

**LEARNING TO SELF-INJECT:  
A COGNITIVE-BEHAVIORAL  
APPROACH TO  
OVERCOMING INJECTION  
ANXIETY**

**David C. Mohr, Ph.D.  
Darcy Cox, Psy.D.**

**University of California  
San Francisco  
Behavioral Medicine Research Center**

**([www.ucsf.edu/bmrc](http://www.ucsf.edu/bmrc))**

**© 2003 David C. Mohr**

# Introduction

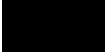
If you are reading this, chances are you have been prescribed a medication that must be injected on a regular basis. Most manufacturers of such medications recommend that people learn how to inject themselves. However, many people find that anxiety and fear can make this impossible. Many people who cannot self-inject are not particularly anxious people, aside from injections. Some people who have difficulties with self-injection have no problem receiving an injection. Some people start off being able to self-inject, but later develop fear or anxiety about the injection that prevents them from self-injecting. And some people have been afraid of needles their whole lives.

Regardless how or when your difficulty with self-injection began, you can learn to self-inject. At the University of California, San Francisco, we have conducted quite a bit of research on what contributes to people being able to self-inject and what interferes with self-injection. Based on this research, we developed a brief program to teach people how to self inject. We have been using this model since 1995 and have helped people have considerable success learning to self-inject.

The goal of this manual is to help you understand and master injection anxiety and phobia. This manual is meant to be used in conjunction with work with a counselor, usually a psychologist or nurse, who can help you tailor the ideas in this manual to your particular situation, and who can train you in proper, safe, and sterile injection technique. If you work with a psychologist, he or she should have a lot of experience working with people with medical problems. If you work with a nurse, he or she should have experience working with people to change thoughts and behaviors.

You are in charge. Neither you nor your counselor should try to force you to do anything you don't want to do. You will set your own goals in conjunction with your counselor. If your goal is to self-inject, great. If, at this point, that goal feels too overwhelming, and you just want to learn how to be more comfortable receiving the injection, that's fine too.

You are also responsible for the results of this program. Learning how to manage anxiety and phobias about injection require a lot of practice, both at



counseling sessions and at home. The more time and effort you put into this program, the more you will see benefits.

How to use this manual effectively:

- Read Chapters 1 and 2 before coming to your first counseling session.
- Write down any questions that come up for you as you are reading.
- Bring this workbook to all counseling sessions, particularly the first one.
- Write down your home assignments in the workbook to help to remember to do them.

Congratulations on taking the first step towards mastering your injection anxiety!

# **Table of Contents**

**Chapter 1:** The Anxiety Response

**Chapter 2:** The Cognitive-Behavioral Approach: How to Control the Anxiety Response

**Chapter 3:** Relaxation

**Chapter 4:** Hierarchies

**Chapter 5:** Learning to Change How You Think

## **Appendix**

I. Multiple Sclerosis an Overview

II. What are the Immune Modulating Medications?

III. Tips to Manage Injections

# **Chapter 1**

## **The Anxiety Response**

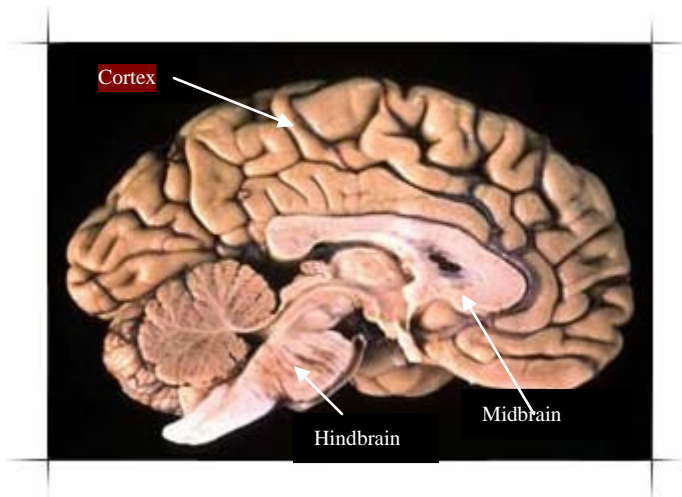
Most people use the words “emotion” and “feeling” synonymously. However, neuroscientists and biopsychologists, who study how we feel, use these words differently. An *emotion* is simply a class of neurochemical reactions in the brain of most animals that motivates behaviors. *Feelings* are our conscious experience of those emotions, and are thought to be present only in humans (there is some debate about whether or not some other animals have “consciousness”).

Emotions serve to direct our behavior. For example, emotions like love or lust (and these are wired somewhat differently from each other in the brain) serve to motivate animals to approach other animals, to stay with and protect other animals, and to procreate. Anxiety, on the other hand, serves to either to paralyze an animal (like a deer in headlights) or to cause the animal to run away (like a rabbit – an animal with a lot of anxiety brain circuitry).

Fear and anxiety operate very similarly in humans. They are controlled by part of the brain that is “old” in an evolutionary sense. This part of the brain is pretty similar in structure for humans, monkeys, mice and other animals. It operates outside of our consciousness or awareness. The anxiety response was very important in the evolution of animals. It alerted early humans and animals to the many dangers that threatened their survival. So when our ancestors saw a lion or other predator, the anxiety or fear would cause our ancestors either to freeze (predatory animals are usually not very good at seeing things that do not move), or to try to run away. There was no need for conscious thought. It was just survival.

Whether we humans needed it or not, we developed consciousness. What allowed us to develop consciousness was the development of the big wrinkly part of the brain on top called the cortex.

The areas below cortex are the midbrain and the hindbrain where the emotional circuits and wires are located (it is, of course, a lot more complicated than that, but this description is basically accurate for our purposes). These areas do most of the things that keep your body going



without you thinking about it (heartbeat, breathing, controlling your temperatures, blood pressure and on and on).

One way they do this is through the nervous system, which can be divided into two parts: the *sympathetic* nervous system, which is involved making you more aroused (increased heart rate,

increased blood pressure, breathing faster to get oxygen into your blood, increased muscle tension, getting your cooling systems like perspiration in gear) and the *parasympathetic* nervous system, which is involved calming you down (lowering heart rate, relaxing muscles, lowering blood pressure, an so on).

Let's look at an example to see how all of this would work. If you were walking through the park and saw a lion, your eyes would send a signal to the midbrain anxiety circuits. These would alert your sympathetic (arousal) nervous system, and you would gear up to run away. Your heart would start pumping more blood through your veins, your blood pressure would go up. Your muscles would tense up, preparing to run. You would start sweating to eliminate heat. And all this would happen, even if you froze, because your body would need to be prepared to flee. Thinking at a moment like this would only get in the way and would likely cause you to lose precious time and endanger your own survival. (And if you have trouble walking, your midbrain doesn't know it – remember, it is not conscious and doesn't really “think”).

So there you are, frozen in the park, with your heart racing, blood pressure up, breathing fast, muscles become tense, sweating. And you have this big conscious layer of brain called the cortex. The cortex is interpreting all this. It notices your heart racing, rapid breathing, increased blood pressure, and it sees the lion. Your experience of this interpretation is a feeling, which in this case is anxiety or fear.



Notice that the whole physiological arousal response to the lion occurs from the *emotion* and is completely outside your awareness. The *feeling* of anxiety comes in part from your physiological response. In other words, you *feel* anxious because your body is behaving in a way that is anxious. Most people think you run from a lion because you feel anxious. In fact, it is the other way around. You see a lion, which causes an emotional arousal response, which causes all the physiological arousal and makes you freeze or run – and the freezing or running contributes to your feeling of anxiety or fear. The important thing for you to remember here is, *what you do creates your feelings!*

This whole anxiety/fear system was designed to protect you from lions and other big threats to life (e.g., fire) that were much more common in early history. But we humans, here in the west anyway, have built a world where it is pretty unlikely that we will run into a lion in the park.

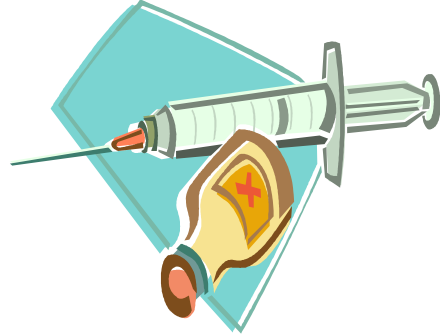
Despite all of our advances in technology, medicine, and survival, we have not outgrown this very simple but very powerful anxiety mechanism. It still gets set off at times. But usually today in modern times, the anxiety response system often gets set off at times that are not very appropriate, like when we are speaking in front of big groups of people, when we are thinking about possible future challenges, and when we are undergoing medical procedures, including injections.

Certainly there is no benefit to being bitten by a lion. But an injection is something that, while potentially unpleasant in the short-term, is actually very good for you in the long-term, because it allows you to get the medicine you need to ensure good health. Perhaps you are beginning to understand

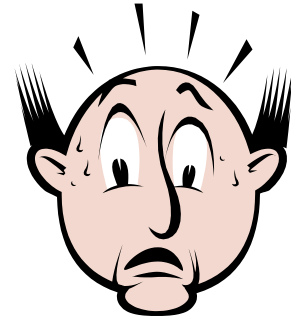
how an injection counselor can help you to become a successful self-injector at this point in our discussion. Whether or not you do, read on.

### **Emotions, feelings, and the injection**

What happens with the injection process is pretty much the same as what happens with the lion. You see the needle and the image goes to the unconscious midbrain. Your midbrain signals your sympathetic (arousal) nervous system, which increases heart rate, muscle tension, blood pressure, and so on. It may also cause you to freeze. This is why a lot of people find they just sit there with the needle in their hand, unable to just carry out that simple muscle movement that would lower the hand holding the needle. Your brain is trying to make sure you survive, but in this case, your brain is overreacting. It can't tell the difference between the needle and lion at this moment. Remember, this part of your brain does not think consciously. It just wants you to freeze or run. For most of you, you will interpret all this and *feel* anxious.



We should also note that the stimulus triggering the anxiety arousal does not have to be seeing a needle. Almost anything you associate with the injection can become a stimulus for the anxiety response. Some people notice anxiety arousal when they approach the time of the injection, or when they smell the alcohol wipes. The point is, you start to associate all of these tools and experiences with the anxiety response and therefore trigger your brain to send out additional danger signals in a haphazard and exaggerated fashion.





## **Summary and Review**

What were the key points brought up in this chapter?

1.

2.

3.

What skills did I learn?

1.

2.

3.

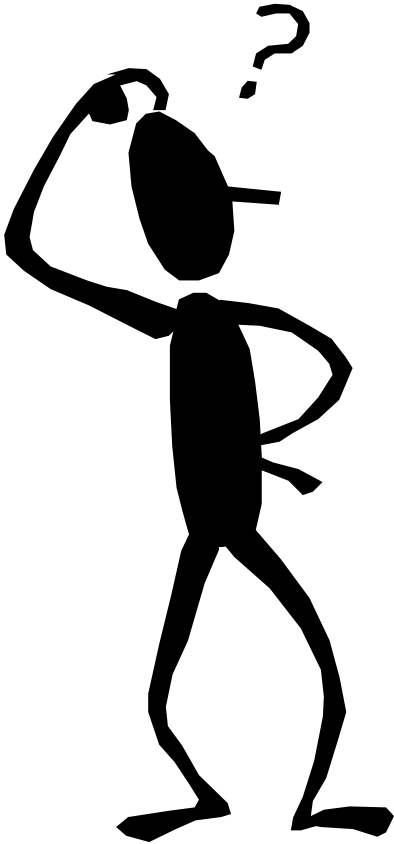
What assignments might help me practice these skills?

1.

2.

3.

Additional thoughts or questions I have about this material.



## **Chapter 2**

# **The Cognitive-Behavioral Approach: How to Control the Anxiety Response**

The last chapter described where the problem of injection problems comes from, and the “mechanics” of it (we use the term mechanics because a lot of it is an evolutionarily old mechanism that functions outside your awareness). Something in your environment (needle), causes an emotion (anxiety), which causes a behavior (or absence of a behavior – not being able to inject or freezing). The emotion and the behavior (freezing) cause a feeling (anxiety). All of this is pretty automatic. However, we can influence this process, as well as our reactions to it, through our thoughts or cognitions. For example, if you experience anxiety around an injection, you may think, “I want to quit,” or “I don’t have time for the injection,” (cognitions). Clearly, these types of thoughts do not help the process. This chapter will present the basic principles of the injection counseling program.

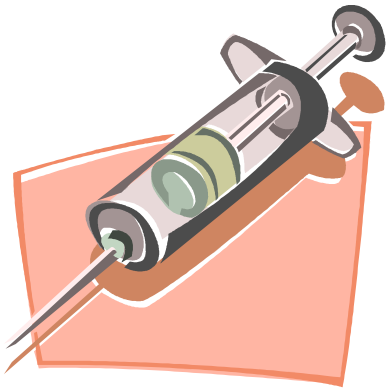
### **Cognition**

Cognition is a fancy word for thinking. Cognition goes on in the cortex – the conscious part of the brain. The cortex is the part of the brain that has been developed most recently in our evolution. Producing thoughts is one of the things that the cortex does. The cortex is always working and always thinking. If you have ever tried to “not think about anything at all”- to go for more than a few moments without having a thought- you know how difficult it is.

