

Chapter 1 ***Self-Management***



Afternoon sun above Spring Creek Canyon
Shawn Green, La Verkin, Utah

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Objectives

After studying this chapter, you will be able to:

- Explain the importance of self-management for chronic illness.
- Utilize steps for self-management.
- Develop a self-management plan.

The Case for Self-Management

This chapter on self-management builds on the introduction to self-management in Session #1: Laying the Foundation in my manual *Let Your Light Shine Through*. Managing daily symptoms is the bedrock of clinical care for any chronic physical or mental health condition. You play the largest role in your own management. Many of you with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM), and Environmental Sensitivities (ES) embrace the concept of self-management. You intuitively grasp that taking an active role in your health management allows you to take your health and life into your own hands, spend less time at health appointments, and do more of the activities you enjoy. Others of you are less enamored of the self-management approach and hold out for a biomedical cure.

In *More Light* you will learn that self-management is not just a psychological Band-Aid. By changing patterns of thinking and behaving, you change your biology. We will come back to this theme throughout the book. If you continue reading, I predict that by the end, you will be more enthusiastic about self-management because you will understand the science behind it. I hope you will put some strategies into action and experience positive results. This will increase your confidence in your intuition and judgment, and you will be motivated to try more management strategies. This will increase your chances of improvement.

A new definition of health is emerging that reflects the awareness that life and health are always changing. An anonymous editorial in the journal *Lancet* defines health as “*the ability to self-manage in the face of changing circumstances*” (Anonymous, 2009). Successful self-management means taking an active role in your care in collaboration with your health-care team and with the support of family, friends, and social supports (Van de Velde et al., 2019). Sounds ideal doesn’t it? For most health conditions, health-care professionals are considered the experts on the medical condition and patients the experts on their own experience. In ME/CFS, FM, and ES, this is rarely the case. Patients often need to learn about their conditions and inform their health-care team about established practice. This means patients need access to accurate information.

***“Health is the ability to self-manage in the face
of changing circumstances”***

With chronic conditions, self-management is a life-long endeavor. Our bodies are in constant flux and medical knowledge is ever-changing. Therefore, we need to re-evaluate our strategies

from time to time. *More Light* provides information to help you do this whether you are newly diagnosed or have been ill for decades.

Self-management is effortful. It requires daily awareness of one's thoughts, sensations, emotions, and behavior and putting plans into action based on those observations. Formal and informal supports are not always available. Why then would anyone embark on the path of self-management? It sounds hard and energy intensive. The answer is that for ME/CFS, FM, and ES, other options are limited. More importantly, self-management works. Hundreds of studies across dozens of physical and mental health conditions show that self-management improves health and function and decreases health-care utilization (Panagioti et al., 2014). While the effects are modest and it remains unclear what types of self-management support are the most effective for which conditions, the research indicates there are health benefits. In other words, self-management is worth doing.

My experience over the past 20 years is consistent with the research that self-management support has profound effects. Here are some comments from people who have participated in the self-management groups I facilitate for patients with ME/CFS, FM, and ES.

Learning about what is happening in my body and how I can manage my symptoms more effectively has brought me a sense of power and hope toward my illness.

I have been able to improve my medical condition by closely monitoring what is important for me to do to avoid flare-ups.

Some of my coping strategies, like creating a safe place and self-soothing, are exactly the kinds of things that are beneficial and good/essential self-management.

My experience is that regardless of symptom profile and severity, the patients who improve are those who know it is up to them to create the life they want and who believe they can impact their well-being. They are open-minded and willing to work with what they observe about their experiences and reactions. They are willing to do whatever it takes to get better. "Whatever it takes" does not refer to travel to far-flung clinics or trying lots of expensive products. In fact, this can be counterproductive if it strengthens the belief that the cure will come from the outside and that one can remain passive in one's own journey.

Whatever it takes refers to being willing to question strongly held beliefs and to try new strategies. It often involves engaging in daily practices that aid healing, increase connection with supporters, and are fun and meaningful. These practices will be different for each person.

There is no single recipe for recovery. Whatever it takes includes figuring out the path that is right for you. That often requires patients to be patient.

