

Psychological Coping With Inclusion Body Myositis (IBM)

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Part 1: IBM – The Good and the Bad.

- The Good:
 - IBM is not considered a fatal disease.
 - IBM does not impair thinking functions.
 - IBM progresses slowly, giving you time to adapt.
 - A well designed exercise program probably helps.
- The Bad:
 - IBM impacts and impairs movement in the hands, arms, and legs, making daily activities very difficult.
 - Serious side effects can become major issues if not managed properly: falling, swallowing, breathing, swelling in the feet.
 - There is no genuine medical treatment: no drug.

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Introduction.

- In this presentation we will discuss the role of experience, information and research in coping with inclusion body myositis (IBM).
- There are many common aspects to IBM, however, each individual case presents its own unique features and challenges.
- This is a *general* talk, not everything will apply to you, some of *your* issues may be left out.
- The impact of IBM is unique for each of us:
 - People *experience* their illness in a unique way.
 - People *react* to their illness in a unique way.
 - People learn how to *cope* in a unique way.

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One Question, Then Many.

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- The first question people usually ask:
 - “What’s wrong with me?”
- Over time, people ask many more questions on their long and slow process of diagnosis.
- People usually start from zero – never heard of IBM; have no experience with it.
- People must find their own “information comfort level,” how much do you want/need to know?
- Because IBM has no effective treatment:
 - “If there’s no medication to take, what do I do now?”

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No Cure, What Now?

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- IBM is complex and chronic. Currently, there is no effective treatment or “magic” cure.
 - Current focus: on *management* – how can we learn to make the most out of life with this illness?
- Our reaction & response has a major impact on how we will live and cope with our illness.
- If we can play an active and positive role, we can better cope with the dis - ease of our body.
- Experience, information, and learning are major factors in how well we cope with things.

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Many Factors Are at Play.

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- Many factors shape the psychological impact of having IBM:
 - Here are a few:
 - When did symptoms emerge?
 - How does it affect *you* physically?
 - What impact does it have on your lifestyle?
 - What impact does it have on your mobility?
 - What impact does it have on your overall health?
 - How fast does it progress in you?
 - What supports do you have?
 - Family, medical team, spiritual, psychological, other?
 - How do you see your illness; your life now?
 - Depressed, hopeless, realistic, positive, stoic?

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Many Aspects of Life Are Affected. ⁷

- What *isn't* affected by IBM?
- Some of the major aspects involved:
 - How we now see our Self and how we see our life (our thinking, attitudes and our feelings)
 - Independence (mobility / movement issues)
 - Primary Relationships (parents / partner / children)
 - Social Relations (friends / family / co-workers)
 - Lifestyle (our day-to-day life routine)
 - School and educational choices
 - Finances: having a disability is expensive
 - Career (job changes, long-term disability)
 - Home and environment (house / car / etc.)
 - Caregivers (both paid and unpaid)

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Personal, Family, Medical and Social. ⁸

- There are 5 critical areas involved in coping:
 1. Personal: Our own internal psychological coming to grips with our illness.
 2. Family: Our partner and family are usually critical players. [However, many do not have family support.]
 3. Medical: Dealing with the medical aspects of our illness and interacting with our medical team.
 4. Social: Dealing with other people in our life:
 - Extended family,
 - Friends,
 - Co-workers.
 5. Eventually, dealing with Caregivers.

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Personal: A Private Issue. ⁹

- We alone must face up to the fact that we are ill and that our life and lifestyle will change.
- Whether you are alone or have family support, this is largely a personal and private process.
- Others can help us, but ultimately, we must "come to grips with it" on our own terms.
- How we see our illness is critical to our subsequent attitude and this is critical to how we will react and cope over the long term.
- Coming to grips is a *process* that occurs in bits and pieces over time.

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Being Alone. ¹⁰

- Many of us will find ourselves dealing with IBM alone, with no spouse or family support.
- Being alone will make it harder to stay positive and to be motivated to look after yourself.
- It's easy to get stuck in negative thinking and to just give up when you are alone.
- When alone, reaching out to other IBM patients in support groups can be a critical support.
- Your doctors need to know you are alone, and how you are feeling – they may be able to help.