You have some control over the thoughts you have – if you want to think about what to get a relative for his or her birthday, you can think about that. But when you are not intentionally directing your thoughts, thoughts still get produced. We will come back to these *automatic* thoughts in a later chapter. For now, you need to be aware that your brain is like a thinking machine. It churns out thoughts, whether you want them, notice them, or ignore them. When you want to control them, and when you are paying attention, you have some control over them. But otherwise, they just keep on coming.

You probably have general thoughts about the injection process, like “I’ve always hated needles,” or “This is going to hurt.” And if you’ve tried to inject yourself, you may have noticed thoughts like “I will never be able to

do this.” It seems like thinking isn’t a big help. But in fact, if you learn *how* to think, thinking can be very helpful.



One of the really good things about thinking is that our thoughts can change our emotions and our behaviors. There are direct neural pathways from the part of the brain that control thinking to those parts of the brain that control the emotion anxiety.

Most of the time the thoughts we have just promote whatever feelings and emotions we are having. When we are anxious, we have anxious kinds of thoughts. But our thoughts can also influence our feelings. Certainly you have had a change in how you interpret or think about something that has changed the way you feel. The following example is commonly used to illustrate this point.

### **Elevator Story**

*Imagine you get onto a crowded elevator. You walk in, turn around, and face the door. As the door closes, you start feeling someone behind you poking you in the back. What do feel? What do you think? Perhaps you think someone is being rude and you feel a little angry or irritated. Perhaps you think someone is trying to pickpocket you, or steal your purse, and you feel a little anxious.*

Now imagine that you turn around and see a blind man, with dark glasses and a white cane, who is clearly disoriented. What do you think? Maybe something like “Oh he’s blind – maybe he’s trying to feel the space around him.” How do you imagine feeling then? Probably not angry or anxious. So you see, your perspective, and your thoughts can also influence your feelings.

### **The Cognitive-Behavioral Approach**

Building on what we have been discussing, there are four important components of a cognitive-behavioral approach to self-injection: thoughts, behaviors, feelings, and physiology. Here is an example to show how these components interact:

*Mary is a 42-year-old single woman with relapsing-remitting multiple sclerosis. She has had two major exacerbations and several smaller ones since being diagnosed three years ago. At the suggestion of her neurologist, she began treatment with an immune modulating medication three months ago. Although she has had training for self-injection, she is unable to get herself to do it. A friend of hers, who lives down the hall in her apartment building, is a nurse, and is happy to help. But Mary would like to be more independent. When Mary tries to give herself the injection, she feels quite anxious (feeling) and wonders if she will fail once again (thought). She notices her muscles are tense, her breathing is faster and shallow (physiological). She sits with the needle in hand, poised above her thigh, but cannot get herself to just lower her hand and perform the injection (behavior). She becomes frustrated with herself (feeling), telling herself that she will never be able to inject herself (thought), and that now she will always be dependent on other people (thought). This starts her thinking about her MS and what will happen to her (thought) and she becomes even more anxious (feeling) around the uncertainty. Eventually she becomes frustrated and walks into another room (behavior). She takes a deep breath, and sits down (behavior) and starts feeling calmer (feeling/physiology). After a moment she decides to call a friend to chat (behavior).*

Notice that each component of the model is connected with every other component of the model. For example, Mary's concerns about failing to self-inject (thought) are triggered by anxiety (feeling). This, coupled with unpleasant sensations in Mary's body (physiological response) causes her to be hesitant (behavior) in moving forward and giving the injection. This leads to more frustration (feeling), concerns about the future (thought) and, ultimately, more anxiety. Finally Mary just removes herself from the situation, and is able to calm herself a bit using deep breathing and by distracting herself with a phone call (physiology and behavior). Notice Mary was able to control her anxiety (emotions or feelings are by nature fleeting). The way that she does this doesn't help her with her injection, but she does have some control.

Although you will be concentrating on how to change your anxiety, please note that the relationships within this model also work for positive emotions (e.g., self-confidence about injection may be associated with feeling calm, relaxation, thinking pleasant thoughts, and behaving in ways that facilitate successful self-injection).

Try this with your counselor:

Experience: Recall a time when injecting or trying to inject was difficult for you. Record it below:

---

---

---

Thoughts: What kinds of thoughts did you have about yourself as a result of this experience?

---

---

---

Physiology: What kinds of bodily sensations did you experience at the time?

---

---

---

Emotional Consequences of experience and thoughts about the experience:  
What kind of mood were you in as a result?

---

---

---

Behaviors: What kinds of behavior(s) did you engage in or stop engaging in as a result of the experience, your thoughts about the experience, and your mood resulting from the experience?

---

---

---

Fill in the cognitive-behavioral model: *Put your example in the model below:*

Date of experience, situation, or event:

## THOUGHTS

---

---

---

---

---

## BEHAVIORS

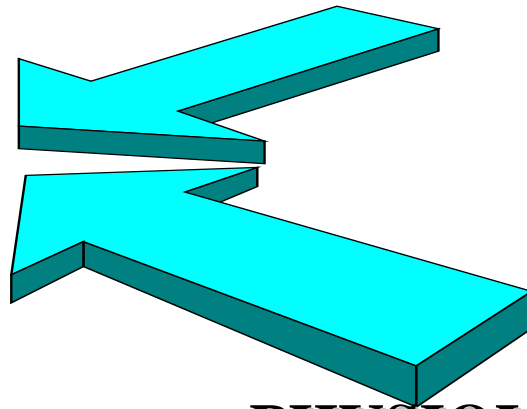
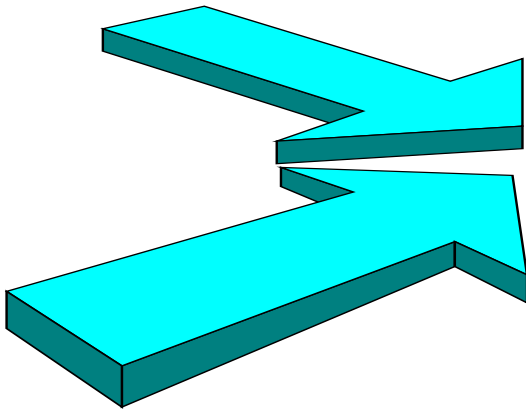
---

---

---

---

---



## EMOTIONS

---

---

---

---

---

## PHYSIOLOGY

---

---

---

---

---

## **How does Cognitive-Behavioral Injection Counseling work?**

Keep in mind an important idea in Cognitive-Behavioral Injection Counseling is that the four components of **THOUGHTS**, **FEELINGS**, **BEHAVIORS**, and **PHYSIOLOGY** have a notable influence on one another, and that this influence is reciprocal in nature.

Unfortunately, we cannot reach down inside of you and change your emotions or your feelings directly. We also can't make you suddenly perform the injection. But there are a lot of places we can intervene.

**THOUGHTS:** We can help you identify ways in which your thinking is contributing to, rather than controlling, your arousal. We can give you strategies for dealing with this.

**BEHAVIORS:** We can help you develop ways of controlling the physiology of the arousal response. We can also develop ways for approaching the injection in smaller, achievable steps.





## **Summary and Review**

What were the key points brought up in this chapter?

1.

2.

3.

What skills did I learn?

1.

2.

3.

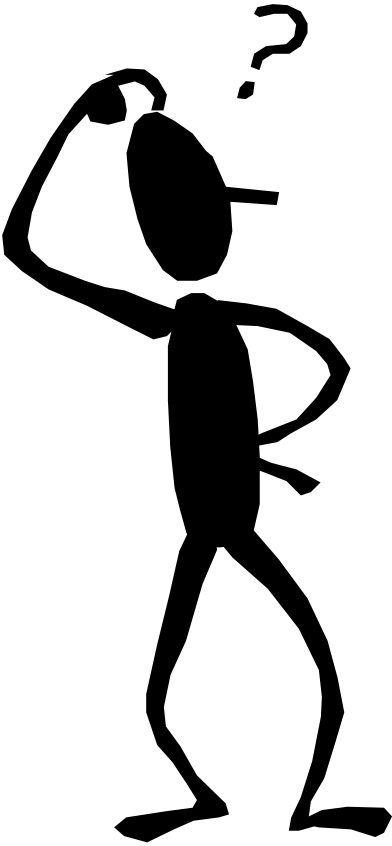
What assignments might help me practice these skills?

1.

2.

3.

**Additional thoughts or questions I have about this material.**



## **Chapter 3**

# **Relaxation**

This chapter is designed to teach you simple and useful *behavioral* strategies and techniques that help you control the physiological part of the anxiety response, and will make it easier for you perform the injection. You may have experience with other relaxation strategies and practices like guided imagery, self-hypnosis, meditation, yoga, and tai chi. All of these are similar in that they use breathing to intervene in the anxiety response mechanism.



### **Why focus on breathing?**

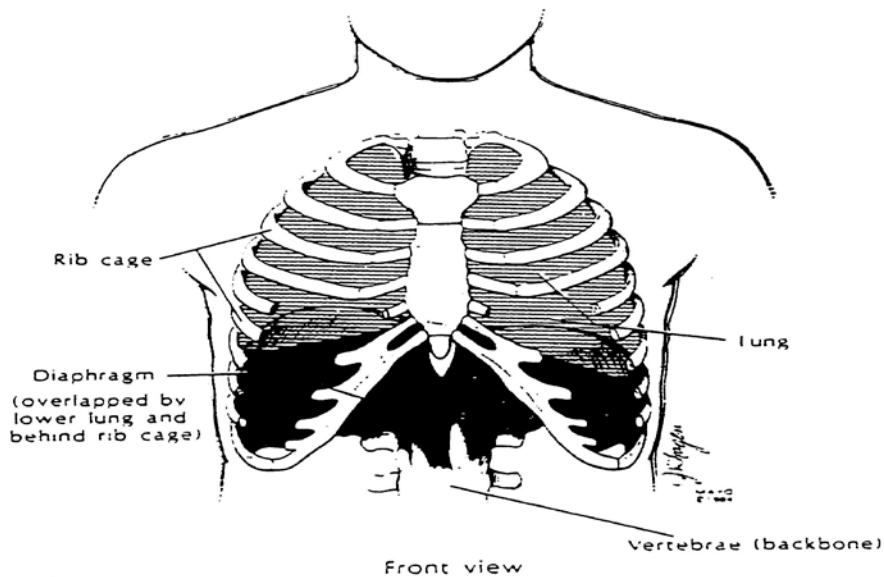
Breathing is absolutely essential to life and yet it goes on most of the time without our being aware that it is even happening. Each breath we take supplies our bodies with a steady source of oxygen. Breathing also

releases the waste product carbon dioxide from our bodies. Breathing is such a basic physiological mechanism and yet it affects every other physiological mechanism in our bodies, including those involved in arousal like heart rate, sweating, and blood pressure.

But breathing is different from all other physiological mechanisms in one major way. We can control our breathing directly. Through controlled breathing, we can fundamentally change the relationship between those parts of our nervous system that cause to feel aroused and those parts of our nervous system that cause us to feel calm and relaxed.

Perhaps you can see how this can be helpful in your injection program. You may also see that learning breathing techniques can be helpful for all kinds of things. Relaxed breathing is a skill that can be learned. The first step is to learn *diaphragmatic breathing*.

**The average person when not aroused or deeply relaxed, breathes in and out about 15 to 20 times a minute. This equals one breath every three or four seconds.**



Most people breathe by expanding and contracting their chests as they inhale and exhale oxygen (chest breathing). Sometimes people lift their shoulders as they breathe in an attempt to fill their lungs with as much oxygen as possible (shoulder breathing). Diaphragmatic breathing, which involves movement of the abdomen, is a superior method for breathing and relaxation because it allows the most efficient exchange of oxygen and carbon dioxide in and out of the body with the least amount of effort. Diaphragmatic breathing also helps enhance general relaxation that sets up an environment that is very conducive to administering your injection. In contrast to diaphragmatic breathing, chest breathing and shoulder breathing are less efficient ways of breathing.<sup>1</sup>

<sup>1</sup> The text on diaphragmatic breathing adapted from Schwartz, M.S. (1995). Breathing therapies (Ch. 11). In Mark S. Schwartz (Ed.) *Biofeedback: A practitioner's guide* (2<sup>nd</sup> Edition). New York: Guilford Press. The figure is also borrowed from Dr. Schwartz's book.

Surprisingly, infants and children are experts at diaphragmatic breathing. As adults, however, we tend to change our breathing patterns, usually as an adaptation to stressful experiences and situations. When emotional, behavioral, and physiological reactions are activated by stressful situations (as may be the case when it comes time for your injection) you may rely too heavily on your chest and shoulder muscles for breathing. Since diaphragmatic breathing involves pushing out the abdomen slightly, many adults avoid this type of breathing out of discomfort with appearing like they have a “gut” or “belly”. In doing so, they deny themselves the pleasure of one of the most efficient and beneficial methods for achieving relaxation.

