certainly many Fibromyalgia sufferers look normal, although they usually do not feel they do.

Chapter 6 : Women V Men with Fibromyalgia

Facts indicate that women with Fibromyalgia predominate men in the ratio 9:1. Men are increasing as a percentage of all sufferers as nowadays they appear to be attending doctors more and seeking a diagnosis rather than suffering in silence as they appear to have done previously.

Statistics and accurate knowledge about men as a Fibromyalgia suffering species is still limited due to the low numbers other than the fact that the detection/diagnosed rate has risen from earlier indicators of a 95:5 ratio.

When comparing the differences between men and women with Fibromyalgia an obvious question is, is there any difference between their symptoms and should a man expect anything different?

Fact is men will clearly approach the illness in a man's way and with a different attitude, as well as in built male/female differences in physical make up and psychological approach.

Some thinking, with little enough proof suggest that men differ in a few ways in how they are affected by Fibromyalgia;

- Their pain is more limited to specific areas and not as widespread in the body as with women.
- The pain is more spasmodic and comes and goes rather than persists.
- They are less tender and reactive than women, reacting less to touch than their female counterparts.

Some men may argue there is no difference in symptoms, but unless they can speak from direct experience and knowledge of women with Fibromyalgia their views cannot be substantiated.

Women may immediately jump to disagree and argue these suggestions too. They may have some merit to that opinion if they have met and had contact with one or more men with Fibromyalgia. That is only normally possible by attending a support group with a large membership where several male sufferer members are likely to exist.

Due to the reduced number of male sufferers it is difficult to group them together to discuss symptoms and compare several men with each other and compare their symptoms with those of women.

Whilst attempts have been made to create men only groups the limited ratio of numbers make this difficult to achieve and the only practical route is to develop sub-groups off existing mixed sex support groups. The bigger the group the more likely for such an initiative to be successful.

The leader of a men's group needs to have wide knowledge of Fibromyalgia generally so they ask suitable questions for comparison and create some feeling of the practical differences in symptoms and life style issues which they then can practically analyse.

Men/Women studies again have to be conducted over a period of years, and direct medical studies using “volunteers” would seem to have a limited chance of success is creating any worthwhile results.

Clearly doctors and consultant rheumatologists who see sufferers of both sexes may form options of the differences of symptoms, whether they can form any opinions of any clear men/women differences seems uncertain.

Men are more likely to respond in a friendly social atmosphere where they meet other sufferers and possible men who care for women sufferers and feel everyone has a similar problem. Discussion can be more accurate as a result of a freer and more open conversation.

The author started an initiative “Fibrolads” in 2007 first as a men’s group for those who where partners of women sufferers. Few attended meetings and the pilot program abandoned after a few meetings.

In 2011 Fibrolads was reformed to encompass men who were both sufferers AND partner and carers. Again holding together a group in viable numbers proved difficult, however group meetings albeit with small numbers were able to be maintained and Rugby Fibrolads still existed at the time this book went to press.

There seems limited (if any) similar initiatives taking place in other parts of the UK or other countries and no joint collaboration of results.

Many women who passed opinions about men groups overall seemed supportive and many would attempt to encourage their partners participation, overall with very low positive results.

A man’s interest and involvement in a men’s support group seem to do best where they take the initiative, rather than if the woman tries to force or stimulate their partner’s interest.

A male review

Overall men seem more affected by Fibromyalgia than women in their reaction to symptoms , if as results suggest pain levels actually differ between the sexes.

This may, controversially suggest that women are better at enduring pain than men in the long term.

As a result men seem more likely to become depressed than women, and less able to “endure” the pain and stress long term. This may be due to do with a “sense of failure”, and general helplessness which women seem more able to accept.

So what if men have different symptoms to women?

They still BOTH have Fibromyalgia and there is little need to argue “my Fibromyalgia hurts me more than yours!!!” and similar comparatives as to who is the greater martyr men or women.

It would seem that in the main there is, and always will be that gulf, that great divide between men and women and each sex in the main more at ease with others of the same gender.

More women seemingly have had Fibromyalgia for longer than men and have different “crosses to bear” when living and coping with Fibromyalgia in their life.

There are no indications that the ratio of men to women with Fibromyalgia will grow much more, certainly women will continue to dominate the percentage relationship for the foreseeable future and the illness remain dominated by women.

Even if there is a difference in the intensity and frequency of symptoms between the sexes then they are both united in a common illness and they need to understand, not so much the differences in gender relationships but how to co-exist and help advance knowledge and treatments for the common good.

Chapter 7 : Women V Men as partners of people with Fibromyalgia

The majority of sufferers with Fibromyalgia are women of various age groups, the majority have a partner, someone they are married to, or live with.

An increasing number of same sex relationships and associated civil marriages complement the range of options of both men and women who have to accept and adapt to the fact their partner has Fibromyalgia.

There are in general 3 time frame issues to consider, and your situation may well fit one of these typical scenarios;

1. The partnership started **AFTER** one partner developed and was diagnosed with Fibromyalgia and both sides are, or should be fully aware of the possible future scenarios caused by the illness and how it may affect their relationship.

2. The partnership or marriage is fairly new (less than 10 years) and since that union started one partner has started to experience Fibromyalgia type symptoms and may have been, or will be diagnosed with it. This brings about a change of life style and finances for them both. The partners may typically aged from 20-40 and may already have children or plan to start a family.

3. The partnership or marriage is well established normally over 10 years, and some initial symptoms may have existed for many years but only later are they diagnosed as Fibromyalgia. The condition may well start to worsen and have associated conditions alongside Fibromyalgia typically of age factors or associated with the condition.

How does a man see Fibromyalgia affecting his partner?

Commonly men know little of Fibromyalgia and often are unwilling to want to find out. It is only after continued exposure to the illness and a desire on their part that they take the initiative to educate themselves about the illness.

Women sufferers may well attempt to encourage their partners interest or simply state "he does not understand." Perhaps he needs to understand and can (or should) be made to understand, but such an adjustment may be hard for both to initiate and maintain.

Pressure and various methods to encourage the male partner to learn about Fibromyalgia are not always successful, in fact usually builds greater resistance and they remain in the main disinterested.

Certainly to have a partner with Fibromyalgia is a difficult cross to bear for many men, and few realise the level of impact on them. Often they are being forced into a change of live style which is not their direct fault, and over which they have little or no control.

Non suffering partners can thus suffer and display various levels of emotion – anger, frustration, and helplessness. Some maybe sad and melancholy for themselves and the partnership as a whole, as one man put it to his partner "it's not much of a life is it love?"

On a positive note with a loving and caring partner one can more readily accept the changes Fibromyalgia brings about and the partner's life style adapted to suit.

Communication is a must, lest both sufferer and their partner endure and hide issues of concern which need to be brought out in the open and discussed frankly and openly. Then suitable solutions can be found for the good of them both as individuals and as a family.