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Family: As You Go, so They Go. ¹¹

- Families are often sources of strength for us.
- Our illness/symptoms has a direct impact on those who love us: spouses, parents & children.
- Spouses must take on new roles as caregivers: a new, complex & very demanding task.
- Spouses often reflect the factors mentioned here but their reactions often go unrecognized.
- Caregiver stress is a huge & unrelenting factor.
- The “patient” and the family should be seen as a unit, neither exists in isolation of the other.

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Family: Spouse Acting as Caregiver. ¹²

- If your spouse takes on the role of caregiver, the extra tasks may become too much.
- As your function becomes limited, your spouse must do more: but, they can only do so much.
- Burnout is physical & psychological exhaustion.
 - Recognition & prevention of burnout is critical.
 - Once burnout occurs it is very hard to recover.
- Good communication is absolutely critical:
 - You both need to plan for the long term, often, eventually, needing to bring in extra help.
 - Built in regular rest periods for spousal caregivers.

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The Medical Aspect.

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- Our medical *team* is a major, ongoing part of coping; finding the *right* team for you is critical.
- The care, compassion and advice of the team is vital, *especially* in “untreatable” conditions.
- Feeling that the team is there and understands is an important support for the patient.
- Doctors “know” about illnesses but don’t have the “wisdom” gained from experiencing them.
- Doctor’s tools: caring, compassion & science.
- Doctors help give us a context for our illness.

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Social: Dealing With Others.

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- “But you don’t look SICK.”
- It is hard for our extended family, friends and co-workers to understand our illness:
 - IBM is not obvious to others – not like a broken leg.
 - Our illness may affect others in unexpected ways – friends may leave.
- We need to educate others about IBM.
- We have to tell “our story” over and over.
- In telling others, we also help ourselves cope.
- Overly ‘helpful’ friends may be a problem: everyone seems to have advice or a “solution.”

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Corresponding Information.

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- Personal/Family: Many types of information can help us develop insight and the strength that we need to face and manage this illness.
- Medical: Medicine is like a foreign language.
 - How much do we need to learn to “get by,” to understand and to talk to the doctor about the diagnosis and our management options?
- Social: “*What’s wrong with you?*”
 - Information helps us to effectively relate with other people and helps us give them a context to understand our situation and the unique challenges we face.

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Different Levels & Types of Information. ¹⁶

- How *much* do you need to know:
 - Set your own balance: don't be afraid to learn, but don't feel forced to learn more than you want to.
- *What* do you need to know:
 - General information on coping with a chronic illness, disability and living a good life ("self-help").
 - Specific information about IBM.
 - Information written for a general audience.
 - Information written by experts; very specific and complex.
- A wide variety of all types and levels of information is readily available today:
 - Patient groups, our medical team, the Internet, books, various not-for-profit associations.

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Information AND Support. ¹⁷

- Seek out an IBM support group:
 - Most people struggling with IBM face many of the same challenges as you do.
 - Talk to others about their experiences and their challenges. How THEY cope may give you ideas about how YOU can cope (and also inspire you).
 - Other people are a great source of information, practical advice and emotional support. Don't be afraid to talk to people about IBM.
 - Example – Inclusion Body Myositis Support and Understanding (Private Facebook group):
<https://www.facebook.com/groups/inclusionbodymyositis>

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Knowledge and Experience. ¹⁸

- A balance of information we learn, combined with our own practical experiences is likely the best approach.
- Coping involves a lot of practical experience that we learn from living life with IBM.
- Practical knowledge that we can learn from other people we talk to is also important.
- Remember: Take it one step at a time and take your time, "learn as you live."

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Part 2: Three Phases We All Share. ¹⁹

- We all go through three basic phases:
 - 1). Before diagnosis (BD): uncertainty/anxiety:
 - We have symptoms but we don't know what's wrong yet.
 - Doctors are often initially skeptical of our "story."
 - 2). Diagnosis (D): frustration/confusion:
 - Experience has shown – IBM diagnosis is not a straightforward and smooth process.
 - All muscle diseases are very difficult to diagnose.
 - Often a long, frustrating, and difficult process.
 - 3). After diagnosis (AD): often, many mixed emotions:
 - Long-term management begins.