No matter what else you are doing, diaphragmatic breathing should be a key part of your physical and mental health program as it may substantially improve your ability to relax during the injection process. With relaxed breathing (diaphragmatic breathing), air flows smoothly into and out of the lungs rather than being drawn in forcefully and blown out with equal force. Diaphragmatic breathing causes the abdomen to rise with each inhalation and to lower with each exhalation. You can track this process by placing one hand on your chest and the other hand on your abdomen as you inhale and exhale. If only the hand on your abdomen is moving up and down, you are probably engaged in diaphragmatic breathing. If the hand on your chest is also moving up and down, you may want to practice some more until you achieve a relaxed breathing state.

### **Diaphragmatic breathing exercise**

Read through these relaxed breathing procedures and then try relaxed breathing on your own. Initially, it may be easier to practice relaxed breathing while sitting and, later, while standing. However, if you find that you fall asleep or become very sleepy as a result of practicing while in a reclined chair, you should practice while sitting in a fully upright position. Before starting, loosen any tight clothing, especially around your abdomen and waist and make sure you are as comfortable as possible without any pressure or constraints on your body.

- *Place your feet slightly apart and rest one hand comfortably on your abdomen, placing your other hand on your chest. Inhale through your nose and exhale through your mouth. Quietly concentrate on your breathing for a few minutes and notice your hand rising and falling with each breath. Inhale while counting slowly to four, about one second per*

*count. As you inhale gently, slightly extend your abdomen, causing it to rise. As you breathe in, imagine the air filling up your body like a vessel. Imagine the air flowing to every part of your body, even hard to reach places. Now exhale to the count of four, and pause one second after exhaling before repeating this process. Now try repeating the whole relaxed breathing procedure. Exhale. Now inhale slowly: 1-2-3-4. PAUSE. Exhale slowly: 1-2-3-4. PAUSE. Inhale: 1-2-3-4. PAUSE. Exhale: 1-2-3-4. PAUSE. Continue on your own for 10-15 cycles.*

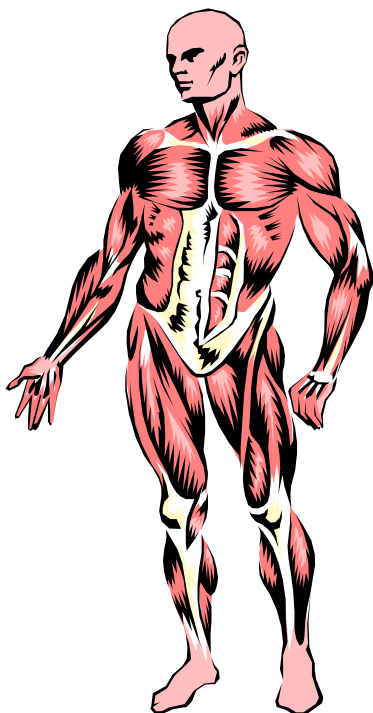
### **Relaxation**

Did you know that it is nearly impossible to have the feeling of relaxation in your body and at the same time experience psychological distress? By systematically and progressively relaxing your muscles, you may be able to reduce your pulse rate, blood, perspiration, and respiration rates.

Progressive muscle relaxation is a simple technique that is highly effective at blocking the anxiety response by shutting down those parts of our nervous system that cause you to feel aroused and activating those parts of your nervous system that cause you to feel calm and relaxed.

In 1929 Dr. Edmund Jacobson first described his simple muscle relaxation technique. Dr. Jacobson observed that the human body tends to respond to anxiety-provoking thoughts and events by increasing levels of muscle tone and muscle tension (almost like flexing your muscles without trying). When this physiological tension occurs without our trying, we develop feelings of anxiety. We literally interpret our own muscle tension as a sign that we are tense and therefore that we should be anxious in response. In other words, our minds work out something like this: “I’m feeling tense, so I must be

anxious, so there must be something to be anxious about”. Dr. Jacobson decided to take advantage of the body’s own physiological functioning by using progressive muscle relaxation to reduce physiological tension, thus lowering anxiety. He correctly suggested that muscle relaxation could interfere with the anxiety response. His progressive muscle relaxation technique is described in more detail below.



### **Muscle Relaxation Exercise:**

Begin by focusing on your breathing as described above. Let your abdomen be soft and supple –

allow yourself to breathe from your diaphragm. Become aware of the sensations of the breath entering and leaving your body, the feeling of your abdomen rising and falling:

*Begin by focusing on your face and head. Become aware of any sensations of tension in your forehead, jaw, lips, eyes, cheeks and other parts of your face. With each breath out, become more aware of these parts of your body and allow them to relax. When you become aware of increased relaxation in your face, move to your neck and shoulders. Many people often carry a lot of their tension and stress in these parts of their body. Notice if your shoulders are slightly raised, as they often are. Encourage them to relax and drop comfortably down. You may want to move your neck gently from side to side to facilitate relaxation. Notice any sensations of tension in your upper back, and encourage those muscles to relax as well. When you notice increased relaxation in your shoulders and neck, move your attention to your chest and upper arms. Return your focus to your breathing for a few moments. Then, move your attention to your hands and arms. Imagine all the stress and tension in your body flowing out of your fingers. As your arms become more relaxed, turn your attention to your legs. Once you have given attention to all the parts of your body, noticed any tension, and replaced that tension with increased relaxation, sit quietly for a few moments. Focus on your breathing and how good and comfortable your body feels.*

## **Practice**

Learning how to use your breath and muscles to relax, like most things, takes practice. The more you practice, the better you will become. It is important during this period of learning to self-inject that you practice breathing and other relaxation exercises regularly. A lot of people find it difficult to practice every day even though it only takes a few minutes and even though most people feel better with increased practice. We have several suggestions for helping you to practice.

First, set a reasonable goal for yourself for the coming week. Remember, you are only committing to this schedule for one week – just to see how it goes. Can you do it every day? Every other day? Two times per week?

Second, pick one time when you can practice that fits easily into your schedule. It is best if you do it either before or after something you do every

day. Don't pick a time when you will be rushed. Most people find it best to practice in the morning after they get up. (If you drink coffee, practice before your breakfast). Some people choose to do it when they come home from work or before dinner. Some people practice the relaxation exercises before going to bed – this is helpful if you have difficulty falling asleep. What time do you think would work best for you?

Third, pick one place where you can practice. This should be a place that is quiet and where you will not be disturbed. Where in your home would be best for you?



## **Summary and Review**

What were the key points brought up in this chapter?

1.

2.

3.

What skills did I learn?

1.

2.

3.

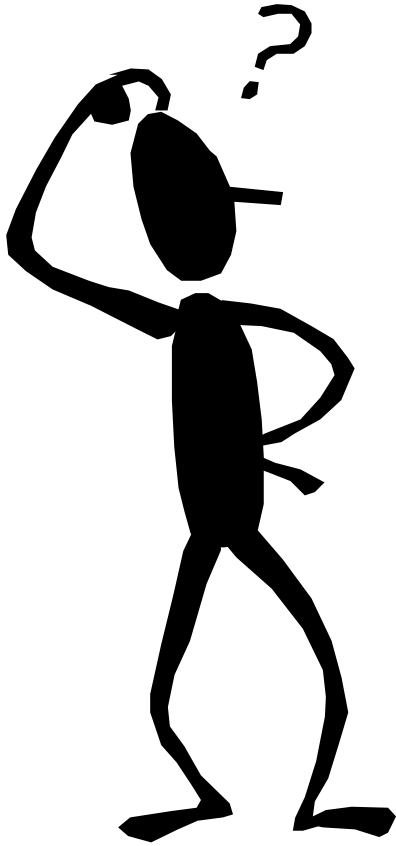
What assignments might help me practice these skills?

1.

2.

3.

**Additional thoughts or questions I have about this material.**



## Chapter 4

# Hierarchies

When people are preparing to overcome a fear, one of the things that can be paralyzing is that they imagine confronting the fear in its worst possible form. A person who is afraid of heights usually imagines themselves at a height that is terrifying, like being at the top of the Empire State Building on a high bridge looking down. They rarely imagine themselves at a height that is not quite so terrifying, like standing on a chair. One way to help people overcome a fear of heights is to gradually increase the height, starting at a height that is easily tolerated, and never increasing it dramatically.



We can do the same thing with self-injection. In this technique, people make a list of the different steps toward achieving one goal (like self-injecting). By working toward a goal in small, achievable steps, you can prevent the frustration, disappointment, and sometimes anger that often make it harder, rather than easier, to do the thing you fear. Breaking down a goal into small, achievable steps or intermediary goals is called “creating a hierarchy.”

The place to start making your hierarchy is by making a list of your goals and intermediary goals with respect to self-injection. Obviously, the main goal is to be able to give yourself your shots without help. But, for many people, that goal seems unachievable. So you break the process down into lots of smaller achievable goals. The good news is: we are advocating that you NOT concentrate exclusively on the big picture, but on the steps necessary to achieve the goal of self-injection.

The next step towards making a hierarchy is to determine how much anxiety different parts of the injection process generate for you. We do this by assigning different SUDS ratings to different steps in the process. SUDS stands for Subjective Units of Distress. As the name implies, these are *subjective* ratings - you should rate how difficult things will be for *you*! Don't think about how difficult a step “should” be, or whether it would be

hard for other people- focus on how hard something would be for you, and rate it from 0 to 100. Zero means “completely easy, could do without any difficulty” and 100 means “the hardest, most anxiety-provoking thing I can imagine doing.”

We can use an example to explain this more clearly.

*Stacy is a 33-year-old MS patient who has been taking an injectable medication for several months. Her husband has been giving her the injections because she is simply too anxious to perform the injections herself. However, because of her husband’s erratic work schedule, Stacy has been receiving her injections at different times and on different days of the week with no consistent schedule. She no longer wants to depend on her husband’s schedule for receiving her injections. She would like to self-inject to be more independent and to adhere more closely to the recommended schedule for her injections. With her counselor, Stacy developed the following injection hierarchy:*



### **Stacy’s Injection Hierarchy**

#### **Activity**

#### **SUDS**

1. Look at the needle in the package	20
2. Open alcohol wipe.	25
3. Take syringe and needle out of package	30
4. Clean leg with alcohol wipe	35
5. Remove protective cover from needle	50
6. Fill syringe with medication	55
7. Hold syringe in hand before injection	60
8. Visualize doing the injection	70
9. Touch needle to skin without injecting	90
10. Watch needle pierce skin	95
11. Push needle into muscle	99
12. Push down plunger on syringe	99

Stacy feels that she can take the syringe and needle out with only mild discomfort (a 30 on the SUDS), and she could fill the syringe with

medication with only moderate discomfort (a 50 on the SUDS). Her



discomfort rises as her ratings increase. As her discomfort level becomes more severe, such as touching the needle to her skin (a rating of 90 on the SUDS), she experiences the physical, cognitive, and emotional symptoms of anxiety.

By taking things one step at a time and using her relaxation tools, she can change this negative downward spiral into a positive upward spiral. True, she probably will never *enjoy* or *look forward to* self-

injecting, but she will be able to take care of herself in this way with very little anxiety and discomfort, and with a sense of pride in her ability to be independent this way and to effectively manage her MS.

## **Creating your hierarchy**

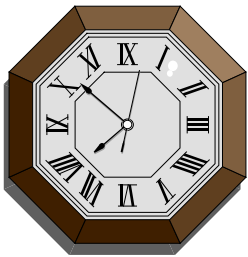
Begin with steps that are less difficult for you, whatever they may be. For some people, these may be very basic steps, like looking at your injection package. For other people, this may be more advanced steps, like visualizing yourself injecting or preparing the materials for injection.

And, as you'll notice with Stacy's example, the steps in a hierarchy do not have to be the same as they would be if you were actually going to inject yourself. For example, someone might be able to prepare for the needle without any problems or anxiety, but may find it very difficult to do a visualization exercise.

When working with a hierarchy of goals, it is important that you choose enough goals so that you will be able to see your progress as you move from completing one goal successfully to completing another goal successfully. It is important that the first goals you choose are not overwhelmingly difficult. They should be ranked between a 20 and a 50 on the scale of difficulty (SUDS). Everyone's rankings will be different, and will mean slightly different things to each person. It is important that your first goals are a little bit distressing, but that they are not overwhelmingly anxiety-provoking.

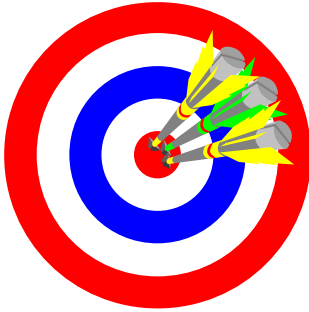
**My Injection Hierarchy (note: feel free to add to the list as needed!)**  
**Activity (starting with easiest)      SUDS (0-100)**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_
8. \_\_\_\_\_
9. \_\_\_\_\_
10. \_\_\_\_\_
11. \_\_\_\_\_
12. \_\_\_\_\_
13. \_\_\_\_\_



As you prepare to work on the first goal in your hierarchy, you should review the tools you have for coping with fear and anxiety, including relaxation. This program will work best if you set aside many small periods of time to practice your goal throughout the week. As you begin to practice the first item on your hierarchy, continuously monitor your SUDS. When your SUDS starts to rise, implement your tools until it goes back down. Practice relaxation, breathe deeply from your diaphragm, scan your body for tight muscles and breathe into them – relaxing them. Distract yourself by thinking of something pleasant or humorous, or take a quick break (20 – 30 seconds).