Man as a carer

Men are reluctant to accept the role of carer and see their primary role as husband, partner and maybe father, rather than carer, even though in many cases that is what they become.

Modern man is adapting to a lifestyle where he becomes interested in house based duties and child care, which many have accepted well, however for men to assume caring roles for illnesses such as Fibromyalgia may, for some (many) be a "step too far."

He maybe forced to take on roles and duties with much reluctance and undertake tasks which are both new and alien to him - cooking, cleaning, washing, ironing, child care and other tasks previously undertaken by his partner and seen very much as "woman's work."

Man may see his role as carer as subservient to his partner which does little to his male ego. Some accept this new found role better than others, whilst some may find that changes experienced as symptoms worsen, difficult to bear. As a result they can become depressed, or more silent and quiet, which may, if left unchecked lead to a breaking down or erosion of the relationship.

A partner may announce to everyone he is his wife's carer to be met with the retort "No you are not my carer, you are my husband" which is typical of attitudes held by many women and one that perhaps reaffirms the correct attitude to the dilemma many husbands find themselves in.

How does a woman see Fibromyalgia affecting her partner?

With fewer men contracting Fibromyalgia the women's role is supporting their husband or partner is less obvious, in fact many people see Fibromyalgia as a woman's illness when it is becoming increasing more obvious it is not.

For a woman to assume a caring role for her male partner is not a big step as by tradition she is more experienced, and some may say suited to a caring role.

Many assume the role of mother to one or more children and undertake naturally a caring role for their offspring, through babyhood and childhood and beyond.

Women are often homemakers and care for their partner by doing normal household duties. Whilst many women now work, run businesses and have independent careers the typical man traditionally avoids childcare and household duties wherever they can, even if they both work.

It may therefore seem obvious than if and when a man attracts Fibromyalgia and they have a partner, that their partner may well be already experienced in a caring role and therefore more able and willing to accept the enforced role than if the role is reversed.

Where a male sufferer sees the advantage of a support group his attendance at meeting is often accompanied by a partner in similar proportions to women sufferers.

Based on the suggestion than men may find Fibromyalgia more stressful when they are suffering with it, suggests their partners role should have a strong focus is maintaining their spirits and confidence upwards, as there is more of a predisposition towards depression in men affected by Fibromyalgia.

Sex and Fibromyalgia

A taboo subject to most and little is talked about this side of the intimate relationship between sufferer and partner.

Where Fibromyalgia is mild then normal relationships can continue, however as tenderness and pain advances normal sexual unions can become more difficult and eventually may become impossible.

A caring man many become concerned, even frightened of hurting his wife, or partner.

A less caring male may well become frustrated and angry at loosing out on "his privileges" which may lead to problems in the relationship.

A woman may feel less cared for, and begin to feel neglected when intimacy becomes less frequent then later if the condition advances, non existent.

Younger women may find problems in attracting a partner due to the pain when attempting even simple closeness, let alone intimacy.

Men with Fibromyalgia may similar have problems attracting girl friends, and this can have a significant effect on their confidence and self esteem, potentially leading to depression.

The way forward to many seems to maintain a caring attitude to EACH OTHER in other ways, and each couple should continue to explore ways of pleasing their partner, showing their love and affection without expecting, or demanding anything in return.

Chapter 8 : Finance needs and tactics

The early stages of Fibromyalgia may have little impact on the way finances are affected, as symptoms may be mild and come and go.

For some people the illness starts to take root and cause increasing problems, the time scale of which is usually measured in years rather than weeks or months.

Most people tolerate and thus endure the problems that Fibromyalgia brings – especially pain and general lethargy.

Finances are only really hit when symptoms increase in severity and/or frequency, and hit those who work, run a business or have some career path which creates a regular income.

Clearly the strain of looking after home and maybe children are extra burdens and you may need to prioritise the amount of physical and mental effort you need, or can put in each day.

First impact

The start of issues comes about when a reduction in income occurs as the sufferer is forced to cut down on the number of hours worked in a typical week, which is due course may well make working at all impossible.

Maintaining the ability to work and thus earn money is an early priority, and most people focus on their current job, and fail to look at alternatives. Working is not a switch you can turn on and off.

It could be that there are money making opportunities from a new work opportunity, not necessarily at the same income level as before. You could also negotiate with your current employer about modifying your duties and times.

Possible options to normal full time work which is no longer possible include;

- Reduced hours and/or day – better maybe to do a few hours over 5 days than work 2-3 days.

- Flexible hours – work different hours, perhaps also making travelling easier.

- Work from home – at least some of the time.

- Switch jobs with same employer, do lighter, less physical work, or less stressful and/or demanding roles.

- Run your own business from home even just part time – usually offering flexible working hours.

If all work becomes impossible this may have a serious impact on family income, unless any partner's income is substantial.

Where care becomes necessary often one looks to the partner to do more and more, household and personal care duties.

For a partner to take on extra work, may jeopardise their own job and career, especially if they are high earners.

Paying for extra care and help with household duties to be done may be far better and cheaper than a partner tossing in a well paid career to do more care and housework.

To force onto a family unit the potential loss of 2 full time incomes may have a serious financial impact on finances, savings, pensions and put the future at risk.

Usually there is ample time to plan each stage, if and when Fibromyalgia symptoms worsen and undermine family living.

The financial need of a family unit where one adult member is affected by Fibromyalgia is often ruled by several key factors some of which are outlined in these simple key questions;

- What is the age of the sufferer and any partner?
- Are they working, if so what is their income and type of work?
- Are there are any children and if so their ages?
- Are there any parents or other close relatives around who may provide some help on a regular or occasional basis?
- Can any care needed be found and funded by state or local council benefits? – ask for Social Services to assess your care needs.
- Can self funded care or support needed be financed, if so to what budget per week?
- Is any redundancy payment or early retirement package on offer from an employer? If so how much and on what terms?
- Do you own your own home, if so how much free equity exists, if any?
- Have you considered moving to a more affordable and easier to manage property? – perhaps rent, or raise capital with a home equity plan or similar.

Review your monthly costs

Once Fibromyalgia starts to intrude into your daily life you should be considering long term options as symptoms may continue and may worsen.

Decisions over finances should not just be short term fixes, plan ahead for the future and look at realistic ways of both saving money, as well as increasing income in the long term.

Carefully plan and consider each option, make no sudden moves, but do take some action to improve your finances, you will need more income or have to reduce costs to combat a reduction on earnings.

Here are a few typical areas to look over, they are by no means exhaustive;

Mortgage and Rent – maybe there are ways you can reduce costs by moving, or renegotiating or refinancing the terms especially interest rates on mortgages. Likely to be the biggest expense on your budget.

