Encountering Neuromuscular Illness

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Introduction.

- In this presentation I will discuss the role of experience, information and research in coping with a Neuromuscular illness (NMI).
- There are many general aspects to NMI, however, each specific type of illness also presents its own unique features & challenges.
- The impact of NMI is also 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.

Information.

- Information & research play critical roles in advancing science & understanding disease:
  - Information can also play a major role for patients.
- Information and coping go hand in hand.
- Aspects of coping with a NMI are covered in more detail at:
  - This site also presents basic medical information in everyday language:

    http://members.shaw.ca/copingwithillness/
- If you have any questions or comments, please contact me at e-mail: btillier@shaw.ca

One Question, Then Many.

- The first question people usually ask:
  - “What’s wrong with me?” (or with my child)
- The next question people often ask:
  - “Is there a treatment or cure for it?”
- Over time, people ask many more questions & embark on a long & slow process of discovery.
- People usually start from zero – never heard of these diseases, have no experience with them.
- People must find their own “information comfort level,” how much do you want/need to know?

We Need to Ask the “Right” Questions.

- Take some time to formulate good questions:
  - People may fixate on “poor” questions & get frustrated:
    - “Why did I get sick?” “Why me?”
- Asking good questions is a critical step:
  - Is the question reasonable, does it have an answer?
  - What kind of information is needed? Who do I ask?
  - How is this question important to me? To my case?
  - If I get an answer, how much will this help me?
- Use an investment strategy:
  - Invest in the question based upon the return you project in finding an answer.

No Cure, What Now?

- NMIs are complex and chronic. Currently, most don't have effective treatments or "magic"cures.
  - 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 and knowledge are major factors in our response and in our coping.

Many Factors Are at Play.

- Many factors influence the impact of a NMI:
  - Here are a few:
    - When did symptoms emerge?
    - How does it affect you (or your child) physically?
    - What impact does it have on your lifestyle?
    - What impact does it have on your mobility?
    - What impact does it have on your basic health?
    - How fast does it progress?
    - Is it treatable?
    - What impact does treatment have?
    - Does the specific illness go into remission?
    - Does the illness lead to premature death?

Many Aspects Are Affected.

- What *isn't* affected by neuromuscular illness?
- Some of the major aspects involved:
  - How we see our self and and how we see 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
  - Career (job changes, long-term disability)
  - Home and environment (house / car / etc.)

Personal, Family, Medical and Social.

- There are 4 important areas involved in coping:
  - 1. Personal: Our own internal coming to grips with our illness.
  - 2. Family: Our immediate family are critical players.
  - 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.

1) Personal: A Private Issue.

- We alone must face up to the fact that we are ill (or that our child is ill) and that our life and lifestyle will be affected.
- 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 in the long term.

2) Family: As You Go so They Go.

- Families are great sources of strength for us.
- Our illness/symptoms have a direct impact on those who love us: spouses, parents & children.
- Spouses (or parents) must take on new roles as caregivers: a new, complex & 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.

3) The Medical Aspect.

- Our medical team is an ongoing aspect of our dealing with our illness.
- 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 these illnesses but don’t have the “benefit” of experiencing them.
- Doctor’s tools: caring, compassion & science.
- Doctors help give us a context for our illness.

4) Social: Dealing With Others.

- “But you don’t look SICK.”
- Our extended family and friends often have a hard time dealing with our illness:
  - Our illness may have a strong impact on them, may affect them in unexpected ways and may be quite difficult for them to deal with – friends may leave.
- We often need to educate others about illness.
- We have to tell “our story” over and over.
- In telling others, we also help ourselves cope.
- Overly ‘helpful’ friends may be a problem.

Corresponding Information.

- 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 treatment/management options?
- Social: "<u>What's</u> wrong with you?"
  - Information helps us to effectively relate with other people and to help us give them a context to understand our situation.

Information: A Very Personal Factor.