When you intervene and stop the anxiety reaction early, it does not have time to reach truly distressing levels. By relaxing as soon as your anxiety starts to rise, you are breaking the patterns of fear. As you practice, remind yourself that you are only working on this ONE goal. Success on this one goal is what matters - do not think about what has happened before or what comes next.

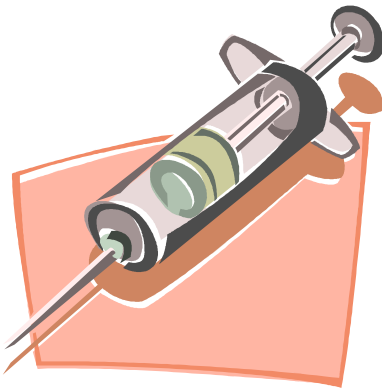


As you practice your target goals over several sessions, you will notice several things. You will notice that you are able to reduce your fear and anxiety more quickly the more you practice. You will also notice that your initial fear and anxiety becomes less intense. You will notice that it is easier over time to do what you used to fear. When you can consistently maintain your distress under a 20 level, you are ready to move to your next target goal! One way to stay on target is to reward yourself for doing so, because you have worked hard to get here! For example, rent a video you have wanted to see, have a favorite snack, read a favorite book. If you have a supportive friend who is encouraging you as you go through this program, ask him or her if you can celebrate your accomplishments together.

My list of rewards:

- 1.
- 2.
- 3.
- 4.
- 5.

If these changes happen very quickly, over the course of only one or two practice sessions, you may have picked a first goal that was too easy for you, and you should move to the next goal in your list. If these changes aren't



happening, you may have picked a first goal that is too hard for you. If you've chosen a goal that is too hard for you, you can break that goal into steps. For example, if your first goal was to practice injecting an orange (people often practice with oranges for intramuscular injections because putting needle into the skin of an orange offers similar resistance as skin and muscle), and you find that your SUDS rises to an 80 or 90 when you hold the needle,

you can break this goal into three parts: 1. Hold the needle, 2. Prepare the needle for the injection, and 3. Inject the orange. Then, you can practice just holding the needle until you can quickly and reliably bring your SUDS under 30 and keep it there. Then, you are ready to move on to preparing the needle.



## **Summary and Review**

What were the key points brought up in this chapter?

1.

2.

3.

What skills did I learn?

1.

2.

3.

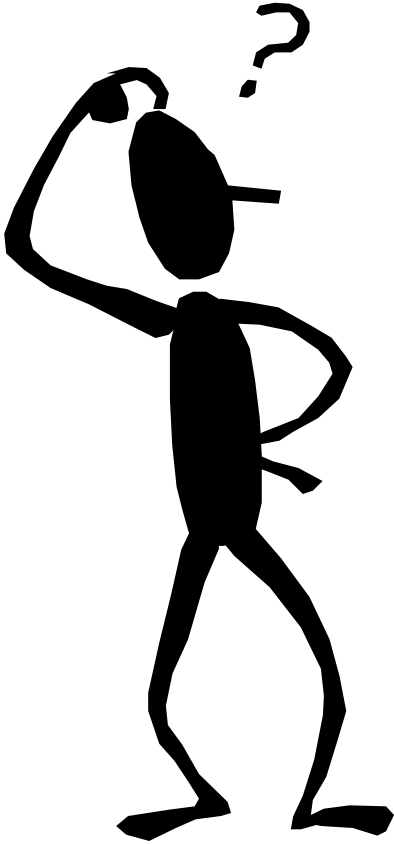
What assignments might help me practice these skills?

1.

2.

3.

Additional thoughts or questions I have about this material.



## **Chapter 5**

# **Learning to Change How You Think**

The basis of cognitive behavioral counseling is the connection between our thoughts, feelings, behaviors and physiology (our bodies). Each of these components of our lives interacts the others, in both positive and negative directions. And, when changes are made to any of these components of our lives, the other areas also will change. As we mentioned earlier, the places we can most easily intervene are by changing our behaviors and changing our thoughts. This chapter will focus on how to assess and change how you think. Learning this will take some work and practice. But these techniques are helpful.



You may remember that we earlier referred to “automatic thoughts.” This is the chatter that goes on in our heads all the time, sometimes with our awareness, but often without us really even paying attention. It is not unlike a TV that is on in the next room. Sometimes we notice a phrase or a sentence. And sometimes the TV just continues without us even noticing. These thoughts have an impact on how we feel and how we interpret ourselves and the world around us.

People can have both helpful and unhelpful automatic thoughts. Helpful thoughts are those that lead to improved mood, enjoyable behaviors, and the successful accomplishment of individual goals. Unhelpful thoughts create negative emotions, and can lead to problems with anxiety or depression. The first step is to become aware of these automatic thoughts, especially the negative ones that are causing problems. Unless we make a conscious effort to slow them down and become aware of them, we’ll never know what they are and they will continue to be able to cause us problems.

This brings us to an important tool for mastering unhelpful thoughts- the Unhelpful Thought Record (UTR). The purpose of an UTR is to become aware of your unhelpful thoughts, the changes they produce in your mood and behavior, and to examine the unhelpful thoughts for accuracy.

# Completing Your Own Unhelpful Thought Record (UTR)

You should begin with

- a. *A brief description of the stressful event* (for example hearing your doctor say “I think you should try this medication”, meeting with a nurse to discuss self-injection training, or having the person who usually helps you with the injection tell you they will be away for a few days.)
- b. *A list of the automatic thoughts* that you had in connection with this event. You should try to remember the first thoughts that popped into your head - write them down without thinking about whether they are realistic, silly, or embarrassing. Sometimes people have images, rather than thoughts - if this is the case for you, write down what the images you saw. It is easiest to do this soon after the event. If it is hard for you to take the time to record your automatic thoughts at the time, try to bring your memory back to the incident in enough detail that it “feels real” again and you experience the emotions you experienced - write down the first thoughts that then pop into your mind.
- c. A list of the emotions you experienced as a result of the automatic thoughts you had in connections with the event.

Complete the UTR provided for you on the following page according to the instructions written above here.

### **3-Column Unhelpful Thought Record**

<i>Situation/Event</i>	<i>Automatic Thoughts</i>	<i>Emotions</i>

Example: *Lisa has had relapsing-remitting MS for five years. She has had 2 exacerbations in the last six months, after having no serious exacerbations for 2 years. Her doctor recommends she start an interferon treatment. Let's look at Lisa's UTR below:*

### **Situation/Event**

Meeting with doctor to discuss treatment options. Doctor recommends starting on an interferon drug.

## **Automatic Thoughts**

*"I'm never going to be able to give myself a shot."*

*"I'm such a wimp- I know I'll start crying."*

*"This means my disease is getting worse- there's nothing I can do."*

## **Emotions**

Fear

Embarrassment

Sadness

<i>Situation/ Event</i>	<i>Automatic Thoughts</i>	<i>Emotions</i>
Meeting with doctor to discuss treatment options.	<i>"I'm never going to be able to give myself a shot."</i>	Fear
Doctor recommends starting on an interferon.	<i>"I'm such a wimp- I know I'll start crying."</i>	Embarrassment
	<i>"This means my disease is getting worse- there's nothing I can do."</i>	Sadness

## **The strength of automatic thoughts**

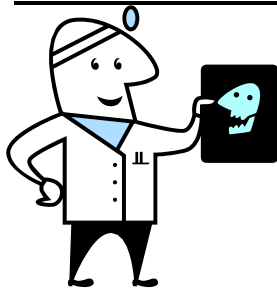
For you to understand the impact that unhelpful thoughts have on your mood and behavior, it is helpful to assign some value or rating to these thoughts to indicate how strongly you believe the thoughts you've just had. These ratings can help you identify which thoughts are the hardest for you to challenge and which thoughts may be easier change. These ratings can also be used to compare the strength of your belief in thoughts across time. For these ratings, you should consider ranking thoughts as 0% (don't believe at all) to 100% (believe completely). Please note that you can use any numbers that fall in that range.

Just as you rank your automatic thoughts, you should rank your feelings in terms of SUDS (Subjective Units of Distress- these are described in the chapter on Hierarchies). These ratings can be from 0 (don't feel this way at all) to 100 (the strongest possible experience of this feeling). In this way, you can see which emotions are most common for you, which feelings are strongest for you, and begin to see the patterns of the types of thoughts you often have and the emotions they can lead you to feel.

## **Event**

Meeting with doctor to discuss treatment options. Doctor recommends starting on an injectable medication.

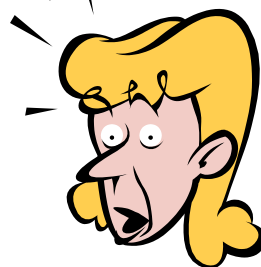
## **Automatic Thoughts**



*"I'm never going to be able to give myself a shot."* (90% sure)

*"I'm such a wimp- I know I'll start crying."* (95% sure)

*"This means my disease is getting worse- there's nothing I can do."* (60% sure)



## **Feelings**

Fear (80 SUDS)

Embarrassment (95 SUDS)

Sadness (50 SUDS)

As you can see, for Lisa what was most difficult was the thoughts that she would be unable to self-inject and that she would start crying. These led to intense feelings of fear and embarrassment.

## **Identifying Unhelpful Thought Patterns**

As you begin to identify and examine the unhelpful thoughts you have, you will begin to notice specific patterns of thinking. You will also begin to notice how certain patterns of thinking arise in specific types of situations. You may notice particular thinking styles that you use in certain types of stressful situations that are different from your thinking styles in other types of stressful situations.

Here are some common patterns many people experience, to one degree or another.

1. **Name-calling:** In this unhelpful pattern, you attach a negative label to yourself or to others. For example, Lisa calling herself a wimp is name-calling. Very often, these names are a lot nastier- people who use this pattern a lot often are a lot harder on themselves than anyone else would be, and often harder on themselves than they would be on someone else.
2. **“Should” statements:** In this unhelpful pattern, people have very strict rules about what they “should” be able to do. Frequently people who have this unhelpful pattern not only expect they should be able to do almost everything, but they insist they should be able to do it perfectly the first time, without any nervousness or anxiety. When their unrealistically high expectations are not met, they can experience a lot of negative emotions- guilt, anger, fear, or frustration. For example, a lot of people think they “should” be able to inject themselves with no anxiety, or they “should not” be having trouble with self-injection.
3. **Accentuate the negative, ignore the positive:** In this pattern, people tend to focus on every negative aspect of the situation or their response to it, while ignoring any positive aspects. For example, some people may focus on the fact that they are still having trouble with injections 3 weeks into this therapy rather than focusing on the progress they have made.
4. **Black-or-white thinking:** In this pattern, people look at the extremes. Very often, they will limit themselves to two opposite and extreme options,



such as *either* being able to self-inject easily *or* not being able to take injectable medications at all.

5. **What's the use?:** This pattern of thinking is common for people who often have hopeless feelings or feel powerless. This pattern of thinking leads to limiting behavior. Someone with this pattern might try to self-inject once, experience anxiety and be unable to do it, and then conclude "I'll never be able to do it- there's no reason to try again."

6. **Catastrophizing:** This pattern is very common in people who are often anxious. In this pattern the automatic thoughts are always the worst possible outcome. People with this pattern jump to the worst or most frightening conclusion when faced with a stressful event. For example "I had those flu-like symptoms last week after my shot, they are only going to get worse – pretty soon I'll have to stop the medication and I will end up bed-ridden."

7. **Overinterpreting/overgeneralizing:** In this pattern, you make assumptions and draw conclusions based on only a few facts. This pattern tends to show up in many other patterns, to a greater or lesser degree.

8. **Personalization:** You assume that others feel negatively about you, are being particularly critical of you, or will be upset and disgusted by your behavior. For example, if while at the supermarket the cashier is unpleasant with you, and you wonder what you did to cause that, that is personalization. You assume that it has something to do with you, when most likely has nothing to do with you at all.

9. **Emotional thinking:** You interpret your feelings as if they were facts. For example, if you feel afraid, you assume that there must be something dangerous happening. Or, if you feel embarrassed, you assume that you are doing something shameful. This is common pattern in people with injection anxiety.

10. **"If only" thinking:** The theme of this pattern of thinking is regret. People with this pattern spend time thinking about the situations in their lives with a sense of regret and disappointment, without being able to focus on the changes they can make in their lives here and now. Pattern and the "what's the use?" pattern often go hand-in-hand.