Savings – check any regular savings being made, maybe you can ill afford to maintain these, and you may be forced to draw on savings later unless you can reduce other outgoings. It makes little sense to borrow money to save as some do.

Heating and Lighting – potentially the second largest expense you may be able to make savings by careful control of usage. Try switching tariffs to ensure maximum saving when using one supplier for both electricity and gas. Ensure full advantages has been taken of any grants for insulation or central heating.

Transport – review costs of owning and running a car, using buses, and other means of transport. Have needs changed? Need a smaller/cheaper car, or no car. Get lifts with other and review if some journeys are really necessary?

Holidays – these may be a luxury you can no longer afford, but there may be cheaper alternatives – short breaks close to home rather than 2 weeks in a foreign clime. Go off season offers big savings and the break can be very beneficial to health. Many sufferers report improvement from holidays taken in warmer areas or near the sea.

Leisure and enjoyment – you may have to review expenses in this area and adjust what you can afford and enjoy most pleasure from. Assess priorities and cut down to suit available budget but not at the expense of other needs. Maybe home based entertainment and educational options may be needed if mobility limits going out as much.

TV/Telephone/Internet – with reduced mobility you may be spending more time indoors with the TV for company and entertainment, as well as the telephone as a key communication tool. The internet is valuable for communication, entertainment and research linked to a PC or Laptop. Looking at the various mix and match options available from your current provider can save money, as can considering switching provider using comparisons services such as USwitch.

Supporting other people – how much does it cost you to support other family members or friends? Or are you well controlled and put yourself No 1 always? Take time to introduce the fact income is down and taking a tumble due to Fibromyalgia. Agree to share costs, or agree a lesser budget most people will be understanding and value your friendship more.

Children – if you have a young family then costs can be huge with clothes, shoes and costs of crèches, and toddler clubs, etc. Looking at ways of saving may be difficult as you will always want the best for your off-spring. You may have to learn to say "No" (and mean it) more often if spending on your youngsters is proving difficult.

Insurances – do you waste money insuring low risks at high premiums, warranties on electrical appliances can be notoriously poor value. Washing machines and tumble dryers being used regularly are examples where breakdown and replacement warranty are wise. Shop around for reduced premiums and check you are not paying for cover unnecessarily.

Borrowing and banking – borrowing can be costly in interest, so reducing your dependence on loans, credit and store cards offers the chance of saving some big money. How much INTEREST do you pay on loans?

Sell surplus goods – not only can it make a few founds but clears up clutter, making more useable space especially if are reorganising your home and rooms to cope with mobility issues. A tidy place is also easier to keep clean. Items of no real value, or are difficult to sell can be donated to charity shops and do someone else a favour.

Sell valuable items – do you have some secret treasures around which could be turned into valuable cash? What do we mean by "valuable"? it may mean something you can sell for £50 or a few hundred, and who knows you may have something that could net you thousands. Paintings and antiques as well as collections of most things could be turned into a valuable asset.

Buy second hand – there are considerable bargains to be had at places such as charity or thrift shops, or via web sites such as EBay. Whilst some people may find buying someone else's cast offs distasteful when faced with a shortage of money you must face the reality you cannot always afford new. Many investments such as cars and furniture can show significant savings if you take time to shop around.

Do without – it is wise to change your thinking from "must have" to "do we really need……." and decide what things are vital and which may be considered luxuries. Getting special needed items as presents from family and friends is much more practical, even if several unit to buy a more expensive item.

If you MUST HAVE something very often you may be tempted to put the cost on a credit card, or it means you cannot afford much more important items and your action is potentially selfish in motive.

Restructuring your income, costs and expenses is an ongoing habit you will need to practice regularly. If and when Fibromyalgia becomes more of a nuisance in your life.

Chapter 9 : Support Groups – a vital lifeline

A support group exists to help people with Fibromyalgia to understand more about the illness and learn how other people are affected by it.

There are not enough support groups around to service the demand from sufferers, their partners and families especially in remote areas. In theory at least every town should have one, and cities more than one.

Support groups are usually set up and run by sufferers for the benefit of others with the illness – herein lies a basic problem that the group organiser is taking on a work load when they are already not well themselves.

Groups are voluntary organisations, most start informally and later may establish a committee and officers such as a chairperson (leader), Secretary and Treasurer. A small annual subscription ensures commitment to the group as a member.

Some groups are set up by one or a few people and start full of enthusiasm but burn out or get limited interest within the first year or so, this may stimulate former members into starting their own group or carry the old one on with new leaders. Some fail, but even more fail to get started as clearly establishing and maintaining a support group needs dedication and a wide range of skills.

Fibromyalgia and a support group's activities is very newsworthy and local newspapers and radio stations are very responsive to stories about groups being formed and holding meetings, running awareness sessions etc. They provide free publicity via articles including full features. Even established groups remain unknown to many sufferers so there is a constant need for groups to promote awareness of their existence.

Support group which encourage members to help each other and the group generally do best, although typically 25% or so will do most of the work whilst the others are unable or unwilling to contribute to the groups continued survival.

Some support group members come into the group briefly, attending a few meetings, obtaining information, chatting about their problems and what is on offer to help, and then leave. This is not a failure of the group, but of human nature. The fact that the sufferer, their partners and relatives are more enlightened and aware is often enough for their needs. Later they may return to the group if their condition or circumstances change or worsen.

Others become long standing loyal members who regularly or from time to time help the group – donating money or goods, manning stalls, helping set up meetings, do admin work, produce a newsletter, keep a scrapbook of groups progress, organise social events and more…

Belonging to a support group can introduce you to new friends who share the same types of problems as you, you can socialise with them separate from group meetings, meeting for meals or coffee, even visit each others homes.

The telephone is a key communication tool in contacting a support group, getting information to suit your needs, and generally having someone to chat to who understands what you are going through.

Most support groups have been started and are run exclusively by women, although a few men have started groups where the bulk of members are women. The ratio of 9:1 seems to suggest women will always be in the majority in support groups.

Many groups have partners of sufferers who help them practically, even being on committees as it is vital to get a perspective of partners and carers issues as much as the sufferer.

Some groups have set up a separate sub-group for male sufferers and/or male partners to meet and discuss issues on a man to man basis, usually lead by a male sufferer or partner of a female sufferer, often someone who is leader or committee member. This works better with larger groups since it needs to attract sufficient numbers and enthusiasm to make such meetings viable.

Groups can vary in size from less than 10 to many hundreds, the larger ones being based in major city locations where a large sufferer base usually exists making recruitment of new members easier.

These larger groups sometimes set up smaller sub groups in local towns where it is not feasible to have a direct group, or travelling is a problem, this helps expand the groups size and service area.

A few larger groups have become registered charities and thus more able to raise larger grant funding to help with costs and large projects. There is often a need for capital equipment such as computers and printers as well as promotional and printing costs.