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BD What could that be from? ²⁰

- As symptoms slowly develop, we come to see that something is wrong.
- A few common reactions during this period:
 - Denial: ignore problems; pretend nothing is wrong.
 - Uncertainty: creates feelings of fear and anxiety.
 - Catastrophize: we imagine the WORST it could be.
 - Guilt: "I must have done something to cause this."
 - Superstition: "If I just do *this*, it will go away."
 - Crisis: feelings, fears and anxiety can build up and burst into crisis – "yep, I'm having a meltdown".
 - Loved ones: You must be aware of the feelings, fears and anxieties your family feel over your health.

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BD "Everything's O.K. vs I'm sick." ²¹

- The phase before diagnosis is commonly a period of ambivalence:
 - We go back and forth in our imagination from: "I'm O.K." to "OH MY GOD, I REALLY AM SICK."
- This is often a period of being frozen: we feel "stuck" and often don't seek help immediately.
- "Sometimes it is better not to know" versus "Whatever it is, I have to face it."
- It takes a lot of courage to end this phase by going to the doctor(s) to find out what's wrong.
- The medical system is complex and hard to deal with, especially with a serious illness.

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| BD | Different Doctors. | 22 |
| <ul style="list-style-type: none">Patients with IBM often must see a confusing series of doctors.<ul style="list-style-type: none">Most patients start out with their family doctor and are then referred to a specialist.Some patients will see a rheumatologist, some will be referred to a neurologist and many see both.Different types of doctors will have different approaches and this can be confusing.Often, a patient is sent to a specialized clinic or hospital for diagnosis and testing.Some clinics also do research on IBM.On average, it takes <i>five years</i> to get a diagnosis. | | |

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| BD | Differing Opinions. | 23 |
| <ul style="list-style-type: none">Seeing multiple doctors can be frustrating: each may have a different idea about what's wrong and what to do about it.<ul style="list-style-type: none">Different <i>types</i> of doctors will approach us from different perspectives based on their training.Two doctors may make a different diagnosis, often with the same degree of confidence.It can be hard for us to deal with different opinions and recommendations.Talking to other IBM patients about their journey may help you navigate yours. | | |

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| BD | "Diagnosis is not easy." | 24 |
| <ul style="list-style-type: none">IBM is well known as being hard to diagnose. Many disorders have very similar early symptoms and many people are initially misdiagnosed (often seen as polymyositis).There are two major aspects to a diagnosis:<ul style="list-style-type: none">Clinical: Doctors examine us and ask questions.Tests: Blood tests, special tests, biopsy, etc..When facing any major illness, it is wise to get a second opinion, both of the clinical aspects and of the test results. | | |

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| BD | The Need to be Heard. | 25 |
| <ul style="list-style-type: none">▪ “I’m not crazy . . . and I’m not just lazy”.<ul style="list-style-type: none">▪ We use this quote for a reason: because sometimes people are initially “put off” by doctors as “imagining things” as “being lazy” or as simply “getting old.”▪ You know your symptoms and you know when something is wrong, no matter how strange it sounds.▪ Sometimes describing <i>exactly</i> what’s wrong is hard.<ul style="list-style-type: none">▪ Your symptoms have come on slowly over time and usually have changed – no single clear picture. | | |

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| BD | Diagnostic Frustrations. | 26 |
| <ul style="list-style-type: none">▪ Diagnosis is a complex mixture of evidence and the doctor’s experience, attitudes and intuition.▪ It seems that many people encounter various “roadblocks” in getting their diagnosis.<ul style="list-style-type: none">▪ Try not to get emotional: always focus on the facts.▪ Don’t take it personally: try to be professional.▪ Consistently return attention to the questions, evidence and issues that are important in weighing your particular case.▪ Many IBM patients go through similar experiences – talking to them will help you deal with frustrations and empower you to get an accurate diagnosis. | | |