In Lisa's example, she saw that she tends to use "what's the use?", name

calling, and personalization. Notice how these labels can be added to her UTR below:

<i>Situation/ Event</i>	<i>Automatic Thoughts</i>	<i>Emotions</i>
<p>Meeting with doctor to discuss treatment options.</p> <p>Doctor recommends starting on an interferon drug.</p>	<p><i>“I’m never going to be able to give myself a shot.” (90%)</i>  <b>(WHAT’S THE USE)</b></p> <p><i>“I’m such a wimp- I know I’ll start crying.” (95%)</i>  <b>(NAME CALLING)</b></p> <p><i>“This means my disease is getting worse- there’s nothing I can do.” (60%)</i>  <b>(PERSONALIZATION)</b></p>	<p>Fear (80 SUDS)</p> <p>Embarrassment (95 SUDS)</p> <p>Sadness (50 SUDS)</p>

# Challenging Your Negative Thought Patterns

The more people practice identifying their automatic thoughts and the unhelpful thought patterns that they lead to, the better they get. In time, identifying automatic thoughts can become automatic! For many people, just being aware of their automatic thoughts can help reduce their anxiety and other negative emotions.

Once you become familiar with the types of unhelpful thought patterns you use, it is time to challenge their validity to determine if they can be replaced with more helpful thoughts. During therapy, you will be introduced to several methods to help you explore and investigate whether your thoughts are actual facts, or exaggerations or distortions based on incomplete information or habitual problematic thinking styles.

These new methods of thinking and reasoning will help you investigate the sources and solutions to difficult emotions and unhelpful thoughts. It is likely that you use many of these methods in dealing with other, external, problems in your life. However, many people have never thought of applying them to making internal changes. These methods are often even more effective at making internal changes, because there are so many more opportunities to practice.

**1. Take action:** Many people engage in specific behaviors to obtain additional information when challenging unhelpful assumptions or automatic thoughts. For example, you are doing this now by doing this therapy and using this workbook. By practicing with hierarchies, you are beginning to take small, manageable steps towards meeting your goal of self-injecting.

**2. Watch Your Language:** If you are someone who engages in a lot of name-calling, it can be very helpful to observe the amount and type of harsh language you use with yourself, and to begin to treat yourself more kindly. You will be much more successful if you stop calling yourself names and start validating yourself for the progress you are making. A helpful way to do this can be to think about a very close and supportive friend or family member. What would you say to them if they were having the same thoughts and problems that you are having? What would they say to you to support you?

**3. Weigh All the Pros and Cons:** This technique can be very helpful for people who use a lot of black and white thinking, catastrophizing, or overgeneralizing. Listing out **all** the pros and cons- without stopping to think about why they won't work for you or won't apply to you. This can help you see the factors which are maintaining the unhelpful thoughts, and can also help you generate new alternatives. Again, thinking about what advice you would give a friend in your situation can help you find new methods of thinking about a situation. Very often, unhelpful thoughts arise when people start to examine new solutions to problems- people will quickly assume "but that won't work for me." However, when people become aware of that unhelpful thought enough to examine the evidence, they often find that those solutions are more workable for them than they initially imagined.

**4. Examine the Causes and Consequences:** This can also be helpful for people who do a lot of "should" thinking. For example, if you think you "should" be able to easily self-inject, and that anxiety about doing this is a sign of weakness, examining the causes and consequences can be really helpful. Why "should" you be able to self-inject easily? Where did you learn that having trouble self-injecting is a sign of weakness? Who made up that rule? Is there any reason to keep follow that rule your life? What will happen if you stop believing that anxiety about self-injecting is a sign of weakness?

**5. Credit the Positives:** This can be very helpful for people who accentuate the negative and also for people who personalize. Making a list of your successes, either mentally or on paper, can help remind you of the many areas in your life where you are not anxious. Training yourself to become more aware of times when others give you a compliment or when you are successful at something, and validating these successes, can have a big impact in terms of reducing anxiety and also improving overall happiness.

**7. Thought Stopping and Thought Substitution:** This technique can be very helpful when anxious thoughts keep arising, even after you have already identified them as unhelpful and have worked to reduce your belief in them. When the thought comes up over and over, try shouting "STOP!" to yourself in a loud voice. Then, replace the thought with a more helpful thought. For example, if the image of the needle breaking when self-injecting keeps coming up for you, although you know that this is

impossible, first shout “Stop!” in your mind. Then, remind yourself of the facts. You may have been worrying about some particular unhelpful thought for months or even years before beginning this program - sometimes it takes time for those thoughts to stop coming up.

## Challenging Unhelpful Thoughts

### Lisa's example.

*Lisa began to challenge her unhelpful thoughts by examining the evidence for and against them. For example, her first automatic thought was “I’ll never be able to give myself a shot”. She was pretty confident in the truth of that thought initially (90% sure). However, when she began to examine it, she saw there was not very much evidence to support the thought and some significant evidence against it. She realized that she had only tried to give herself a shot once, so she really wasn’t sure what would happen if she tried again. She realized that her use of breathing and muscle relaxation to manage pain during injections was going well. She knew that she had been able to do a number of difficult and scary things in her past, including giving a talk to 200 people and bungee-jumping with a friend. She was surprised to find that she had initially just accepted her belief she couldn’t inject. She also noticed that her emotion of fear became slightly weaker (moving from a SUDS rating of 80% to 45%) after examining the evidence in this way. She added some revisions to her UTR as shown below, including another column to reflect the way her emotions changed after examining the evidence for and against her unhelpful thoughts:*

### Unhelpful Thought # 1: “I’ll never be able to self-inject” (90%)

#### **Examining the Evidence For and Against Unhelpful Thoughts:**

1. I’ve never tried to self-inject before, so I don’t really know if I can or not - never say never!
2. While self-injecting is scary, I’ve done lots of other things that have scared me.
3. I’ve been able to let other people give me shots and draw my blood, and it hasn’t killed me.
4. I would really like to be able to self-inject, because then I’ll be more independent.
5. I almost always can do things that I really want to do, and I really want to do this.

<i>Situation/ Event</i>	<i>Automatic Thoughts</i>	<i>Emotions</i>	<i>Examining the Evidence For and Against Unhelpful Thoughts</i>	<i>Emotions After Examining the Evidence</i>
<p>Meeting with doctor to discuss treatment options.</p> <p>Doctor recommends starting on an interferon.</p>	<p><i>"I'm never going to be able to give myself a shot."</i> (90%)  <b>(WHAT'S THE USE)</b></p>	<p>Fear (80 SUDS)</p>	<p>"I've never tried to self inject before, so I don't really know if I can or not - never say never!" (75%)</p> <p>"While self-injecting is scary, I've done lots of other things that have scared me." (85%)</p> <p>"I've been able to let other people give me shots and draw my blood, and it hasn't killed me." (95%)</p> <p>"I would really like to be able to self-inject, because then I'll be more independent." (90%)</p> <p>"I almost always can do things that I really want to do, and I really want to do this." (80%)</p>	<p>Fear (45 SUDS)</p>

Lisa repeated this exercise with her second and third thoughts

**Unhelpful Thought # 2:** *"I'm such a wimp- I know I'll cry"* (95%)

### Examining the Evidence For and Against Unhelpful Thoughts:

1. Even if I cry, who cares? It's not a big deal.
2. I'm not a wimp - that's just name-calling and it doesn't help me.
3. Everyone cries sometimes- I'm sure the nurse has seen worse.
4. If a friend of mine was going through this, I wouldn't judge her for crying.

<i>Situation/ Event</i>	<i>Automatic Thoughts</i>	<i>Emotions</i>	<i>Examining the Evidence For and Against Unhelpful Thoughts</i>	<i>Emotions After Examining the Evidence</i>
<p>Meeting with doctor to discuss treatment options.</p> <p>Doctor suggests starting on an interferon.</p>	<p><i>"I'm such a wimp- I know I'll start crying."</i> (95%)</p> <p><b>NAME CALLING</b></p>	<p>Embarrassment (95 SUDS)</p>	<p>"Even if I cry, who cares? It's not a big deal." (70%)</p> <p>"I'm not a wimp - that's just name-calling and it doesn't help me." (90%)</p> <p>"Everyone cries sometimes- I'm sure the nurse has seen worse." (88%)</p> <p>"If a friend of mine was going through this, I wouldn't judge her for crying." (95%)</p>	<p>Embarrassment (35 SUDS)</p>



**Unhelpful Thought # 3:** *“This means my disease is getting worse- there’s nothing I can do.”* (60%)

**Examining the Evidence For and Against Unhelpful Thoughts:**

1. MS is a progressive but *unpredictable* disease- I don’t *know* if I’m getting worse or not.
2. The medication will slow the progression of the disease.
3. I’ve had exacerbations in the past, but then nothing happened to me for 2 years- maybe it will be like that again.
4. I can’t tell the future- there’s no way for me to predict what will happen. All I can do is take care of the present and meet the future when it comes.

<i>Situation/ Event</i>	<i>Automatic Thoughts</i>	<i>Emotion</i>	<i>Examining the Evidence For and Against Unhelpful Thoughts</i>	<i>Emotions After Examining the Evidence</i>
<p>Meeting with doctor to discuss treatment options.</p> <p>Doctor suggests starting on an interferon.</p>	<p><i>“This means my disease is getting worse- there’s nothing I can do.”</i> (60%)</p> <p><b>PERSONAL-IZATION</b></p>	<p>Sadness (50 SUDS)</p>	<p>“MS is a progressive but <i>unpredictable</i> disease- I don’t <i>know</i> if I’m getting worse or not.” (65%)</p> <p>“Medication might actually help me get better.” (75%)</p> <p>“I’ve had exacerbations in the past, but then nothing happened to me for 2 years- maybe it will be like that again.” (85%)</p> <p>“I can’t tell the future- there’s no way</p>	<p>Sadness (25 SUDS)</p>

			for me to predict what will happen. All I can do is take care of the present and meet the future when it comes.” (90%)	
--	--	--	--	--

As a result of using these unhelpful thought records, Lisa’s unpleasant feelings decreased significantly, and her belief in her unhelpful thoughts also decreased.

You’ll notice that Lisa’s feelings and thoughts didn’t go away completely. Instead, they reduced to a *manageable* level. As she worked on UTR’s more and more, she became more able to reduce unhelpful thoughts and feelings, until eventually they faded to a minimal, and often nonexistent, presence.

## **Reducing Your Unhelpful Thoughts**

Look at the Unhelpful Thought Record you completed a few pages ago. What evidence is there for or against each thought? Try completing the 5-Column UTR we have provided for you on the following page. Sometimes it can be difficult to generate evidence- if so, bring that thought to your next counseling session so you and your therapist can work on it together.

## **Directions for Completing the 5-Column UTR**

Remember to start with

- a. *A brief description of the stressful event*
- b. *A list of the automatic thoughts* that you had in connection with this event. You should try to remember the first thoughts that popped into your head - write them down without thinking about whether they are realistic, silly, or embarrassing. Make sure to include your ratings of how much strength you have in the thoughts.

- c. A list of the emotions you experienced as a result of the automatic thoughts you had in connections with the event, including a SUDS rating of between 0-100 for each emotion listed.
- d. A list of the evidence for and against the automatic thoughts you had in conjunction with the event, including your ratings of how much strength you have in the thoughts.
- e. A list of the emotions you experienced as a result of examining the evidence for and against your automatic thoughts and your SUDS ratings for each emotion after examining the evidence.

### **5-Column Unhelpful Thought Record**

<i>Situation/ Event</i>	<i>Automatic Thoughts</i>	<i>Emotions</i>	<i>Examining the Evidence For and Against Unhelpful Thoughts</i>	<i>Emotions After Examining the Evidence</i>

## **Summary and Review**

What were the key points brought up in this chapter?

1.

2.

3.

What unhelpful thought patterns do I fall into?

1.

2.

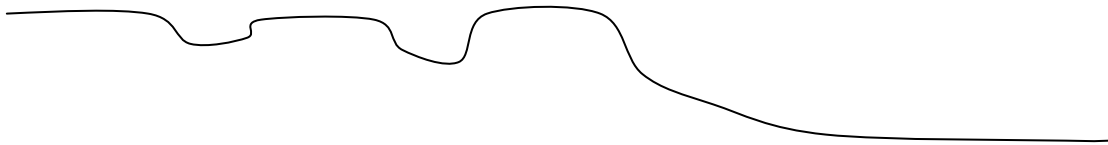
3.

**Additional thoughts or questions I have about this material.**

## **Chapter 8**

### **Lapses and Relapses**

People with many different medical experiences in their backgrounds develop injection anxiety. It is possible that you were able to self-inject for quite a while before developing the anxiety that led you to this program. Or, you may have used this program to learn to self-inject for the first time. Regardless of your self-injection history, once you have completed the program and are self-injecting regularly, it is important to monitor yourself for lapses and relapses. A lapse is a small problem or setback that is often indicative of problems to come. For example, you may have quit smoking yourself or known someone who has. Very often, when people quit smoking, they find that if they have even one cigarette, within days or weeks they are smoking as much as they were before they quit. That first cigarette is a lapse. A relapse is the return to daily smoking. Most of the time, a lapse is a sign that a relapse is coming.