There is an International Awareness Day and National Awareness Day each year when groups promote themselves and develop more awareness of Fibromyalgia to the public at large as the illness still remains largely unknown or mis-understood.

Many groups run local awareness events to help recruit new members and make the public and related health organisations and voluntary groups aware of Fibromyalgia. This “networking” is vital to continue the good works of support groups and necessary for their continued growth and survival.

Some groups have established online forums or Facebook pages, either just for the groups own members or publicly available. These social networking systems help sufferers find new friends, seek advice for people in similar circumstances or just share a rant or moan about their problems or on bad days.

In the USA most states have a wide range of support groups which usually meet regularly in public places such as libraries, and health clinics again started and maintained by sufferers.

In Europe ENFA (The European Network of Fibromyalgia Associations) exists to link together organisations who provide help and information and advice for sufferers and their families.

Overall the number of Fibromyalgia support groups is still small compared with the need for them. There is in general no state aid available and whilst some are able to obtain localised town, city or area grants to get established most rely on voluntary donations and member’s subscriptions to thrive.

Find out if there is a support group near you by using the web based resources detailed in Resources later in the book, many which have details of UK support groups.

Otherwise use a web search engine using the keywords “Fibromyalgia Support Group <town/city name> and/or <county/state>” adjusting the details to suit your location.

Chapter 10 : Age Factors and Fibromyalgia

Some knowledge suggests that people can be affected by Fibromyalgia at any age, and some people may have a greater chance of displaying symptoms than others.

It is claimed generally that over 2% of the population suffer from Fibromyalgia is some form, but there is no specific proof to reliably support that claim, as clearly many may have Fibromyalgia type symptoms and have not been formerly diagnosed with it.

Chances are once you know about Fibromyalgia and its symptoms then you will know at least one person with it. Perhaps a relative or friend. Many sufferers think they alone, and isolated the truth is different and more widespread than you may have thought.

It can be common for someone you talk to for the first time about you having Fibromyalgia for them to retort that "my auntie has that" or "our next door's wife has this too."

This greater awareness of Fibromyalgia is helping more people understand;

- What Fibromyalgia is – a painful neuro muscular condition which some people may call an illness or syndrome.
- Who get its – mainly women although an increasing number of men.
- What typical symptoms are – all over pain, sleep issues, bowel problems (IBS), mood swings, lack of energy etc.
- What happens physically to people with it – they become less mobile due to the pain and tiredness, and are less able to work or function normally.
- How they are affected by having it – sufferers may have to reduce or give up work, do less household duties, be unable to take holidays or care for children.

This book is primarily looking at people from age 20 and onwards who may be experiencing Fibromyalgia type symptoms or who have already been diagnosed with it.

People aged over 50 are, it would seem from experience more likely to have had Fibromyalgia for some time, potentially at least from childhood but symptoms have never become severe and they have learnt to live with the condition.

If you are aged 20-40 and experiencing Fibromyalgia like symptoms then consulting your doctor to confirm or rule out Fibromyalgia is vital to free you of worries that it may be something more serious and life threatening.

For people in this age group being affected by Fibromyalgia can create many social and financial problems as well as the effects of the illness itself.

In many ways younger people in this age group may be better equipped to deal with the changes that are necessary to cope with and live with this untimely and unwanted intrusion into their lives.

In theory they are better educated, have more energy and a wider circle of friends, all useful attributes to fight or cope with illness.

In other views such younger people are less well equipped, typical reactions can be anger “why me?” - and they can quickly become depressed and this can affect family life and relationships with partners.

Sufferers can become frustrated because there is no “instant cure” or indeed seemingly any cure at all.

They may have to change daily routines, take more pills to combat pain and other related issues. Change diet, do mild exercise, modify or be forced to change sleeping patterns.

Do older people cope better?

Many people over 50 have more than likely learned to live with Fibromyalgia and become resigned to their condition. Even if they are only getting formerly diagnosed now chances are they have had symptoms for some years, albeit mild, yet diagnosis has been slow or difficult.

This does not imply they are happy to have Fibromyalgia, in fact far from it. Any survey would not find many sufferers who are happy with their affliction, and all remain interested in possible cures and improvements to symptoms.

The conclusion “they can’t do anything for it” really means Fibromyalgia cannot be cured, only controlled, and in the main with pain killers and depression reducers.

Doctors treating the more mature sufferer continually monitor progress and may from time to time change medication, especially if any new drug comes into common use or the condition worsens.

Some older people may be reluctant to talk much about their Fibromyalgia, even to other sufferers and take time to settle in with support groups.

Other, more outgoing and confident sufferers can be of considerable help to others with the same condition. Many start or are active within support groups in supporting and befriending fellow sufferers.

The Young V the older sufferer

By experience the younger sufferers are less tolerant of their condition and are often seeking a quick fix, so they can get on with their life.

In the early stages of contact with an older sufferer they may appear to be in a different world with a wide range of different attitudes to each other and Fibromyalgia the symptoms of which may differ, in some cases widely.

As time progresses and if both side allow themselves to look at each others point of view, good, solid friendships can be built across a wide range of age groups.

The youngster may be brash, often with an over confident attitude which can often change into a genuine awareness and acceptance that the older sufferer does speak wisely about their experiences and life style with Fibromyalgia.

Properly addressed both young and old can learn from each other, this is only possible with a light hearted, open attitude on both sides, if one side has a serious approach then this creates a difficult, potentially impossible barrier to break through.

Fibromyalgia as a laughing matter? Well yes, otherwise you would cry and become sorry for yourself and the “poor me” attitude can often be displayed.

Young sufferers may want to talk about little else than “a cure” or themselves, and often this is vital if they have no one close who they can talk to, who understands what they are going through.

An older person more readily understands this and is likely to more patient of their younger counterpart with “she(he) will learn!!” is a frequent conclusion.

Two or more young sufferers together may well be of a similar age group with modern interests compared with the more mature sufferer, but they need support from fellow sufferers of any age whom they can relate to who has been diagnosed for some years.

If there is a large number of young sufferers in a support group they may well consider starting a spin off group for the young, often this may be difficult to achieve due to limited source numbers and ability to convince enough to make a sub-group viable.

Frequently friendships are formed and fellow sufferers meet and socialise by meeting for coffee in public places or in each others homes. This has considerable benefits to both sides.

Many support groups offer social events outside normal meetings which adds to the opportunity of mixed age groups to meet and socialise – trips to the theatre, fitness and health locations, garden centres or a restaurant are a few typical examples.

Group social meets can often be upbeat, and friendly since for many this is a welcome release from a normal day of pain, discomfort and tiredness. It is often the case that the next day may be uncomfortable for some sufferers who need extra time for recovery than normal healthy people. The effort of “getting out” may well be worth the discomfort of tomorrow!