When I meet with a new patient and ask them what their hopes are for working with me, they often “joke” that they are hoping for a cure. Then they state a more modest goal like learning more or managing better. However, I know that most patients are hoping to find something that is treatable or curable. That is why normal test results are often met with disappointment. Most people hope for the easier, softer way; that the treatment or cure will come from the outside in the form of a medication, treatment, or nutritional supplement. But external substances only work as long as they continue to be taken. In chronic conditions, substances rarely cure the underlying problem. Over time, people often discontinue medications, supplements, and other treatments because of cost and/or side effects. So, as enticing as it is to take a substance or undergo a treatment to decrease symptoms, the benefits of these types of treatments are usually short-lived.

Self-management can be a more powerful intervention than many mainstream drug treatments. In medical research, a statistic called the *number needed to treat* (NNT) represents how likely an intervention is to benefit people. For many commonly used medical treatments, many patients need to be treated for one additional person to achieve a positive result. As an example, the number of patients needed to take pregabalin, a drug approved for use in fibromyalgia, in order for one patient to achieve a 30% reduction in pain after 12 to 13 weeks of treatment is seven to 14. The number needed to continue on pregabalin for 13 to 26 weeks in order for one patient to achieve a sustained benefit is 12. Eight of 10 patients in studies of pregabalin experience side effects (Derry et al., 2016).

By comparison, in a study of a psychoeducational group therapy for fibromyalgia, people attending the group (as compared to people getting usual medical care) reported less physical impairment, pain, general fatigue, stiffness, anxiety, and depression (Luciano et al., 2011). The number needed to treat was only three. No side effects were reported. Of course, not every self-management approach is this successful.

Many health regions in Canada offer and promote self-management education. The United States Centers for Disease Control and Prevention (CDC) offers self-management information online: (<https://www.cdc.gov/learnmorefeelbetter/programs/general.htm>). The more cynical among you may feel this could be an off-loading of responsibility onto patients as a cost-saving measure. This may be, but it also works.

I am belaboring this point because our beliefs are powerful. If we believe something works, it may, even if it contains no active ingredient. In research, this is called the placebo effect. In trials of antidepressants, the placebo effect is 30–45% in many studies, meaning that 30–45% of people who improve are taking the placebo and not the antidepressant being tested:

(<https://time.com/4053881/antidepressant-placebo-effect/>). So why not utilize belief to our benefit?

This is a good place to mention that severity matters. People who are severely ill may not be able to read this book or implement the self-management strategies discussed. If you are severely ill, you may still benefit from having the manual read to you. You or your carers may read an idea that you can try, even if you are spending most of your time in bed and keeping sensory input to a minimum. You may gain hope from hearing about emerging ideas. Hopefully you will take heart in the knowledge that prominent researchers are studying the most severely ill. You are not forgotten. An example is the Severely Ill Patient Study undertaken by Dr. Ron Davis and colleagues at Stanford University. Go to the website of the Open Medicine Foundation for more information: (<https://www.omf.ngo/>).

Self-Management Begins with Awareness

Self-management starts with careful, non-judgmental observation of one's symptoms to figure out what is going on. Most people with ME/CFS, FM, and ES have several, often dozens of, physical and emotional sensations. We typically judge them negatively and call them "symptoms." It is easy to feel overwhelmed and confused. Observing and recording what you experience can help you make sense of your experience.

While you are in the active stage of observation, it is best to record your symptom ratings once or twice daily. Giving each experience a rating (out of 10 or 100, for example) allows the scores to be put in graph form. This makes it much easier to observe patterns. This is called charting and is described on page 1-10 of *Let Your Light Shine Through*. The purpose of charting is twofold. Knowing you are going to rate and record a symptom, you pay closer attention. In doing this, you begin to notice what makes you feel better or worse.

Virtually everyone who devotes time to awareness observes valuable information about themselves. In the participant evaluations from the self-management groups I facilitate, observation and charting are regularly mentioned as the intervention having the most impact. Here is a typical comment.

Learning about things that can have an impact on my health and how I am able to stay within my energy envelope was greatly helpful. The charting helped to see patterns and how to make changes that would benefit me.