The first few bumps on this graph represent lapses. Examples of lapses could be:

- forgetting to give yourself an injection, but then not calling a doctor to find out if and when you should take a make-up dose
- letting someone else at home give you an injection when you're feeling particularly anxious about injecting because "it's easier- just this once"
- experiencing a strong increase in anxiety around injections
- finding excuses to be in the clinic anyway on the day of your injection, and then asking a nurse to do it for you
- forgetting to reorder supplies on time or missing injections because you didn't have necessary supplies with you

It is important to watch for lapses because they can lead to a relapse. A relapse, obviously, would mean that you stop injecting yourself or that your anxiety increases to the point where you can only self-inject with extreme

distress. However, some relapses may be more subtle. Remember cognitive distortions? Those can play into relapses as well.

Examples of relapses could be:

- significantly increased anxiety over many days or weeks.
- telling yourself “this medication isn’t working for me- I’ll just stop taking it” without discussing this with your doctor, having MRI studies done to check whether the medication actually is helping you, or giving the medication enough time to work
- forgetting to take precautionary measures against side effects, and then quitting because of those side effects.
- having someone at home start to do many of your injections for you “because it’s quicker” or “because they’ll have to know how to do it anyway, in case I have more physical problems.”
- stopping injecting, but telling your doctor that you are continuing to take the medication

However, by monitoring for lapses, a relapse can be avoided entirely. All of the tools discussed in this workbook can be applied when you notice a lapse, and you can use these tools to reduce your anxiety quickly and effectively. When you notice a lapse, you should immediately apply the appropriate tools you have learned, and begin practicing the necessary skills to overcome that lapse.

For example, if you realize that you have gone on vacation for the week and have forgotten to bring your injection supplies, what tools should you use?

First, you should examine your cognitions. What unhelpful thoughts may have led to this lapse? Did you think “oh, my vacation won’t be any fun if I have to self-inject?” or “my friends will be disgusted if they know about this?” If you can’t find any unhelpful thoughts, you should think about how you may have allowed yourself to forget. While we all forget things sometimes, sometimes we find it’s easier to forget things that we would prefer not to have to deal with in the first place. Your injection supplies are just as important as your plane tickets- making a plan to insure you won’t forget them in the future is important. You should also examine your feelings- are you starting to feel anxious about self-injecting? If so, you can use your relaxation tape and deep breathing tools to relax your body. You can also use your guided imagery to help keep yourself focused on the

benefits of the medication. You may also want to review the information and procedures on self-injecting, to use the benefits that knowledge can give you to reduce your anxiety. You may need to construct a quick hierarchy or plan for how to get back on track with self-injecting.

It can also be very helpful to plan ahead for lapses, before you have any difficulties at all. For example, by examining the parts of the injection process or cognitions that have been most difficult for you, you can identify possible trouble spots that might lead to lapses.

My possible trouble spots:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

Once you've identified areas that could mean trouble for you, you can now make plans to avoid having a relapse or a lapse when you encounter one of these areas. Think about the different thoughts, feelings, and behaviors that could come up for you in the above situations. Which tools can you apply to ensure that you avoid relapsing? It can be helpful to make a contingency plan if you do find that you're having trouble.

If I start to have difficulty injecting again, what can I do? (who can I use for support, what resources can I access, which tools can I use from this book)

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_



6. \_\_\_\_\_

7. \_\_\_\_\_

8. \_\_\_\_\_

If you do feel like you are at risk for or have started to relapse, what can you do? You can always refer to this book for review of the tools that have worked in the past! You can also return to your counselor for a “booster” session. He or she can help you cope with renewed anxiety. While self-injecting may never be fun, it doesn’t have to be particularly difficult or frightening.

## **Summary and Review**

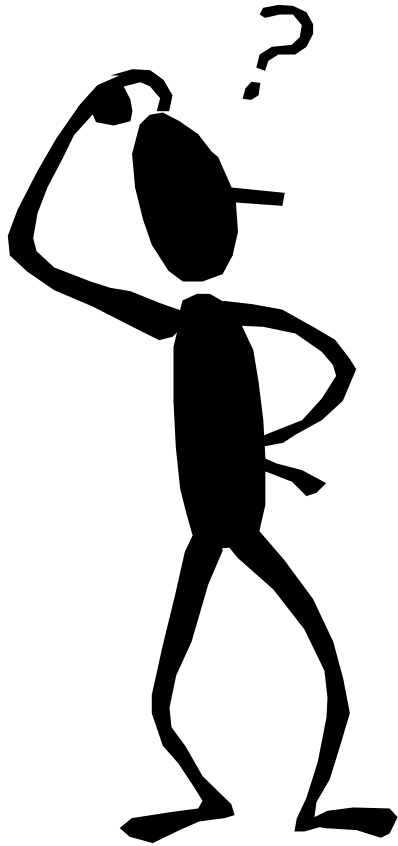
What were the key points brought up in this chapter?

1.

2.

3.

**Additional thoughts or questions I have about this material.**



# **Appendix for Patients with Multiple Sclerosis**

## **I. Multiple Sclerosis: An Overview**

### **Why a chapter on MS?**

This chapter is to provide a basic understanding of what we know about MS today. Some people may know most of this material, and others may not. We believe that understanding MS is the first step towards beginning to cope effectively with the disease.

### **What is MS?**

MS is a chronic, often disabling disease of the central nervous system. Converging lines of evidence point to the possibility that the disease is associated with a disturbance in immune system function. This disturbance permits cells of the immune system to “attack” *myelin*, the insulating sheath that surrounds the nerve cell processes located in the central nervous system.

When the myelin is damaged, electrical impulses cannot travel along nerve fiber pathways in the brain and spinal cord that are responsible for vision, strength, coordination, balance, sensory perceptions, and normal bladder and bowel function. The MS lesion is called a plaque. Plaques seen under the microscope are characterized by inflammation and destruction of the myelin sheath. Larger plaques may be seen on MRI scans of the brain and spinal cord. The Latin word for scar is "sclerosis". Multiple sclerosis was chosen as the name of this disease because it described the multiple areas of scar tissue seen in the brain and spinal cord of patients. The loss of myelin is called *demyelination*. Demyelination produces the same consequences as might be expected when the insulator around a lamp cord develops cracks or tears.

Under these circumstances the lamp will "short-circuit" and the light bulb will flicker or no longer illuminate. Loss of myelin surrounding nerve fibers also results in "short-circuits" in the nerve pathways located in the brain and spinal cord.

In contrast to a single wire pathway in a lamp cord, there are thousands of nerve pathways in the brain and spinal cord. The symptoms of multiple sclerosis depend largely on which particular nerve fiber pathway is involved. Tingling, numbness, sensations of tightness, or muscle weakness may result when loss of myelin occurs in the spinal cord. If the nerve fibers to the bladder are affected, urinary incontinence may follow. If the cerebellum of the brain is affected, imbalance or poor coordination may result. Since the plaques of MS can arise in any location of the CNS it is easy to understand why no two MS patients have exactly the same symptoms.

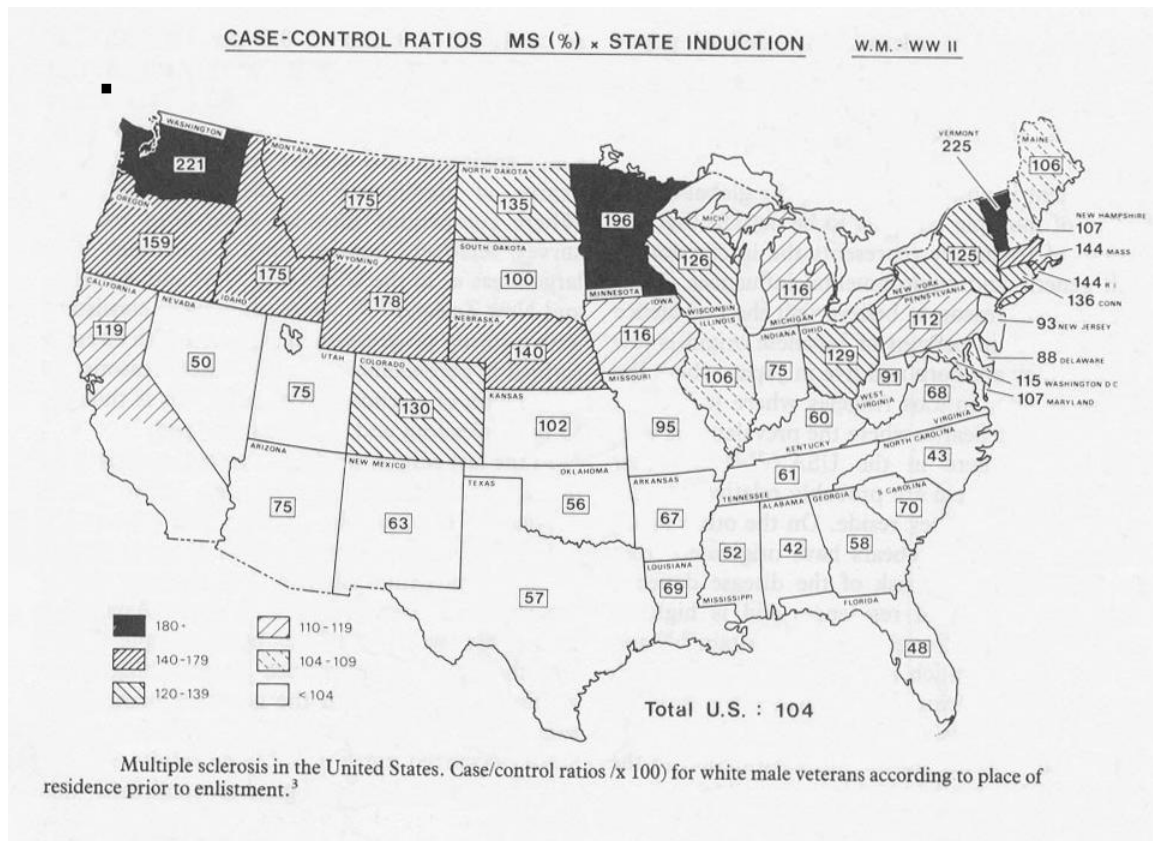
## **CAUSES OF MULTIPLE SCLEROSIS**

Although the cause of multiple sclerosis remains unknown, evidence suggests that the disease is produced by an environmental factor that triggers the illness in a genetically susceptible person. These lines of evidence have given rise to the environmental and genetic theories for the cause of MS.

### **The Environmental Theory**

The environmental theory suggests that an environmental factor predisposes to MS. Support for this theory includes the observation that multiple sclerosis is diagnosed more frequently in temperate than tropical or subtropical climates. A map of the United States shows that the prevalence of MS increases with northern latitude. For example the number of cases seen per 100,000 persons in the population is approximately 2 ½ times greater in North Dakota than Florida. This relationship between latitude and prevalence of MS is also evident in other countries throughout Europe, New Zealand and Australia. Studies of population migration patterns have found that people who move before the age of 15 have the risk factor of their new environment, while people who move after the age of 15 retain the risk factor of their environment in which they grew up. Thus, moving south as an adult is not likely to help.

Investigators have explored the possibility that exposure to viral or bacterial infections, environmental toxins, duration of sunlight, changes in temperature and humidity, or diet might in some way predispose to MS. To date no specific environmental factor has been proven to cause MS.



There is only indirect support that a virus can cause or trigger an attack of MS. It is known that viruses are capable of causing demyelination in the brain and spinal cord of humans and animals. Small clusters of MS appear to occur in some communities. Attacks of MS appear to be more common during certain seasons when viral infections are common. Despite these observations, there is still no convincing evidence that a viral infection of the brain or spinal cord causes MS.

The concern that viral infections may trigger attacks of MS remains, even if they do not actually cause the disease. Investigators have shown that attacks of MS are more frequent following upper respiratory infections and flu-like illnesses. Recently, antibodies directed against a Herpes type 6 virus have

been found to be increased in patients with MS when compared to persons who do not have MS. Attempts to isolate this virus from the brains of patients with MS have been unsuccessful.

### **The Genetic Theory**

This theory suggests that susceptibility to develop MS is influenced by genetic factors. Several lines of evidence support this theory. For example, MS is common in Caucasians but occurs less often in Native Africans, Asians, or Native Americans even when these people live in the same community. This suggests that if an environmental factor contributes to MS, only those who are genetically susceptible actually develop the illness.