Fibromyalgia strikes all ages and, although different in attitudes and social needs, a wide range of ages can co-exist and benefit from each other’s contact and friendship.

Those who cope with Fibromyalgia better are those who are open and friendly, and receptive to ideas to improve their condition and respectful of others regardless of their age, sex or race.

Chapter 11 : Depression and withdrawal

Fibromyalgia has a potentially serious effect on someone's life who has this illness or lives with someone who has.

People who live alone can be especially prone to periods of melancholy and depression, so it is essential they are provided with regular support to suit their physiological needs as much as their physical ones.

Even if someone appears to be "coping" and cheerful on the outside the truth of their condition may well be hidden below this outward show of bravado.

There is often a tendency to play down symptoms and pretend to be better than you are, we all do it. How many time have you heard the phrase "how are you? – FINE thanks!!!"

With a loving and understanding partner by one's side mood swings can, potentially at least be coped with better. One positive partner can understand when to be quiet, or when to distract the other with outings, questions, suggestions or anything to divert the mind from feeling down.

Often Fibromyalgia symptoms are misunderstood needing the partner to understand that getting low is potentially a link to the illness. Constant pain and lack of energy can drain a sufferer emotionally, as well as suck physical and mental energy from their carer.

Ignorance of depression occurring with either sufferer or their partner can lead to much unhappiness and any outward signs should be treated with urgency. It remain difficult always to summon enough emotional strength to help lift another's spirits, however close they are to you, when you yourself are also feeling low.

It is certainly true that the constant and nagging pain so often experienced by sufferers with Fibromyalgia can wear down the strongest of person in it's relentless onslaught of symptoms.

Mood swings and depression can hopefully only be temporary and quickly pass. If however they become more regular in occurrence or become deeper, driving the sufferer down further into melancholy then medical advice should be sought without delay.

It is not unusual for some sufferers to be prescribed anti-depressant tablets at least for a short period, to help reduce and ideally eliminate bouts of depression.

The non suffering partner may, and often does get down too, hopefully not at the same time as the sufferer, and their plight is often misunderstood or ignored.

Caring for someone with Fibromyalgia can be an ongoing battle, and without their love and support the sufferer could lead a less happy life, with considerable emotional problems added to their existing Fibromyalgia symptoms. An additional burden they can well do without.

A brief word about suicide

A taboo subject for many, but a reality to a few who come to a crossroads in their life when they may feel they can no longer "stand it."

Fibromyalgia sufferers who are perhaps isolated with little, if any close family and few friends can become seriously depressed which may lead to a serious desire to end their suffering.

If you are or know some who is suffering with Fibromyalgia it is vital spirits are regularly lifted and maintained to live and enjoy as normal life as they are able.

Fibromyalgia is not a terminal illness and people have different levels of symptoms so react is different ways, and most can adjust well to the enforced new life style.

Morbid fears and feelings can and must be lifted by constant support and encouragement from a variety of people, it is both unfair for the sufferer to be told to "get over it", and unreasonable to suppose they can modify their life without considerable aid from others.

Positive boosters to lift depression

Each person has a different need, but based on experience these tips may prove useful in both avoiding depression, and weaken it's impact;

Keep busy – you may not be able to be busy in a physical sense due to your condition but being alert and active mentally helps divert the mind onto other issues and can avoid boredom and negative thoughts. Read newspapers, books, watch TV, phone someone, have someone in for tea or coffee, call on a neighbour, the list is endless.

Avoid boredom – involve yourself in interesting things, spend more time on your hobby, take up a new one, allocate a time limit especially for things that need doing but you are not keen on. Try changing routines, sufferers often are worse in the morning so planning afternoon activities could be best.

Two way conversations – many people bore their listener by talking too much about themselves – you have to give as much as receive, so making enquires about another person's, home, job, heath etc makes you less selfish. Balance and sharing is a major key to good friendships, and good friends can do a lot to help boost low periods then you need an uplift.

Join a local support group – not every town or city has a local support group you can visit, even so many are happy to be contacted by telephone and you are able to talk to a fellow sufferers about your problems and get advice. Even a phone chat can lead to information being sent to you for further study, and you could be given contact telephone numbers to call for more local advice.

Get a computer – whilst more and more newly diagnosed sufferers already have a PC or laptop those who have failed to embrace modern technology should consider the advantages. Computers are a great source of knowledge and information. Using email, telephone services such as Skype and social networking you can keep in touch with friends and relatives on a regular basis. You can educate yourself and also enjoy online entertainment, music, films, games etc. Often machines can be bought second hand, however new machines are amazingly low priced considering the value they offer in features, speed and storage options.

Keep mobile – whilst there is a frequent tendency to stay in and sit in your chair, getting out and mobile helps boost mood swings – " a change is as good as a rest" is very true and well worth remembering. A short walk to the park, to the shops or just out to your own garden. Maybe you still work so your mobility may be good a lot of the time and making special efforts may be unnecessary. Do you drive or take the bus? More and more local buses are especially adapted for people with disabilities, so contact your local council or bus company to make enquires. Some services will collect you from your door and deliver you back. Many taxi services now have special vehicles with wider doors, better seating and even wheelchair carrying capacity, check round. Get a friend or relative to give you a lift or take you somewhere special.

Remember depression and low moods is a state of mind – keeping busy both physically and mentally helps distract the mind from events or circumstances which can lower your mood and make you depressed.

Dealing with Fibromyalgia is all about adapting, but do not morn those things you can no longer do due to your pain and energy swings but applaud your success in modifying your life style to bringing in new life events that interest and stimulate you.

Not only do you change but hopefully friends and relatives who know you too. Their education and awareness about Fibromyalgia is a vital key to helping you take a positive look at the future and adapt accordingly.

If you have a partner remember they too can suffer bouts of feeling low. True they do not have Fibromyalgia, and cannot fully appreciate what it is like to have it, but they are never-the-less having to change and take on more duties for which they may be ill suited.

Coping with Fibromyalgia is not about being alone and isolated, but having a "team" around you who can help in different ways and at different times, all of whom are learning to adapt and change, with you and for you.

Chapter 12 : The long term prognosis

The onset of Fibromyalgia in someone's life creates concerns about how long this problem may exist, in fact people are affected in many different ways, and also react differently to the various traumas the condition may bring.

Fibromyalgia is a long term debilitating condition which may worsen with time, the sufferer may be able to halt or delay its progression but any potential permanent cure is not known to exist.

A change in lifestyle may act positively to combat the effects of Fibromyalgia, but the condition's symptoms may return more severely if the treatment lapses or is modified with less beneficial results.

In your travels and thirst for knowledge about Fibromyalgia you may meet or hear about people who confidentially claim to have been cured, usually by their own efforts.