- Knowledge and information play different roles for different people and in different cases:
  - There is a wide range of “knowing enough.”
- You may need to know very little or a great deal, what is important, is what is right for you:
  - Set your own balance: don’t be afraid to learn, but don’t feel forced to learn more than you want to.
- Knowledge sets the stage:
  - We need to know enough to allow us to feel O. K.
  - Too little, or too much info. may cause anxiety.
  - Our emotions are our ultimate & critical guide.

No One Pattern of Stages.

- NMI are often insidious, coming on slowly.
- As physical symptoms progress, people are usually also affected psychologically.
- There is no one pattern of stages for everyone:
  - Stages are different depending on factors like:
    - Age of onset – especially child versus adult.
    - Our unique personality, attitudes and view of life.
- As a result of these types of individual differences, each of us go through slightly different stages, at different rates and sometimes, in different sequences.

Three Phases We All Share.

- We all go through three basic phases:
  - 1). Before diagnosis:
    - We have symptoms (or we see symptoms in our child) but we don’t know what’s wrong yet.
  - 2). Getting diagnosed:
    - Often a long, frustrating and difficult process.
  - 3). After diagnosis:
    - Long-term management.

Phase 1: What could that be from?

- As symptoms slowly develop, we come to see that something is wrong.
- A few common reactions during this period:
  - Uncertainty: creates feelings of fear and anxiety.
  - Denial: ignore problems and think nothing is wrong.
  - Catastrophize: we imagine the WORST it could be.
  - Guilt: “I must have done something to cause this.”
  - Superstition: “If I just do this, I’ll get better.”
  - Blame: look for a scapegoat.
  - Crisis: feelings can build and erupt into crisis.

“Everything’s O.K. vs I’m sick.”

- 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’M REALLY SICK.”
- This is often a period of immobility: 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 to find out what’s wrong.

Phase 2: Different Doctors.

- Patients with NMIs may see a confusing series of doctors.
  - Most patients start out with their family doctor and are then referred to a specialist.
  - Some patients will then 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 NMIs.

Scientific Research.

- New information on NMI is coming out everyday.
  - Muscular Dystrophy Canada is a major source of information:
    - Canada: http://www.muscle.ca/
  - MDA USA is another: http://www.mdausa.org/
  - Research is very slow and many problems need to be understood and solved before it helps patients.
  - Rule of thumb: it generally takes at least 5 to 10 years for advances to go from the laboratory bench to treatments used on patients (“bench to bedside”).

The Need to be Heard.

- I'm not ***crazy*** . . . and I'm not just ***lazy***
  - The MDA (USA) uses this quote for a reason: because many people are initially "put off" by doctors as "imagining things" or as simply lazy.
  - You know your symptoms & you know when things are wrong, no matter how strange it sounds.
- You have a chronic illness – you now need to see your role as a patient as a full time job:
  - Your medical team are professionals, you now need to interact with them as a professional patient.

Self-education.

- 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 believe that patients should learn all they can about their particular NMI.
- Staying current with medical research often helps people feel hope and that “something is being done, even if it might not help me.”

Diagnosis.

- Diagnosis of NMI is a long, complicated and slow process with many steps – we need to be patient patients as the steps unfold.
- Diagnosis of chronic conditions is of critical importance as it forecasts our expectations and determines long-term management.
- The patient and health care staff form a team:
  - With good Health Care, you will feel supported by, and feel a part of, the medical team:
    - Gives us confidence in the diagnosis.
    - Gives us support in long-term management.

Diagnosis Points the Way.

- The role of specific information and research will hinge on the exact diagnosis.
- The more certain & specific the diagnosis, the more a role for specific information & research.
- Today, most specific research is very complex and hard to understand, even for doctors.
- Information can't cure NMIs but it often helps:
  - We can't hide behind ignorance – we have a serious and chronic illness, but finding out real "difficult" facts is better than our imagined demons.

Diagnosis Matters.

- This diagnosis is critical because there are treatments to help reduce the impact of MG.
- NMI have a reputation as very complex and usually untreatable and SOME doctors may take a blasé approach to diagnosis – if you encounter this attitude, you need to confront it.
- This diagnosis is very personal and important to you. For some doctors, you are just patient number 35 for today. You need to approach this whole process with a positive and patient attitude.