My favorite moments facilitating groups are when a participant notices something for the first time. I observe them realizing that there are things they can do to improve their health. I observe the motivation for change increase as they begin thinking of ways to put a plan into

action. The impact of observing how your symptoms and behavior interact is a powerful motivation to change.

Mind-Body Connections

You are an interconnected web of physical body, thoughts, and emotions. A change in one dimension impacts the other dimensions. Your physical sensations affect your thoughts and emotions. Your thoughts affect your sensations and emotions. Your emotions affect your thoughts and sensations. Tuning into your whole being will give you valuable insight about what you can change to improve your well-being. We will learn in Chapter 3 how thoughts and you can change to improve your well-being. We will learn in Chapter 3 how thoughts and emotions impact the body through biological mechanisms such as neuroplasticity and epigenetics. Throughout the book you will learn to design self-management interventions to change your biology. In order to design effective interventions, you need to know your unique patterns of reaction.

The Diamond of Awareness, Figure 1.1, guides you to become aware of connections that exist between your physical body and your thoughts, emotions, and actions. The experiences you want to change may be primarily physical health symptoms such as post-exertional malaise, nausea, elevated heart rate, or brain fog. Alternatively, you may experience strong emotions such as hopelessness or fear. If you observe yourself closely over a period of time, you are likely to find connections between what you think of as your mind and what you think of as your body.

In each chapter of *More Light*, I recommend an awareness exercise to assist you to learn more about yourself. The Diamond of Awareness introduces you to gentle, non-judgmental awareness. Non-judgment means observing what is going on in and around you without labelling it as good or bad. Why would you want to do this? Because you don't know yet if a symptom or situation is warning you of something you need to attend to (helpful) or is a non-productive rut of misery. Judgment of whether something is good or bad creates bias.

To assist you in avoiding judgment of your experiences, I use the neutral word "sensation" in the Diamond of Awareness rather than the word "symptom," which has a negative meaning. If you experience harsh judgment of your symptoms for being present, of yourself for not solving your problems, of your friends and family for not understanding, or of your health-care team for not being more helpful, your focus is drawn to the problem and you may miss hints that would lead you toward a solution.

You will learn more about yourself and be more creative if you observe like a neutral reporter. Try avoiding emotional descriptions of your experience. You could even try recording your

experience in the third person. The third person is a technique to gain perspective. The two descriptions below demonstrate different ways to describe the same scenario.