Miracle pills and potions in the main are commercial products and have little impact on Fibromyalgia and are often more of a placebo that authentic cure, and can be costly.

If relief is achieved it is often short lived, or less welcome side-effects are experienced so the treatment may have to be stopped or changed with less positive results. Moral here is if you find a regime which produced beneficial results see how you cope over the next 3 to 6 months, if results are still positive then you could be onto potential long term control which suits you. Your successful methods may not suit others, and theirs you.

The medical profession dispense pain and depression control based on the individual sufferers needs. They may also have other issues such as IBS and sleep problems and addition medication may be needed to treat those.

What is the truth then?

There is no absolute truth about how YOUR Fibromyalgia will control your future life, if you have a robust mental approach you may be able to control it more than others are able.

If you have limited ability to take control of your life you may be affected by Fibromyalgia to a higher degree, this is not a sign of weakness but reflects the differences in peoples attitude based on their life experiences and knowledge, and to some degree hereditary.

The mentally strong and forceful person may not be able to control and take charge of their Fibromyalgia as much as they may feel they can or should. Fibromyalgia may however take the upper hand and force the strongest of constitutions into submission.

Where does it all lead?

The path of Fibromyalgia in your life leads to CHANGE and learning to cope with various issues, it requires a constant view and adjustment of finances, life style, eating and dietary habits as well as a constant monitoring of medications coupled with regular visits to ones doctor.

If you have Fibromyalgia your condition may not necessarily progress, but can be controlled by your doctor and prescribed medicines and never cause major problems. You may still be able to work, even if just part time.

Adjusting your schedules and looking at diet, reduced stress and modest exercise are additional aids you can and should consider studying and trying to assess results to suit you – both good and bad. It will take time to readjust your life style.

As you age then one could naturally expect some health problems so these may well be worsened by Fibromyalgia pre-existing. Other health conditions may come along to which potentially makes prescribing and taking medication more complex. Regular reviews with a doctor becomes more vital.

It is rare but potentially not impossible for both partners to both have Fibromyalgia, and a great need exists for non-sufferers whether partner, friend or family member to know and understand more about Fibromyalgia

A summary of the long term

- Fibromyalgia may not worsen, but have limited impact on your life style and may be easily controlled by medication and changes to work/home life style patterns and changes to diet.

- Keep in touch with the latest news about treatments and other hints about living with Fibromyalgia, use web sites, forums and support groups on a regular basis.

- Maintain communication with family, friends and a local support group so that both you and they understand Fibromyalgia better and you are well informed on new options to try. Having a shuttered view of options will not make Fibromyalgia any easier to live with.

- Stay positive, there are many good, proven solutions to your problems and many routes to find them. Talk over the implications, good and bad - successfully living with Fibromyalgia is possible with an open, outward seeking approach supported by your partner, close relatives and friends.

Chapter 13 : Keep laughing and sane

To many having Fibromyalgia in their life is a frightening and scary event and something that can depress the sufferer, and maybe their immediate family.

Life is changing already and potentially will change over the coming years. This fear of the unknown often forces some people to image all sorts of horrors to come and many negative questions come to mind;

- Will I end up in a wheelchair?
- How long have I got?
- How can we cope?
- Who is going to help me?

The simple answer is for the sufferer and their partner to get some reliable and update information and built up their knowledge of Fibromyalgia and what it is all about. Knowledge is best sought from these typical areas;

- If you have internet access use the various web sites in the resources page at the end of this book.
- Join an online forum or two and read about other people's experiences - ask questions about issues that concern you.
- Whilst your doctor may have little information to provide they may be able to refer you to local knowledge and support.
- Seek out and make contact with any local support group which you can find via the web sites mentioned, the top 3 UK ones have regional lists or maps.

The result of your initial research is that many of your initial fears and worries will disappear, to be replaced perhaps by some new questions, rather than the former concerns you formerly had.

The typical next stage is to talk things through with people who can help your dilemma, this can include doctor, consultant, husband, wife, children, brothers and sisters, parents, maybe grandparents or uncles and aunts and close friends.

You are bound to be confused so the key now is to take your time, Fibromyalgia has not arrived overnight, nor is it going to advance at a lightening pace.

People are often optimists or pessimists with a few who may claim to be "middle of the road", or average or just plain normal.

Pessimists are not going to do well with living with Fibromyalgia, they are lost before they set out on the difficult journey ahead, they will be only too ready to be critical of their treatment, their doctor, their family and those who they meet on a regular basis.

They may over exaggerate their symptoms and pain levels, possibly to gain sympathy or attention. Whilst this may get short term support and encouragement, unless the moans are substantiated family and friends may soon get used to it and start to ignore their condition. Not many people want to hear about other peoples problems day in and day out.

This does not suggest one should become silent and endure the pain and discomfort, but to be realistic to both yourself and when talking to others.

"How are you?" is a common enough question, and especially significant to those with Fibromyalgia, so if you are a sufferer what is your usual reply? Or does it depend on who is asking the question?

- "Oh, I'm fine thanks" – (which may mean in reality - I am having a good day, despite some little twinges and I am not going to let it get me down.)

- "Not too bad thanks" – (implying you are not well, but today is a good, or better day than others.)

- "Very well thanks" – (you are probably lying, you are full of aches and pains and had little sleep last night, just what are you trying to achieve? Or maybe it is an usually good day!)

- "Oh, its been a terrible week first……….. " – (maybe you are sorry you asked!!! Get ready to be bored.)

Having met and been in contact with hundreds of sufferers by various means such as personal meetings, telephone and email the author may be able to conclude that some people have a better, more positive attitude to the fact they have Fibromyalgia. This more buoyant attitude can have good, positive results in the way Fibromyalgia is handled and accepted.

Does this make a difference in the way you can cope?

It should do, its better to be happy, open, and friendly and be in a positive frame of mind.

People do not really want to hear about your troubles, well only in small doses, so it is easy to become boring, so keep your responses short and to the point.

If you regularly can attend a support group you may meet different people with different levels of symptoms and time they have had Fibromyalgia.

Types of sufferers you may meet, regardless of your situation may include these examples;

- **the old stager** – has had Fibromyalgia for many years, no need for them to talk a lot about their condition, tends to come to group meetings for companionship and/or perhaps to help others. Tends to have become resigned to their current level of discomfort and symptoms and life style. Maybe has learnt some good techniques which suits them and helps control their Fibromyalgia.

- **The staunch member** – well established sufferer who is keen to help within the group suitable to their abilities and time available – typical duties may include – tea making, greeting new members, helping set up rooms, clearing away, selling goods, running draws, helping man awareness events, giving lifts to other members, organising trips and social events, visiting members at home and more ……..

- **The sit back and take it member** – comes to occasional meetings and says little, even if talked to they answer questions put to them but find it difficult to start conversations. With some care and interest shown them by other members they may become long standing members.