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| BD | Hard Diagnostic Choices. | 27 |
| <ul style="list-style-type: none">▪ You may have to make choices in diagnosis.<ul style="list-style-type: none">▪ Should I ask to have a second opinion?▪ Should I have that extra expensive test done?▪ What if the Doctor suggests I try a treatment? Management options? Try a clinical trial?▪ Doctors will summarize information, however, in the end, the patient must make the choices.▪ We may need a “crash course” to be able to know what to do:<ul style="list-style-type: none">▪ We often need help understanding some of these choices. | | |

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| AD | After Diagnosis. | 28 |
| <ul style="list-style-type: none"> ▪ We need an ongoing and open relationship with our medical team after our initial diagnostic phase is over: <ul style="list-style-type: none"> ▪ IBM is dynamic: as it progresses, things change. ▪ We need to continue to monitor our symptoms as they unfold with the following questions in mind: <ul style="list-style-type: none"> • Was the initial diagnosis right? • Emerging complications: detected & dealt with? • New tests may come out, do they apply to me? • Ongoing implications for physical rehabilitation? • Practical occupational and home care advice? • An individually designed exercise program? | | |

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| AD | Your Role as Self-advocate. | 29 |
| <ul style="list-style-type: none"> ▪ You are the <i>constant</i> element in your case. ▪ You must be a firm and consistent <i>advocate</i> for yourself, especially during the diagnostic phase. ▪ An IBM diagnosis has many implications: <ul style="list-style-type: none"> ▪ People need time for the diagnosis to “sink in.” ▪ Many people will want to learn about the illness. ▪ People need to think about the implications of this illness for themselves and their family and, if necessary, return to the doctor to ask questions that come up. ▪ If you are alone and without family, being a self-advocate is harder but may be <i>more</i> important. | | |

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| AD | Self-education. | 30 |
| <ul style="list-style-type: none"> ▪ We need to “let the doctor be the expert,” however, a major trend in medicine is patient involvement – we need to understand enough to help us make informed decisions about our care, based on the evidence (another trend). ▪ Many people now believe that patients should learn all they can about IBM. ▪ Getting involved with other IBM patients for information, ideas and support may be critical. ▪ Participating in research is an empowering way to help other IBM patients, and helping others also makes us feel good. | | |

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| AD | Treatment Dilemmas. | 31 |
| <ul style="list-style-type: none">▪ In spite of the advances of “modern science” IBM is not well understood and the consensus today (2021) is that no treatment is effective.▪ “It doesn’t matter, there’s no treatment anyway.”▪ No “treatment” does not mean no help – we need advice and support from our medical team as we learn to cope and adapt to our situation, often with special equipment and extra help.▪ Both the patient & the doctor need to deal with these issues and both need a positive attitude of “compassionate and supportive realism.” | | |

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| AD | Bad medicine, bad advice. | 32 |
| <ul style="list-style-type: none">▪ We need to use good, logical judgement – not emotion, in making decisions about what to do.▪ There is no recognized medication to treat IBM.▪ Many of us will feel desperate to try something.<ul style="list-style-type: none">▪ This makes us very vulnerable to get involved in all kinds of “miracle cures,” diets, supplements, etc.▪ People may give us advice based upon what they <i>believe</i>, stories they’ve heard, etc. but no real proof.▪ The best path is: follow medical advice: a healthy diet and lifestyle, avoid “quack” remedies, and a <i>supervised</i> exercise program. | | |

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| AD | Specialized Equipment. | 33 |
| <ul style="list-style-type: none">▪ Patients must be VERY careful when buying equipment: this market has a bad reputation.▪ It seems that many times, poor or wrong advice is given (sometimes just to make a sale?).▪ Equipment is very expensive and to be right, it needs to meet your needs; not just for today – remember your needs will change over time.▪ You will need to find a trusted vendor(s) to work with you and your health care team to determine just what you need, when you will need it, how and where to get it, and pay for it. | | |

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Part 3: Psychological Stages.