This Diagnosis Has to be Right.

- Don’t feel rushed; it is your life and your future.
- Ask questions until you feel you understand.
- As a patient, you have to feel this diagnosis is right: ask about the evidence for the diagnosis.
  - Situations that need the best & clearest evidence to make a diagnosis:
    - The rarest conditions,
    - Very serious conditions and chronic conditions,
    - Conditions that require treatment(s) having serious side effects.

"Diagnosis is not easy."

- NMI are very well known as being hard to diagnose. Many disorders have very similar early symptoms and many people are initially misdiagnosed.
- There are three major aspects to a diagnosis:
  - ***Clinical***: Doctors examine us and ask questions.
  - ***Tests***: Blood tests, special tests, biopsy, etc..
  - ***Genetic testing*** may apply to the disorder.
- When facing any major illness, it is wise to get a second opinion, both of the clinical aspects and of the test results.

Differing Opinions.

- During the course of diagnosis, we may see a number of different doctors:
  - This can be frustrating: each may have a different idea about what's wrong and what to do about it.
  - Different *types* of doctors will approach us from different perspectives based on their training.
- Two doctors may make a different diagnosis and suggest different treatments, often with the same degree of confidence.
- It can be hard for us to deal with different opinions and recommendations.

Diagnostic Frustrations.

- 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.
- If we get frustrated by a diagnostic roadblock:
  - Try not to get emotional: always focus on the facts.
  - Don't take it personally: remember, be professional.
  - Consistently return attention to the questions, evidence and issues that are important in weighing your particular diagnosis.

Hard Choices.

- In many cases, the patient is faced with choices about diagnostic procedures and treatments:
  - Should I ask to have that extra test done?
  - Treatment A or B? No treatment? Try an experimental treatment?
- 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:
  - We often need help understanding some of these choices.

Phase 3: Ongoing Medical Contacts.

- We need an ongoing & open relationship with our medical team after our initial diagnostic phase is over:
  - NMI are not static: as they progress, things change.
  - We need to continue to monitor our symptoms as they unfold with the following questions in mind:
    - 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?

Treatment Dilemmas.

- In spite of the advances of “modern science” many NMI are not well understood and few direct treatments are available (MG is THE exception here, one of the BEST understood).
- “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 with our illnesses.
- Both the patient & the doctor have to deal with these issues and both need a positive attitude of “compassionate and supportive realism.”

Specialized Equipment.

- Patients must be VERY careful when dealing with vendors of equipment for the handicapped.
- 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 exact needs (that often change over time).
- You will need to find a trusted vendor and work with your health care team to determine just what you need and how and where to get it.

Different Types of Information.

- General information on coping with illness / disability & on living a positive life (“self-help”).
- Specific information about your illness.
- Information written for a general audience.
- Information written by and for experts, often very specific and often very complex.
- A wide variety of all types and levels of information is readily available today:
  - The Internet, bookstores, various not-for-profit associations, University libraries.

Knowledge Translation.

- A recent trend is knowledge translation and exchange (KTE). This involves making complex research and medical information understandable and meaningful to both doctors and patients.
- Medicine is full of jargon and we often need help in translating it into language that we can understand.
- We need to be able to make decisions based upon a clear understanding of the issues.

Information Management.

- Based on your own style and personality:
  - How much do YOU need to know?
  - Manage information wisely:
    - If you can't look, don't (but don't deny it's there).
    - If you need more, keep looking and asking.
    - MDC can help us find & understand information.
- Think broadly, how can I find and use information that will make my life easier?
  - What? What level? How much? Where is it? Need help understanding? How to use it?

Information AND Support.

- Get information on your illness from: the internet, disorder associations, libraries or other sources.

- Seek out a support group:
  - Even with rare disorders, there are others like you.
  - Talk to others about their experiences and their problems. How THEY cope may help you get ideas about how YOU can cope (and inspire you).
  - Other people are a great source of information, practical advice and emotional support. Don’t be afraid to talk to people about your illness.