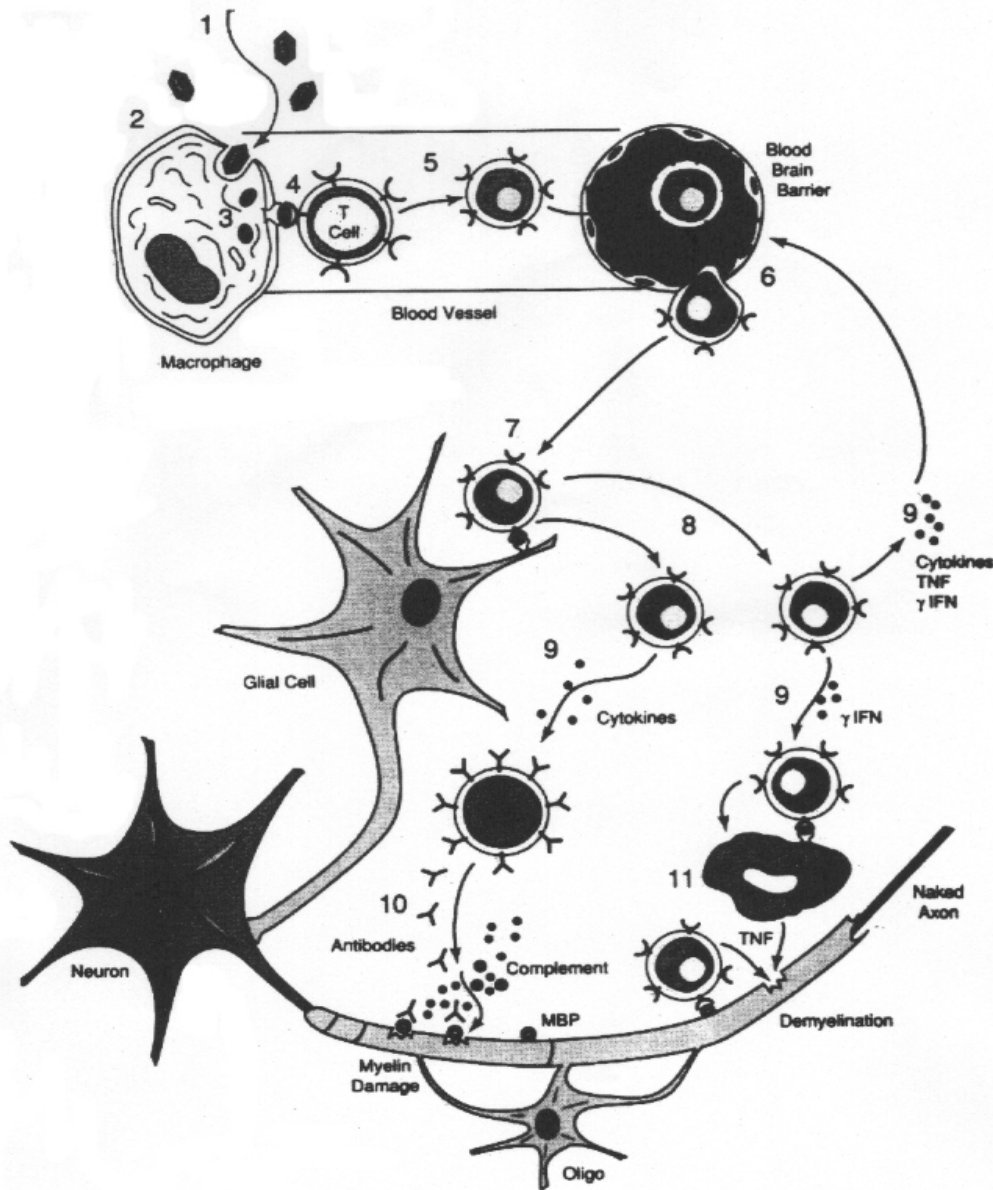
It is known that certain genes are found more frequently in persons with MS than people without MS. Studies of families in which more than one member has MS show that unaffected family members have an increased risk to develop MS when compared to individuals in the general population. For example the risk of developing MS in the general population is approximately 0.2% but the risk for members of families who have a father, mother, sister, or brother with MS is 2.0-4.0%. The risk for developing MS in an unaffected fraternal twin is 2% and the risk in an identical twin is 25-35%. These data strongly support the hypothesis that genetic factors play a measurable role in disease susceptibility. However, the contribution of genes to MS susceptibility is likely only partial since *only a minority* of known identical twins are both affected with MS.

### **The Role of the Immune System**

Whatever the cause of MS, there is considerable evidence that indicates that the disease is ultimately mediated by the immune system. The cartoon on the following page illustrates a complex model, as yet unproven, of how an environmental factor might trigger and sustain an immune mediated attack on myelin.

In the model on the next page, the process begins with an infection by a virus or some other “foreign invader” in the blood stream (1 in the diagram). Once the virus gains access to the blood stream it is “eaten” by a large cell called a macrophage (macrophage means “big eater”) (2). This macrophage digests the bits of virus and makes smaller particles called peptides (3).

These peptides are sort of like descriptions of the foreign invader. Some of these peptides are then brought to the surface of the macrophage where they are displayed in a hand-like structure. When the macrophage shows these peptides, it is essentially saying, "I've found a foreign invader and this is what it looks like. Does anyone want to do anything about it?" Specific T



cells may recognize these peptides when they are presented. T cells are highly specialized cells that are designed to recognize and fight only one specific type of peptide. If a T cell recognizes a peptide, it sounds a battle call. It calls on other T cells of the same type and they begin to divide. This is called T cell proliferation. To attack all the foreign invaders, the T cells have to get out of the blood stream and into the rest of the body. To do this,

the T cells puncture small holes in the blood vessel, which allows them to leave (5 & 6). As the T cells travel, they may encounter a glial cell in the central nervous system. Glial cells are cells that help keep the neurons in shape by cleaning up for them. Among other things, they clean up old myelin. Some of these glial cells present peptides from old myelin they have cleaned up, much as macrophages present the peptides of foreign invaders (7). In MS there is reason to believe that the myelin peptide that is presented by the glial cell looks to the T cell exactly like the original peptide from the foreign invader. This “mistaken identity” excites the T cell. Renewed proliferation occurs, like before, with a call to battle (8). T cells divide and attack the myelin sheath, thinking it is a foreign invader. Other cells (e.g. B cells) and proteins (TNF, cytokines) join in for a full force offensive on the myelin sheath (9).

For example, these cytokines can stimulate B-lymphocytes to produce antibodies that may be instrumental in the destruction of myelin(10). Alternatively, some cytokines including tumor necrosis factor (TNF) and gamma-interferon ( IFN-g) may trigger a complex series of events resulting in the destruction of myelin(11).

## **BEYOND THE DIAGNOSIS**

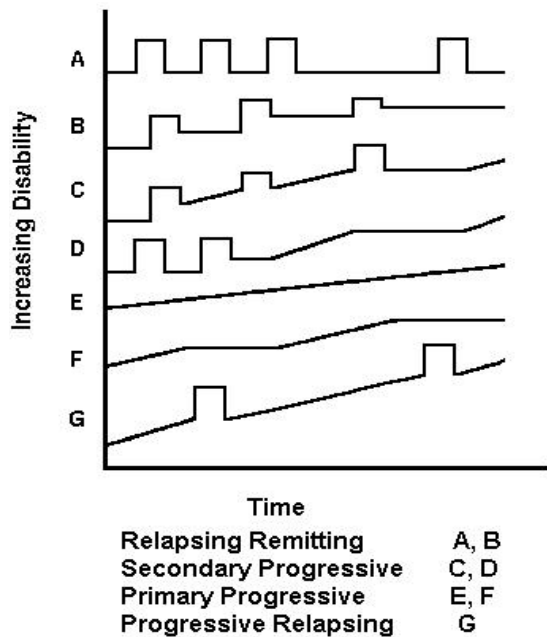
### **The Natural History of MS**

What is going to happen to me? Can you tell me if I will be disabled? Is there anything I can do to improve my prognosis? These are some of the most common questions asked by recently diagnosed MS patients. Studies of the natural history of MS will help us understand the answers to these questions.

Studies of the natural history of MS suggest that there are different patterns of disease activity. Some patients have rare attacks, some have frequent attacks, and others gradually but steadily worsen without experiencing attacks. Those people who have rare attacks and are minimally disabled ten years after being diagnosed with MS are said to have benign MS. This group constitutes approximately 10-15% of the total MS patient population. People who have attacks with full or partial recovery and are otherwise stable between attacks are defined as having relapsing-remitting MS (A & B in the chart on the next page). Approximately 80-90% of people with MS



initially experience a relapsing-remitting course but approximately 50% of those people later experience gradual progression of disability with or without attacks. For those people who later experience gradual progression of disability, they are said to develop **secondary progressive MS** (C & D in the chart).



As many as 10-20% of people with MS do not experience an initial attack. Those people who gradually worsen from the onset of symptoms are now defined as having **primary progressive MS** (E & F in chart). A few people with primary progressive MS will experience an occasional attack. These patients are now defined as having **progressive-relapsing MS** (G in chart).

The clinical course of MS is unpredictable. Neurologists are not able to foresee which newly diagnosed patients will have a benign course, who will have attacks, or who will chronically progress. Nonetheless, studies of large numbers of people with MS suggest that some disease related factors do have some predictive value. The following factors are more likely to be associated with a favorable prognosis: (1) female gender, (2) age of disease onset less than 40 years, (3) a first attack consisting of optic neuritis or sensory symptoms without sustained impairment in coordination or walking and (4) minor abnormalities of brain MRI scan at the time of diagnosis.

It is widely perceived that clinical deterioration is most noticeable during the first five years of the disease. Thus it is often said that people who have little or no disability five years after their diagnosis have the most favorable prognosis. Twenty years following diagnosis approximately 60% of people with MS are still able to walk without aids, 20-30% maintain employment, and less than 15% require custodial care. Life span is not substantially shortened compared to the general population.



## **Pregnancy**

There is evidence that the frequency of exacerbations is reduced during pregnancy but increased during the six months following birth. Although the short-term increase in exacerbation rate is a significant concern, the long-term prognosis of MS does not appear to be worse for patients who have been pregnant. Decisions regarding pregnancy are personal and each patient has individual circumstances that may bear on that decision. We encourage you to

Speak with your neurologist about the relationship between pregnancy and MS disease activity.

## **SYMPTOM MANAGEMENT**

**1. Exacerbations.** The term exacerbations (also called "attacks" or, "flares") is used to describe a recurrence of old symptoms or the appearance of new symptoms. In contrast to brief fluctuations in symptom intensity, exacerbations last longer than twenty-four hours. By definition, a patient who experiences an exacerbation must have been clinically stable for a period of at least 30 days. Most exacerbations usually last from three weeks to three months and then improve spontaneously. Often they are accompanied by anxiety and depression. Treatment has traditionally included intramuscular or intravenous ACTH (adrenocorticotrophic hormone) or oral corticosteroids (prednisone or methylprednisolone). It appears that high doses of intravenous methylprednisolone (IVMP) may be more effective than ACTH. The current practice at the UCSF MS Center is to use 500 mg of IVMP for three days followed by a tapering dose of oral prednisone for the subsequent eleven days. Others use 1 gram of IVMP for 3-5 days with or without a tapering course of oral prednisone. Side effects with this treatment are usually modest but may include fluid retention, restlessness, difficulty sleeping, acne, or euphoria. Psychosis is a rare side effect of IVMP therapy.

**2. Fatigue.** Fatigue is the most common problem faced by people with MS. Estimates are that over 40% of people with MS experience fatigue severe enough to prevent sustained physical exertion. Fatigue is characterized by diminished energy and endurance. Many patients with MS also experience

an overwhelming sense of exhaustion that requires them to sit, recline, or fall asleep. This symptom is often aggravated by elevated temperature and can be reversed by cooling. Several effective medications are now available for the treatment of fatigue, including amantadine, pemoline and fluoxetine. These medications can be helpful for some people, but for many they are not. A cooling vest or cap may be helpful when symptoms are provoked by exposure to elevated temperatures. For most people, learning to manage fatigue and energy reserves is the most effective tool available.

**3. Spasticity (stiffness).** Spasticity is usually accompanied by weakness, slowness of movement, poor coordination, and spontaneous spasms. Spasticity can be improved with several medications. These drugs include baclofen, diazepam, cyclobenzaprine, dantrolene, tizanidine, gabapentin, or corticosteroids. Patients who cannot tolerate usual doses of oral baclofen may be treated effectively by administering this drug into the fluid that bathes the spinal cord (intrathecal infusion).

**4. Pain.** MS-related pain can be experienced as jolts of electricity, continuous dull burning, disagreeable tingling or raw sensations. These symptoms often respond satisfactorily to oral carbamazepine, diphenylhydantoin, gabapentin, or tricyclic antidepressant medications. Pain management techniques such as relaxation, and the use of visual imagery are used by many people experiencing chronic pain.

**5. Tremor.** Tremor may involve the hand, arm, leg, head, or voice. These movements may be barely noticeable or severely incapacitating. Unfortunately, treatments for tremor are marginally effective. Some patients will experience improvement with clonazepam, primidone, or propranolol. The use of weights on the wrists may occasionally reduce tremor in the arm or hand.