- As physical symptoms progress, people are also affected psychologically.
- No single pattern of stages people go through:
 - Rates of *physical* progression vary widely.
 - Age of onset varies widely.
 - The pattern of weakness varies widely.
 - Our personality, attitudes and view of life impact how we see and deal with IBM.
- As a result, each of us generally goes through slightly different steps in psychologically adjusting to, and living with, IBM.

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Anxiety: What Will Tomorrow Bring?

- Often, people imagine what might happen tomorrow and develop strong anxiety over it.
- People with IBM may fixate on “future anxiety.”
- Many try to deal with this anxiety using denial.
- Controlling “future anxiety” is the hardest point discussed here and it is critically important:
 - Knowledge can help ground a runaway imagination.
- We need to focus on today and live for today:
 - We need to learn to relax and let the future unfold, and to “take life one day at a time.”

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Life Challenges.

- IBM has a very disruptive impact on lifestyle.
- Many day-to-day routines are affected:
 - Bathroom and bedroom are key areas: activities we now take for granted may drastically change.
- Complications must be watched for/managed.
 - Weak swallowing may develop, leading to choking.
 - Weakness in breathing (diaphragm) may develop.
- Outside caregiver help will often be needed.
- It is a major challenge to see that you need, and to get, the right equipment at the right time.
 - Examples: walkers, wheelchairs, home renovations, ceiling lifts, shower chairs, handicap vans, etc.

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Multi-Management.

- A muscular illness challenges us to organize and manage our lives more effectively.
- There are many different aspects to living life and most are affected by IBM.
- Coping involves learning how to manage many different aspects of life with a chronic illness.
- The next few pages describe aspects involved in an overall approach to managing life:
 - What do you need to do to make these steps a success?

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Life Management.

- IBM calls on us to be excellent life managers.
- Everything we do takes longer, is more difficult, and uses much more energy.
- Great advance planning is our best defense.
 - Progressive movement disorders call for ongoing adaptations: e.g. house modifications, transportation.
 - We need to increase efficiency, reduce redundancy and generally be very well organized in all we do.
- Several aspects require a dual focus:
 - Activities in the house / activities when going out.
 - What we can do ourselves / where we need help.
 - Time management / managing activities.

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Stress Management.

- Stress (whatever causes it) creates a complex series of mental & physical impacts on people.
- Stress is normal, but two types are harmful:
 - Short periods of very strong stress (acute stress).
 - Moderately raised stress for a long time (chronic).
 - People with IBM must be aware of stress and learn to manage it.
 - Working with a therapist may be very helpful.
- Mental aspects: part of the solution (how we see our stress, learn to cope/relax, our attitude).
- A healthy physical lifestyle: part of the solution (Smoking? Drinking? Diet? Proper exercise?).

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Health Management.

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- Many factors contribute to our overall health:
 - Genetic factors: interact with our environment.
 - Environment: what we do, all that is around us.
 - Social: psychological and emotional well-being, stress, support network (family, friends, medical team, psychologists).
 - Diet: amount & type of food, hydration, exercise.
 - Nicotine, alcohol usage, all types of drug usage.
- We need to be very aware of our overall health status — our “health quotient.”
- We must develop positive practices and minimize factors harmful to our overall health.

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Major Lifestyle Choices.

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- Life, health and stress management often involves many lifestyle choices and changes:
 - Often major and very hard choices:
 - Stop smoking, lose weight, reduce alcohol, etc.
- People with chronic disorders need to put these changes into the context of their illness:
 - Balance and weigh changes against our goals:
 - What is our central goal in making hard changes?
 - To maximize our quality of life.
- The choices we each face will be different depending on our situation: we all must try to make positive changes that will improve life.

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Blame.

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- Blame is a common reaction when you feel bad, or when something bad happens to you.
- Blaming IBM on “X” may make you feel better.
 - Medications you used, things in your life (“new carpet in the house”), blame high life stress, etc.
- People often blame themselves, causing guilt.
- It is hard to accept, but: the triggers of IBM are likely beyond anyone’s control, or prevention.
- Blaming something or someone for one’s illness is ultimately simply a waste of valuable energy, and often leads to frustration and bitterness.

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Acceptance.