- **The clever clogs** – arrives like a whirlwind, claims to know everything about Fibromyalgia (have been on the WWW) and has come to look over the group just out of interest. Makes suggestions as to what is lacking, but expects others to do it. Maybe never seen again after one meeting, so one looses touch with how they get on the future. Do they cure themselves, or live in sad, painful isolation?

- **The loyal member** – comes as often as they can to meetings and general participates in the group. Not likely to be able or willing to help the group but is nevertheless a valuable member and hopefully derives useful benefit from their membership of the support group.

So you can begin to see that having the right mental approach can do a lot to help you live better with Fibromyalgia, why is that?

- Approaching your illness with a bright and confident manner can help you cope and be open and responsive to new ideas and strategies to help combat symptoms.

- Avoid using an outward show of happiness and confidence to hide an inner, unhappy and insecure person. Often others who know you well can see the "real you", despite your show of bravado.

- Trying to see the funny or lighter side of typical things that happen to you, maybe as a result of Fibromyalgia. The commonest is the confusion with the use of words, or forgetting, for example, when referring to the term "Placebo" (an imitation pill which has no actual medicinal value but convinces the user it will work, so it does!!!) a sufferer used the term

"Gazebo" (a portable garden structure.) You have to be a positive thinking Fibromyalgia sufferers with a sense of humour to understand this example.

- Laugh at yourself (rather than others) when having "Fibro moments" fellow sufferers will understand and often retort "I am like that."

Maybe you lack the ability to be the "life and sole of the party", but trying not to take yourself, your circumstances and Fibromyalgia symptoms too seriously, can mean you may be able to live a better and happier lifestyle despite that unwelcome guest – Fibromyalgia.

Chapter 14 : 10 positive things to do

Being diagnosed with Fibromyalgia to many is very worrying and scary, you may make wild guesses as to where it all might lead and frighten yourself with some serious "what if" questions and answers.

Perhaps you may think that you may end up bedridden or in a wheel chair, no wonder many get depressed and angry, and this has a knock on effect on all the family too, some of whom are having to change and adapt their life style to work around the limitations and needs of the sufferer.

Each person and their partner, carer or close family will have to find their own route, but here are some key elements that many people find beneficial in future life planning. You may not like some of these, or try and fail.

1. **Have a sense of humour**, stay optimistic and open minded. All too many people become glum and assume this is the end of their world, their ambitions, hopes and dreams. Sure you have to change and adapt and take on a new life style, but this may not be as bad as you may assume, the illness MAY progress, but if it does it will be SLOW, giving time to adjust.

2. **Talk and Chat -** to your partner, friends, relatives about your needs, but in a friendly and positive and constructive way – stop moaning about your troubles, everyone has their own, but people are willing to listen and help if they know you need help. Avoid demands, but polite "optional" requests.

3. **Keep active** – mentally and physically (as much as you are able anyhow) develop a range of different interests and activities, perhaps some new ones which are better suited for your reduced mobility.

4. **Get a computer** – there are a lot of online newsletters and chat forums connected with Fibromyalgia as well as numerous web sites as outlined in the resources section later in this book. There are good opportunities to educate yourself, communicate with family and friends especially if you become less mobile and less social active. Besides traditional PCs there are laptops, note books, tablets and smart phones some of which may suit you better. Some even have touch screens if you have hand problems, or special software to help.

5. **Read** – books, magazines, newspapers – it's a dying art but there is so much to find out, help expand your current interests or give you ideas for new hobbies or even a home based business. There are books about Fibromyalgia is local libraries and many support groups offer a lending library. Many online forums and newsletters are vital ways of educating yourself.

6. **Stay on top of finances** – income may become an increasing problem and costs still have to met. Budgeting is a must and look at all types of free aid and state benefits you can obtain.

7. **Develop new interests** or rekindle old ones – adjust hobbies and interests to suit any new limitations. Talk over you're your partner, family or friends fears, and thoughts, "brain storm" things that interest you and be willing to "have a go" at. You may find some new hidden talent in you, or a new interest that amazes and absorbs your interest. Learn to speak a new language, paint, draw, learn about space and the universe…….. the list is endless, never again need you say "I have nothing to do, I'm bored."

8. **Use the telephone more** – ring people and encourage them to call you even for a brief chat. Most phone providers offer fixed price unlimited calls packages, but watch calls to mobiles which can be costly. Make full use of any free call allocation for you and the caller. With services such as Skype you can call for free worldwide via your computer. Same network to network calls are usually free. Check your monthly bill for any sudden costs increases and relate to some calls which cost excessively.

9. **Use Fibromyalgia Support Groups** - make contact with, and consider joining a local support group, it will give you the chance of making new friends and sharing experiences. Most groups are run by sufferers with some partners and other members helping. Do not expect miracles and look at benefits over the long haul, it takes time to get to know the group and they you. Consider starting one if none exist in your area, the resources page gives a web link to show you how. Even if you cannot attend meetings due to distance or your condition a lot can be gained by regular contact via newsletter, email and telephone.

10. **Your Fibromyalgia will change your life style**, so do re-read this book from time to time, a year from now other aspects or chapters may be useful or more important whereas than they are not now.

Get others to read the book too, they may find some of the chapters of vital interest, all it takes is a single, meaningful sentence or paragraph to get partners and family to change their attitude to you.

Knowledge and understanding is a powerful tool, without it we are prey to become withdrawn and depressed weighed down by negative thoughts and emotions.

Coping with Fibromyalgia is best done day by day, with others at hand to chat to and to meet.

Chapter 15 - Resources and More Information

Below are a selection of useful web based resources covering UK, US and Europe. They are in no particular order, nor are they specific recommendations.

Often there are links to treatments and medication which may offer to improve or indeed cure Fibromyalgia but may have limited value to individual sufferers.

- http://www.fibromyalgia-support.net – the authors own web site which provides a wide range of useful information about Fibromyalgia as well as an interactive map of UK support groups. A useful section also explains how to set up a local support group and promote it.

- http://www.ukfibromyalgia.com is a commercial web site which has a wide range of up-to-date knowledge and information about Fibromyalgia as well as an online forum which is widely used. It also publishes in printed version the monthly magazine Family – specifically for Fibromyalgia sufferers and support groups. Back copies and free downloads are available. There is an up-to-date list of UK support groups by region.

- http://www.fibromyalgia-associationuk.org is the national charity for Fibromyalgia which provides information of national and international awareness events and latest trends in treatments across the world. Most of the UK support groups work with this organisation which operates through various regions controlled by an RC (regional co-ordinator) to whom enquires should be made for details of groups in their area. New support groups are encouraged to be set up.

- http://www.fibromyalgiasyndrome.co.uk The Fibromyalgia Syndrome website is designed and written to help support people with fibromyalgia, and their families, friends and colleagues. It provides an approachable and easy-to-read introduction to fibromyalgia syndrome, and gives no-nonsense information about living with this potentially long-term disorder.