Types of Experience.

- Information we learn (mostly by reading) is combined with our experience from living.
- A balance of seeking information and practical experience is likely the best approach.
- Coping involves a lot of practical experience that we learn from living life.
- Practical knowledge that we can learn from other people we meet is also important.
- Remember: Take it one step at a time and take your time, “learn as you live.”

Your Role as Self-advocate.

- You need to be *strong* and stay *positive*.
- You are the *constant* element in this process.
- You must be a firm and consistent *advocate* for yourself, especially during the diagnostic phase.
- Often a NM diagnosis has many implications:
  - People need time for the diagnosis to “sink in.”
  - Many people will want to learn about their 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.

What Will Tomorrow Bring?

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

Multi-Management.

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

Life Management.

- NMIs call on us to be excellent life managers.
- Everything we do takes longer, is a bit more difficult and uses more energy.
- Great advance planning is our best defense.
- We need to increase efficiency, reduce redundancy & generally be very well organized.
- 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.

Life Challenges.

- NMIs have a very disruptive impact on lifestyle.
- Many day-to-day routines are affected:
  - Bathroom and bedroom are key areas: the normal activities we take for granted drastically change.
  - Sleep changes/problems often disrupt your partner.
  - Eating may become a problem that needs attention.
- Outside help (care) may be needed and our lifestyle must accommodate these changes.
- Coordinating medical care with personal care (nursing help) and getting the right equipment set up in the house can be a major challenge.

Health Management.

- Many factors contribute to our overall health:
  - Genetic factors: interact with our environment.
  - Environment: what we do, all that is around us.
  - Social: psychological & emotional well-being, stress, support network (family, friends, professionals).
  - 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 encourage positive practices and minimize factors harmful to our overall health.

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.
  - Moderately raised stress that lasts for a long time.
- People with NMI need to be aware of stress factors and learn how to manage stress.
- Unchecked stress can aggravate NMIs.

Major Life Choices.

- Life, health & stress management often involve many lifestyle choices and changes:
  - Often major & very hard choices:
    - Stop smoking, lose weight, no 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 changes?
    - To maximize our quality of life.

Acceptance.

- No one asks 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.”
- How we “see” this and deal with it makes a big difference to the kind of life we will live.
- Accept that life will be different and adapt to get the most out of life as it unfolds.
- Coping with a NMI challenges us to face and to rise above many everyday problems.

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.

Depression: A Major Factor.

- "Get through it and rise above the bleak times"
- It is normal to feel anxiety and to become depressed – these feelings are to be expected.
- Let yourself "live through" these feelings: it's O.K. to feel sad sometimes, however:
  - Take things one small step at a time.
  - Try not to dwell on the sad & negative aspects.
  - Try to turn these "negative feelings" into positives: if you feel sad, what is a positive action you can take to deal with it?
  - Try to spend more time being happy than sad.

Compassion.

- Have compassion for yourself.
- Have compassion for others.
- 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.

Resources.

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

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 do control this).
- Many people are very different but very able.
- Don’t be too quick to put yourself into the “disabled category.”
- With NMI, abilities will change, however, with the right attitude, we can still be very happy and able individuals.

Adapting to Life.

- Human beings are wonderful at adapting.
- Adapting means finding different ways to “learn to live with it.”
  - We need to see what is under our control in life.
  - We need to adapt to what we can’t change.
- Some changes are sudden but static:
  - Paraplegia: challenge consistent, adaptation static.
- Some changes are progressive: challenges keep changing – requires ongoing adaptations:
  - Progressive NMIs call for progressive adaptations.
  - These adaptations occur over long time frames.

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 or have an illness.

Doors Close, Others Open.

- 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.

We Live, We Die.

- ***Death*** is a fact of ***life***.
- Death is a question of “from what” and “when.”
- We often DO NOT have a lot of choice over HOW or WHEN we DIE.
- However, we DO have a lot of choice over HOW we LIVE life.
- Let’s not choose to give up and “die before our time.”