- No one *wants* to be ill, it is not something that we would choose.
 - However, we were not given a choice – this is the way it is: “It is what it is.”
 - I am *still* me, I *have* IBM – don’t let IBM define you.
- How we “see” this and deal with it, makes a big difference to the kind of life we will live.
- Accept that life will change and be different and adapt to get the most out of life as it unfolds.
 - Acceptance and adaptation are hard and take time – may occur in small steps for the rest of your life.
- Coping with IBM challenges us to face, and to rise above, many everyday problems.

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IBM and Falling.

- Many patients with IBM will experience falls.
- IBM makes the muscles in the legs unstable.
- Falls occur unexpectedly – you hit the ground in an instant: lose balance or legs give out.
- Many are *injured* from falls, some seriously.
- Fall prevention is critical but complex.
 - Keys: Awareness, Attention, Attitude.
 - Like any complication, we must be *aware* of the danger
 - Must be open to use a brace, cane, walker or wheelchair.
 - Must pay close *attention* – in the bathroom, bedroom, on uneven ground, stairs: prevention is better than an ER visit.
 - *Attitude* is critical to awareness and attention.
 - We see many broken bones from “false pride” and denial.

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IBM and Pain.

- Medical papers do not mention pain in IBM.
- Many patients with IBM report having pain.
- As IBM affects muscle, it becomes brittle and inflexible: stretching may cause pain.
- Pressure on the muscle may cause pain.
- Some patients report constant muscle pain.
- As IBM progresses, the flexibility and range of motion of the limbs is reduced; pain may result.
- Being in one position for a long time may cause pain, for example, when sitting or sleeping.

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IBM and Feeling Tired.

- IBM patients often feel “very tired all the time.”
 - May lead to exhaustion/burnout – more serious.
 - Fatigue: often reduced motivation and energy.
- Tiredness can sometimes cause depression, or, it may be a symptom of depression.
- Overactivity can lead to several days of exhaustion and a slow recovery of energy.
- Tiredness needs to be taken into consideration ahead of time when planning activities.
- Do not plan too many activities in one day.
- If you overdo it, stop and let yourself recover.

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Emotions.

- “Is it normal to feel this way?”
 - No matter how you feel, it is a normal reaction for *you*. There are no “right” or “wrong” feelings.
- Roller coaster: We will all have a wide range of feelings, some positive, some negative.
 - It is important to try to be open to both our happy and sad feelings and to try not to deny them.
- To experience *all* of our feelings is a natural and important part of our lives and learning.
 - Important to get through and rise above bad times.
 - Have gratitude and appreciate the good times.
 - Focus on the positive more than the negative.

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Sadness versus Depression.

- Sadness is a normal emotion in response to something that makes you feel unhappy.
- Sadness is a brief feeling, it lasts a few hours or a day or so. It’s normal: we all feel sad at times.
- Depression is a longer, deeper feeling of being empty, down, hopeless, etc. Lasts at least a few weeks; involves broad, negative changes in outlook. May develop into a major problem.
- A continuum:







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Minor Depression: A Major Factor. ⁴⁹

- Mild, brief bouts of anxiety and depression are common and expected when faced with IBM.
- Let yourself “live/work through” these feelings: it’s O.K. to feel down sometimes, however:
 - Take things one small step at a time.
 - Try not to focus on the bad or negative aspects.
 - Appreciate and focus on gratitude for the positive.
 - Try to turn “negative feelings” into positives: if you feel sad, what is a positive action you can take to deal with it? A positive attitude is your best asset.
 - Spend more time doing things that make you happy.

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Major Depression: A Medical Problem. ⁵⁰

- The red flags of major depression:
 - Length: lasting for more than 2 weeks.
 - Intensity: deep negative feelings, loss of hope.
 - Impact: normal, routine life activities are disrupted:
 - loss of appetite, feeling exhausted, loss of motivation, lack of focus, feel hopeless, see no future/no solutions.
 - Thoughts of self-harm or suicide.
- Mention depression to your medical team.
- Counselling is a good idea for those with IBM and is often effective in dealing with depression.
- Many are helped by taking medication.
- Do not suffer in silence: talk to someone.