- http://www.painsupport.co.uk founded by Jan Sadler, Pain Support provides a wide range of advice and techniques about controlling pain generally not just for Fibromyalgia sufferers. An online forum provides a wide range of experiences.

- http://www.controlpain-livelife.com offers a free booklet "Control Pain Love Life" via download of a useful read for general pain.

- http://www.paintoolkit.org The Paintool Kit is an excellent read for anyone with persistent pain. Besides the web resource you can download the Pain Toolkit from the site for later reference. Also available in French, German and Italian. There are an excellent range of links to other useful related pain control web sites.

- http://www.en.wikipedia.org/wiki/Fibromyalgia Wiki on Fibromyalgia. A Wiki is a series of linked web pages on a variety of subjects which people can contribute new and changed facts to. The Wiki community monitors pages so this link provides some useful and up-to-date information as well as providing links to Wiki pages on other related illness or treatments.

- http://www.afsafund.org The American Fibromyalgia Syndrome Association (AFSA) is a non-profit organization dedicated to research, education and patient advocacy for FMS (Fibromyalgia) and CFS (chronic fatigue syndrome)

- http://www.fibrocoalition.org founded by Yvonne Keeny this is a US inspirational site about many people who have recovered from Fibromyalgia, including the founder, or are much improved. Many useful newsletters packed with practical tips available at small cost.

- http://www.fms-help.com founded by Dominie Bush a Fibromyalgia survivor this US site lists 100 symptoms and 100 tips for coping with Fibromyalgia plus useful links and a free newsletter with online back issues going back to 2003.

- http://enfa-europe.eu is the European Network of Fibromyalgia Associations comprising members who provide a wide range of support services to sufferers within their individual country. Countries not represented may have a developing but potentially fragmented support network and may join ENFA later in their development.

- http://www.fmpartnership.org The National Fibromyalgia Partnership offers medically accurate information on the symptoms, diagnosis, treatment, and research of fibromyalgia.

- http://www.livingwithfm.com a DVD documentary recounting the experience of 7 sufferers lives. An inspiring and educational journey. Many local support groups have a copy in their lending library.

- http://www.nfra.net The US National Fibromyalgia Research Association is a source for what's new in fibromyalgia.

- http://www.rheumatology.org The American College pf Rheumatology mission is one of research, treatments and knowledge improvement which includes Fibromyalgia.

- http://www.who.int The World Health Organisation looks at Fibromyalgia and other illnesses and treatments worldwide.

- http://www.friendswithfibro.org/support.html Links to US support groups state by state.

- http://www.secretstorecovery.com looks at differences between CFS, ME and Fibromyalgia, and offers a free e-book on the subject, although commercially based is of interest to those seeking a better understanding of the possible links.

- http://www.afme.org.uk Action for M. E - Improving the lives of people with M.E. M.E. is also known as Chronic Fatigue Syndrome (CFS). It is sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS).

- http://www.meassociation.org.uk provides information, support and practical advice for people who are affected by ME/CFS/PVFS (Myalgic Encephalopathy/Chronic Fatigue Syndrome/Post Viral Fatigue Syndrome), their families and carers. They also fund and support research, and offer education and training.

Home Based Business

If you are considering starting a home based business as an enforced alterative to traditional paid employment these organisations may provide useful help and advice.

- http://www.smallbusiness.co.uk/ a useful arrange of news, and advice links for new business starters.

- http://www.businesslink.gov.uk is the governments advice service for small business with sections for England, Northern Ireland, Scotland and Wales.

- http://www.thisismoney.co.uk/small-business a wide range of free financial advice including how to start a new business.

- http://www.freshbusinessthinking.com a useful service stimulating new ideas for business.

Your local bank may offer free banking services for an initial period as well as access to advice and support. Open a separate business account and talk your ideas through with them.

Mobility support and aids

- http://www.mobilise.info Disabled motoring UK - help and advice for anyone drives and who has a mobility problem including the Blue Badge parking program.

- http://www.boots.com online catalogue of over 700 mobility aids to help people with reduced mobility problems.

- http://www.halfords.com offers a range of mobility aids including mobility scooters, mobility wheelchairs and walking aids. Order for delivery or reserve and collect in store.

- http://www.benefitsnowshop.co.uk for aids to daily living, has over 16,000 products including mobility aids, bathroom aids, exercise products, kitchen and dining aids and many more. Separate site gives advice on claiming financial benefits.

Benefits and finance support

- http://www.benefitsnow.co.uk is a comprehensive online resource for mobility benefits. Find out what is available via an online checker. Helps you understand the application process and dealing with appeals.

- http://www.turn2us.org.uk The charity Turn2us exists to help people access the money available to them – through benefits, grants and other financial help. Their free, accessible website has been designed to help people find appropriate sources of financial support, quickly and easily, based on their particular needs and circumstances.

- http://www.entitledto.co.uk/ People across the UK are missing out on benefits and tax credits worth more than £5 billion a year. Entitled to can help make sure you get what is yours. Just use this simple calculator to work out how much you could claim.

General Information

- http://www.facebook.com is a social networking site to make friends with fellow sufferers and swap experiences and knowledge. Many support groups have their own page, which may be restricted to their own members. Some web sites may also have a linked page.

- http://www.twitter.com a simple web based service similar to text messaging via a mobile phone. Link up with people with similar interests and post "tweets" a short message to be shared by your "followers". "Follow" interesting other people.

This book and resource links above are provided for general education only. Individuals should consult a qualified health care provider for professional medical advice, diagnosis and treatment of any medical or health condition.

The inclusion of any links or reference to a resource is not an endorsement or personal recommendation by the author or the publishers. Readers should take suitable advice and exercise good judgement when making decisions which may affect their health or finances.

Donations and Assistance

Fibromyalgia UK Org is a small UK based international voluntary organisation helping people understand and cope with Fibromyalgia.

This e-book has been provided to you free of charge, as we appreciate that many sufferers have limited finances and we continue to provide as much support as possible through the web site and this resource book without charge to the user.

If you feel we deserve any help with the continuing and increasing costs of running this vital service we welcome any contributions, from a few stamps, a PayPal donation (to - support@fibromyalgia-support.net), a cheque, or ever leave us a £5 in your will. Thanks Fibromyalgia UK Org.

Changes and Updates

Please contact the publisher with news of any useful new resource to be added to future new editions of this book. Similarly report any errors or omissions, or web resources which have closed, or changed name.

Friends, relatives or support groups can freely download their own copy of the latest edition of this book from http://www.fibromyalgia-support.net/book

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Knowledge and information. Free, Unbiased Sources of Information for Fibromyalgia sufferers, their partners and carers.