**6. Urinary Incontinence.** Urinary symptoms are among the most common symptoms experienced by MS patients. Fortunately they are among the most easy to treat. These symptoms include: (1)urinary frequency, the need to go to the bathroom frequently; (2)urgency, the need to go to the bathroom immediately; (3)hesitancy, difficulty initiating the urine stream;

and (4)incomplete emptying, the inability to completely empty the bladder. Most patients can regain continence or experience significant improvement in symptoms with oxybutynin, levsin, or propantheline. Some patients learn to use a condom catheter; others learn to intermittently drain their bladder using a painless catheterization procedure.

**7. Bowel Incontinence.** Symptoms of constipation are commonly experienced by MS patients. Dietary management, natural laxatives, and an adjustment of medications will often relieve these symptoms. Bowel incontinence is much less common but is also frequently responsive to dietary management and careful planning of activities.

**8. Paroxysmal symptoms.** These symptoms may be experienced as tic douloureux or other brief neuritic pain, forced tonic spasms of the face, arm or leg, or dysarthria. Most of these symptoms respond rapidly to therapy with tegretol or gabapentin. Interestingly the tonic spasms may be provoked occasionally by hyperventilation, exercise or sexual activity.

**9. Heat Sensitivity.** Many symptoms are aggravated by exposure to heat or with fever. Keeping away from the direct heat of the sun and the use of air-conditioning are often necessary to prevent these symptoms. Cooling vests or caps may be useful in select patients.

**10. Weakness.** Weakness does not respond satisfactorily to medication but is frequently compensated by the use of adaptive equipment such as braces or splints. The treatment of weakness depends on the involved area of the body and is tailored to an individual's needs by a physical or occupational therapist.

**11. Sexual dysfunction.** Women experiencing sexual dysfunction most frequently experience numbness in the genital area, diminished orgasmic response, unpleasant sensations and diminished vaginal lubrication. Men commonly report impaired genital sensation, delayed ejaculation, decreased force of ejaculation and/or inability to achieve and maintain an erection. Individualized treatment will result in significant improvement of symptoms in the majority of patients. Communication between partners is essential.

Teaching your partner how you need to be touched or positioned can result in a return of pleasure and excitement instead of discomfort or pain. The use of water-soluble lubricants may be an essential aid in genital stimulation and sexual arousal. The use of vibrators may provide pleasurable and sexually stimulating sensations. Medications that alleviate spasms, pain, spasticity, fatigue, bladder/bowel dysfunction may unfortunately contribute to sexual dysfunction and their use should be reviewed with your care provider. For men, self-administered injections of papaverine or prostaglandins, as well as the new medication sildenafil (Viagra), are often helpful in producing a sustained erection. Penile prostheses are also available for individuals who experience difficulty maintaining an erection.

**12. Depression.** Depression is experienced to some extent by most MS patients at some time during their illness. Estimates are that at any given point in time, around 25% of all MS patients experience a depression severe enough to be treated. Depression is characterized by feelings of hopelessness, loss of pleasure, feelings of worthlessness, sadness, tearfulness, disruption of sleep, changes in appetite, social isolation, irritability, or thoughts about death or suicide. People often have some, but not all of these symptoms. Depression is very treatable. Individual psychotherapy has been shown to be very effective, as are antidepressant medications. Depression is one of the most treatable problems associated with MS.

### **13. Cognitive Problems**

It is estimated that between 40% and 70% of all people with MS experience changes in their thinking and memory, which are referred to as *cognitive impairments*. These cognitive changes can vary considerably from one person to another both in type and severity. The types of cognitive problems people may experience include slowed speed of thinking, problems in attention and concentration, word finding difficulties, memory problems, difficulties problem solving, and visual scanning. There is very little relationship between the severity of physical symptoms and the severity of cognitive problems. One person may have severe physical symptoms but be able to think very clearly. Another person may be very physically fit but have severe problems with thinking and remembering. There are no

treatments to improve these problems. However, many people can learn coping strategies that can help compensate for these losses. Psychologists and occupational therapists can help with adaptation to cognitive problems.

## **II. What are the Immune Modulating Medications?**

All of the immune modulating medications share certain properties. All of them have been shown to be effective in reducing exacerbation rate. All have been shown to be effective in reducing the occurrence of new brain lesions. And all must be injected on a regular basis.

All of the manufacturers of these medications recommend that, if possible, people learn to inject themselves. Yet as many as 50% of all people prescribed these medications are unable to self inject due to fear or anxiety. You might wonder why it is so important to self inject. One important reason is that people who self-inject are more likely to continue using their medications, while people who rely on family members or a clinic to receive their injections are more likely to quit. Part of this may be because, no matter how wonderful the person is giving you the injection, everyone has times they are unavailable or unreliable. Also, relying on others has problems. Sometimes there are logistic problems, such as making sure the person is available at the right time, or that you can get to the clinic. Other times it can be complicated by feelings of dependency. Having to get someone to inject you can lead to feeling like you are a burden. Whatever the reason, research shows that people who self-inject are more likely to continue taking their medications. Working with your counselor and this manual, you can learn to overcome and fears around self-injection that you may have.

An important step is to understand the medication you are taking, what it can do for you, what it cannot do, and what the side effects might be.

### **Interferon beta (IFN $\beta$ )**

In 1993, based on the results of a large multi-center placebo-controlled trial, IFN $\beta$ -1b (Betaseron) was approved by the Food and Drug Administration (FDA) for the treatment of relapsing/remitting (RR)MS in the United States

(US). Subsequently, based on an independent multi-center placebo-controlled trial, IFN $\beta$ -1a (Avonex) has also been approved for use in the US. Another brand of IFN $\beta$ -1a (Rebif) has also recently been approved.

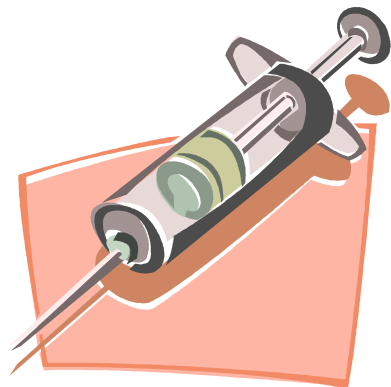
Betaseron and Rebif both require subcutaneous injections (under the skin) once every other day. Avonex requires an intramuscular injection (into the muscle) once each week.

All of the IFN $\beta$  medications have been shown to reduce the rate of exacerbation and the occurrence of new brain lesions. In addition IFN $\beta$  medications reduce sustained progression. This means that people taking the drug will experience less deterioration in physical functioning than people not taking these medications. There is also evidence that Avonex reduces the rate at which cognitive functioning worsens, and this is also likely true of the other IFN $\beta$ s.

Two recently published trials of Avonex and Rebif have demonstrated that the early treatment with IFN $\beta$  for people who have had a single attack of suspected MS delays significantly their progression to clinically definite MS. Thus, for people with suspected MS, these medications can increase the time to onset of full-blown MS. Such findings support for the notion that people with MS or suspected MS should receive treatment early in the course of their illness.

**Side effects of IFN $\beta$ s:** Side effects of the IFN $\beta$  drugs (e.g., flu-like symptoms, fevers, muscle pains, and injection site reactions) are not uncommon although these typically but they usually diminish over with continued therapy. Usually taking a “non-steroidal anti-inflammatory drug (NSAID)” an hour before your injection will help. These include aspirin or ibuprofen (Motrin or Advil). Acetaminophen (Tylenol) can also be helpful for side effects. You may need to take one or a combination of these medications for 24 hours before the injection for greatest benefit.

If flu-like symptoms are a problem, people also cope by timing the injection. If you take the injection before going to bed at night, you can sleep through most of the symptoms. If the flu-like symptoms sometimes extend into the next day, you may want to choose an injection day that will least interfere with your life. For example, a



person who needs to be alert during the week for work, and spends Saturdays with family, may choose to inject Saturday night.

For example, injection site reactions are considerably less common with the intramuscular route of administration. Also, some patients develop neutralizing antibodies to IFN $\beta$ . These antibodies may be associated with a loss of therapeutic benefit with any of the IFN $\beta$  preparations. The actual clinical importance of these antibodies is, however, unclear. Thus, some patients who develop neutralizing antibodies to IFN $\beta$  seem to continue responding favorably to treatment and many patients who are antibody positive at one point in time will revert to being antibody negative at a future time point.

### **Glatiramer Acetate**

A second form of immunomodulatory treatment, glatiramer acetate (Copaxone), has also been approved for use in the US based on the results of a multicenter placebo-controlled trial published in 1995. Copaxone is administered by subcutaneous injection every day.

Like IFN $\beta$ s, Copaxone reduces exacerbation rate and the number of new brain lesions. However, unlike IFN $\beta$ s, the reduction in new brain lesions appears to require at least 6 months of treatment. The data on whether or not Copaxone can reduce sustained progression of MS (overall worsening outside of exacerbation) have been mixed.

One of the reasons that people use Copaxone, compared to the IFN $\beta$ s, is that it is well tolerated and generally produces fewer side effects than the IFN $\beta$ s. Thus, particularly for people have difficulty tolerating the IFN $\beta$ s, Copaxone can be a good option.

### **A note on Depression**

Initially there was a lot of concern about depression as a possible side effect of the IFN $\beta$ s. The data over the last few years has been very consistent: Depression is NOT a side effect. It is always possible that there are exceptions to this. If you have had difficulty with depression in the past, you should mention this to your doctor. Regardless where depression comes from, depression is one of the most treatable problems encountered by people with MS.



### **What these medications do not do**

It is important to have realistic expectations. The immune modulating medications are not the cure, or the magic bullet that we have been waiting for. They do not repair damage that has already been done to the nervous system. They do not stop the progression of MS – they only slows progression. Thus, these are difficult medications to take. It easy to start thinking “This isn’t helping,” or “It is just not worth taking this anymore.” Because these medications prevent progression or reduce exacerbation rates rather than curing disease or stopping exacerbations all together, it is hard to tell if your medication is working or not. For this reason, if you begin to have doubts about the effectiveness of your medication, it is best to talk it over with your neurologist before deciding whether or not to stop, or to switch to another medication.

### **Some common questions.**

*Q. Why isn’t there a pill?*


A. Because these medications are proteins (like many foods), they would be easily digested if swallowed. Digestion would break down the medication and keep it from working. Injecting the drug avoids the digestive tract. Some people are trying to develop a version that can be inhaled, but this is a long way off – don’t hold your breath (sorry).

*Q. Do injections hurt?*

A. Most people experience little or no pain with the injection. Around 10% of people report some injection pain. For those who experience pain, the amount of pain will likely vary from injection to injection. The risk of pain is increased if you are not performing the injection properly. Pain from the injection is also made worse by anxiety and muscle tension. Part of what you will be doing with this program will help you reduce the risk of pain.

*Q. What if I'm afraid of needles or injections?*

A. Then you’ve come to the right place. We have found that many people, who are fearful of needles or injections, learn to successfully inject themselves after a few meetings with a counselor. The fear people have about needles is usually based on misinformation, automatic thoughts that



pop into your head about the injection process (e.g., “This is going to hurt” or “I will never be able to do this.”), and/or a “vicious anxiety cycle.” The fear people have about injections operates in the same way. Common misperceptions about the injection process include “The needle will break off”, “I’m going to hit a major artery” or for intramuscular injections, “I’m going to hit the bone.” Hopefully now you have more information than you had before you read these first two chapters. How to deal with anxiety and those automatic thoughts that undermine your goal of successful self-injection will be the focus of the rest of this workbook.

*Q: What are some of the thoughts you have about self-injection?*

---

---

---

---

---

*Q: What are some of the feelings you have about self-injecting?*

---

---

---

---

---

*Q: What are some other questions, comments, or concerns you have about the injection or administration of the medication? (Suggestion: Make your list complete so that your counselor can help you better).*

---

---

---

---

---

# III. Tips to Manage Injections

## To manage intramuscular (IM) injections (for MS, Avonex):

1. Use controlled breathing and progressive muscle relaxation to reduce pain- when injecting IM, **the most important factor to control pain is relaxation**. If your muscles are relaxed, there will be less pain.
2. If you are injecting a medication that needs to be stored in the refrigerator, inject only once the medication reaches room temperature. Injecting chilly medication will increase the sting.
3. You or partner can inject into your buttocks, thighs, or arms.
4. Insert needle quickly to reduce pain. If you slowly put the needle in, it is more likely that you will tense your muscles and increase the pain.
5. Ice skin above injection site to reduce pain.

## To manage subcutaneous injections (for MS, Rebif, Betaseron, Copaxone):

1. Tighten muscles and pinch up a layer of subcutaneous tissue (fat). Because the needle is smaller and can not reach the muscle, there is no need to worry about muscle tension increasing pain. And, tightening up the muscle will make it easier to pinch up the fat.
2. If using an auto injector, be sure not to pull back after pushing the trigger. Continue to hold the injector to your skin for 10 seconds after pushing the trigger.
3. If using a syringe without an injector, be sure to insert the needle all the way in. If you don't push the needle far enough in, you will inject too close to the top layer of skin, and it is more likely that you will have site reactions.
4. Use ice to numb skin to manage pain, if needed.
5. Rotate sites after each injection- use a chart to keep track of where you injected to help your memory.