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IBM and Death. ⁵¹

- With proper medical management, *most* IBM patients will die *with* IBM, not *from* IBM:
 - IBM is not considered a fatal disease.
 - Complications are *usually* not fatal if well managed.
 - IBM is a disease of aging; as we age, various other health issues tend to arise that may lead to death.
 - The average person dies of: 32% cardiovascular, 25% cancer, 9% dementia, 7% respiratory, etc..
 - <https://ourworldindata.org/what-does-the-world-die-from>
- IBM complicates one’s other medical issues.
- Our medical team must manage our illnesses.
- It is wrong to see IBM as a death sentence.

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Suicide.

- IBM often has drastic impacts on one's life.
- For some, suicide may seem like a solution.
 - Suicide usually has great impacts on families.
 - A suicide attempt may fail: end up worse off?
 - Are your feelings from depression, or, a realistic appraisal of your physical situation and illnesses?
- If your feelings are from depression there may be treatments that may help you.
- If you have reached the point where you cannot go on, then reaching out to others for help would seem like the best step to take.

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End-of-life Options and Choices.

- Depending upon where you live, there may be options your medical team may be able to offer you to make your passing easier.
- In some cases of IBM, especially those involving severe complications, it may be helpful to explore end-of-life options. There *are* better choices available than suicide.
- As you age and as problems add up, it is important to discuss the various end-of-life options with your family and your medical team.
 - Like the security of having a will, this planning may help reduce the stress and anxiety of your passing.

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Compassion.

- Have compassion for yourself.
- Have compassion for others in your life and for their stress, anxiety and problems.
- Encourage others to be compassionate:
 - Many people simply are uninformed about illnesses.
 - Education overcomes ignorance.
- Become a "calm but strong" advocate for yourself and others, not just for the ill, but for everyone you meet.

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Resources.

- Many people “sell themselves short.”
- We often have more resources than we think:
 - Both *inner* resources and resources within our network – family, medical team, caregivers, etc.
- The most important resources we have are:
 - Ourselves, our families.
 - Our intelligence, common-sense and personality.
- I am still me, (albeit, me with IBM):
 - I have not lost myself and become my illness.
- Remember: Our resources are greatly influenced by our attitude – how we see life.

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Abilities.

- Who is “able”? Who is “disabled”? Who decides?
 - Two aspects:
 - how others see us (we can’t control this),
 - how we see ourselves (we can control this).
- Many of us are very *different* but still very *able*.
- Don’t be too quick to put yourself into the “disabled category.”
- With IBM, abilities will change, however, with the right attitude, we can still be very happy and able individuals.

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Adapting to Change.

- The impact of change depends a lot on how we look at change.
- Change often presents opportunities for growth.
- We need to look for the positive, “silver lining.”
- We need to see what is under our control in life.
- We need to adapt to what we can’t change.
- Try to see change as a learning opportunity.
- Adapting to change is an ongoing part of life, especially as people age and deal with IBM.

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Doors Close, Others Open.

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- As people get older, everyone’s life changes.
- As our health changes, we will need to curtail some of our activities.
- For each activity you have cut back on, try to find a new one to begin.
- Our lives will change more than most, so we need to focus more than most on coping with changes.
- We need to (and can) become experts at coping and adapting.

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The Big Picture.

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- We ended up having a very strange and very rare disease that has no known cause and no available treatment.
- We had no control in getting this disease.
- We do have control over how we see ourselves and how we deal with the impacts of IBM.
- IBM causes a slow but sure decline in our ability to move and to do things: a very challenging and always changing situation.
- Our happiness will depend on how well we can deal with and adapt to these changes.

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Further Information.

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- <https://www.hopkinsmedicine.org/health/conditions-and-diseases/inclusion-body-myositis>.
- <https://www.mda.org/disease/inclusion-body-myositis>
- <https://www.myositis.org/about-myositis/types-of-myositis/sporadic-inclusion-body-myositis/>
- https://en.wikipedia.org/wiki/Inclusion_body_myositis
- <https://understandingmyositis.org/myositis/inclusion-body-myositis/>
- <http://www.ibmmyositis.com/>

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