

# Coping, Caring and Communicating

*When someone  
you love has  
Ankylosing Spondylitis*



*Solace for those  
supporting AS Sufferers*

# **Coping, Caring and Communicating**



## **When Someone You Love Has Ankylosing Spondylitis**



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# Introduction



This book was written to help family and friends who love and care for people with Ankylosing Spondylitis ("AS"). AS is a debilitating disease for which modern medicine has no cure. Those afflicted with AS ("AS Sufferers") cope with tremendous physical and emotional pain. Consequently, you (the "AS Comforter") also bear a significant emotional burden from the disease.

It's hard to sit back and watch a loved one face the emotional and physical ups and downs of AS. It's like walking on a frozen lake in early spring; with each step you wonder if you'll remain on solid ice, if the ice will crack or if you'll fall perilously into the lake.

Ankylosing Spondylitis can be the source of marital problems, depression that afflicts an entire household, and financial devastation. Sometimes AS goes undiagnosed for years, creating stress and emotional pain well before you even know just what you're dealing with.

As you well know, daily life for friends or family members can be exacting. You might "walk on eggshells" each day, wondering how bad tonight's pain will be for your loved one, when the next major flare-up will occur or how to deal with the side effects of a new medication. You see mood swings, changes in personality, frustration and stress affecting your loved one with AS.

You also know and experience the plain fact that the closest people to AS Sufferers are most often the target of emotional upheaval rooted in the disease.

This book is designed to help you navigate the day-to-day emotional ups and downs caused by AS. It offers guidance to assist you in keeping your own stress at bay—to remain sane in what sometimes seems an insane situation.

The tips and techniques in this book will help you:

- ◆ Improve your relationship with the AS Sufferer.
- ◆ Reduce and avoid conflicts rooted in chronic disease.
- ◆ Improve your level of happiness so you can offer more empowered support to your AS Sufferer.

Each person's experience with AS is unique. Still, there are feelings and behaviors common among AS Sufferers. Similarly, AS Comforters face typical challenges and emotions. In the proper handling of these challenges we find wisdom and empowerment to navigate the “icy lake” as lightly as a feather.

For an AS Comforter, YOUR emotional health is the critical component of YOUR physical and emotional well-being. The importance of emotional health cannot be understated, for both you and the AS Sufferer.

The key to creating a happy and harmonious life lies in improving your own emotional psyche, transforming the emotional pain that comes from being in the inner circle of an AS Sufferer.

This book provides the tools to help you improve your emotional state and boost your health and happiness. You become a more effective supporter, teacher, sounding board, and role model for a loved one with AS.



## SECTION I:

# Setting the Stage For Success



## A Story of Suffering

Emily is married to Michael who was diagnosed with AS five years ago. Michael's AS causes debilitating pain that typically attacks at night and often keeps him from getting a good night's sleep. During the day, he works in an office, where he experiences mild discomfort throughout the day. He rates his pain most often at about a four or five. Michael feels unable to function properly in the "normal" world on a daily basis because of his pain. He rarely enjoys going out, and he sometimes feels isolated from the outside world. Three or four times a year, Michael experiences a drastic flare-up. During these episodes, sleeping is more difficult or even impossible; his pain ratchets up to around nine. Anti-inflammatory drugs are part of his plan, but Michael has to add narcotics or heavy alcohol consumption during flare-ups to bear the pain. It can take a week or more to return to his "normal" routine.

Michael feels AS has taken over his life. He meets with his doctor bi-monthly to review and adjust his medications. Michael has settled into a tortured existence of pain and uncertainty. He's convinced this is how it will be for the rest of his life.

*Michael is not happy, and he's certainly not living the life he once envisioned for himself. As he sees it, the life he knew before AS is over. He has lost his passion and ambition; he can be moody or irritable and he often feels isolated and alone.*

*Emily's life has turned upside down too. She loves Michael, but it can sometimes seem like he's not the man she fell in love with years ago. He's certainly not the same man he was before AS. Emily's life is consumed with constant worry over Michael's condition, medications, doctor appointments and frightening moods. Her sleep depends on what kind of night he's having; her happiness is affected by his daily moods. She lives with constant fear and dread of the next major flare-up.*

*Most of all, Emily wonders what she can do for the man she loves. She wants to help him with his challenges, but she often feels helpless.*

Like Michael, Emily is a victim of AS. She may not feel the physical pain, but she experiences a great deal of emotional suffering.

This is a common scenario for those who love and support a person with AS.





## **A Letter to Supporters**

A letter from AS Sufferers to AS Comforters:

*Dear Loved Ones:*

*AS has taken root in our bodies. Illness has turned our lives upside down. It's robbed us of the lives we dreamed of.*

*It feels like we have no control...*

*We are hurt and angry...*

*We feel powerless.*

*You cannot understand how unbearable the pain can be. Sometimes it's mind-numbing agony. You cannot truly know how difficult it is. It's not your fault, and we do not hold you responsible for any lack of understanding.*

*We're sorry that illness has turned your lives upside down too. Every day, we try to adjust to our own lives and accept our limitations. There are people who face more difficult challenges than we do. Life is not over, but it's changed in a major way.*

*We know you are trying help.*

*We know you don't want us to be in pain.*

*We know you wish we could be like we once were.*

*We are sorry for the burden we place on you.*

*We are sorry we often take our frustration out on you.*

*Always, we are infinitely appreciative of your endless support.*

## Perspective

Let's review some of the feelings commonly encountered by AS Sufferers.

Many AS Sufferers experience feelings of:

- ⇒ Devastation due to changes in future plans, finances, work, family life and relationships.
- ⇒ Hopelessness, sadness and mourning, as life is forever changed.
- ⇒ Envy of those whom they perceive to have a much better life than their own.
- ⇒ Powerlessness over their condition and pain.

Attention to these intrinsic feelings helps you remain supportive, receptive, respectful, kindhearted and understanding.

## Coping Mechanisms

An AS Sufferer's method of coping may be to retreat into solitude, exhibit despair, display anger or show apathy. Whatever the chosen coping strategy, it is usually the result of *feeling powerless*.

The objective is to notice how they cope with the situation. Do they choose to retreat into solitude by keeping their pain and emotions to themselves? Do they tend to take their frustration out on you by picking fights or lashing out?

It helps to realize that AS is the cause of the solitude, despair, anger or apathy you witness. These behaviors aren't meant to be

a personal attack on you, so recognize the behavior as a means of coping. You must learn to respect the sufferer's chosen method of expressing pain; then you can begin to foster an environment for improvement.



END OF EXCERPT

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