Date _____ Experience _____

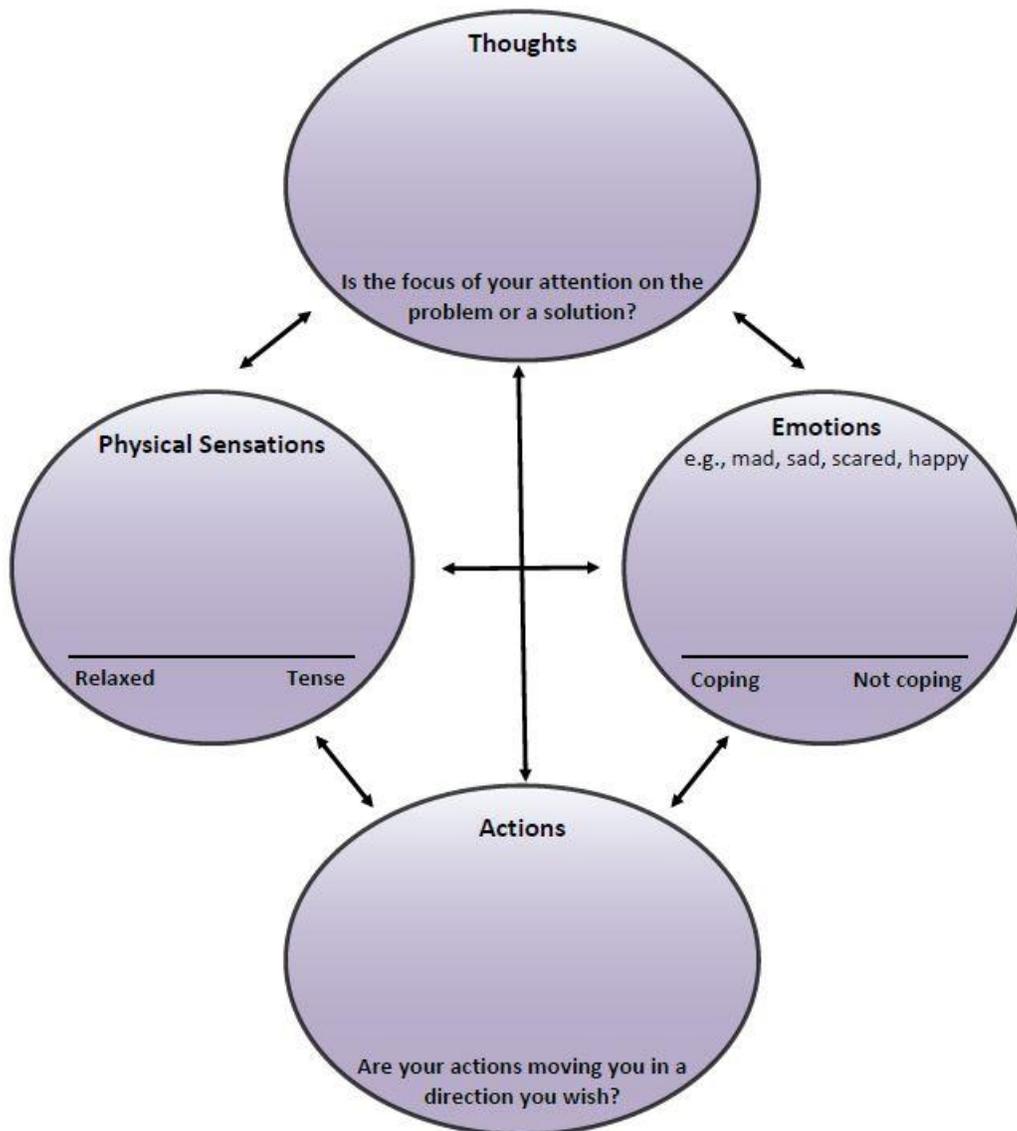


Figure 1.1 Diamond of Awareness

You will learn more about yourself and be more creative if you observe like a neutral reporter. Try avoiding emotional descriptions of your experience. You could even try recording your experience in the third person. The third person is a technique to gain perspective. The two descriptions below demonstrate different ways to describe the same scenario.

I just finished vacuuming half the living room and I crashed. I'm in the worst crash ever. I can't believe this is happening again. My place is a disaster because of my inability to function. I am a horrible mother because I will miss my daughter's soccer game again. There is nothing I can do to stop this from happening.

She finished vacuuming half the living room. She feels increased fatigue, nausea, and dizziness. She is disappointed because she had hoped to go to her to her daughter's soccer game this evening. Now she isn't sure if she will be able to go. She plans to watch one of her favorite movies until she feels well enough to start another task. She will assess about the soccer game later.

Using the Diamond of Awareness

Any time you become aware of a sensation, it is a good time to pause for a few minutes and complete the diamond. Fill in the domain that caught your attention first. For example, if your awareness is of a physical sensation, start there. If it is an action or emotion that you notice, start there. Then work your way around the diamond, observing each domain in turn until you have some observations in each of the four ovals. In each oval you are asked to evaluate your experience on a simple scale. Rather than judging the experience as good or bad, rate it based on whether the experience is moving you toward your goals or not. Focusing on the problem may prevent you from brainstorming solutions. Bodily tension tends to worsen physical sensations such as pain. Emotions are not good or bad but can be problematic if they are so strong that you are not coping or are becoming hopeless or suicidal. Actions may be moving you toward your goals or getting in the way. Please read the example below before trying your own Diamond of Awareness.

Diamond of Awareness Example: Nausea

Physical Sensation: In this example, a hypothetical person we'll call Beatrice becomes aware of a sensation — nausea, a common and hard-to-treat symptom in ME/CFS, and ES.

Thoughts: For most people, awareness is quickly followed by thoughts. In this case, the thoughts are full of anger at the symptom and discouragement about how nausea negatively

Date April 2

Experience Nausea

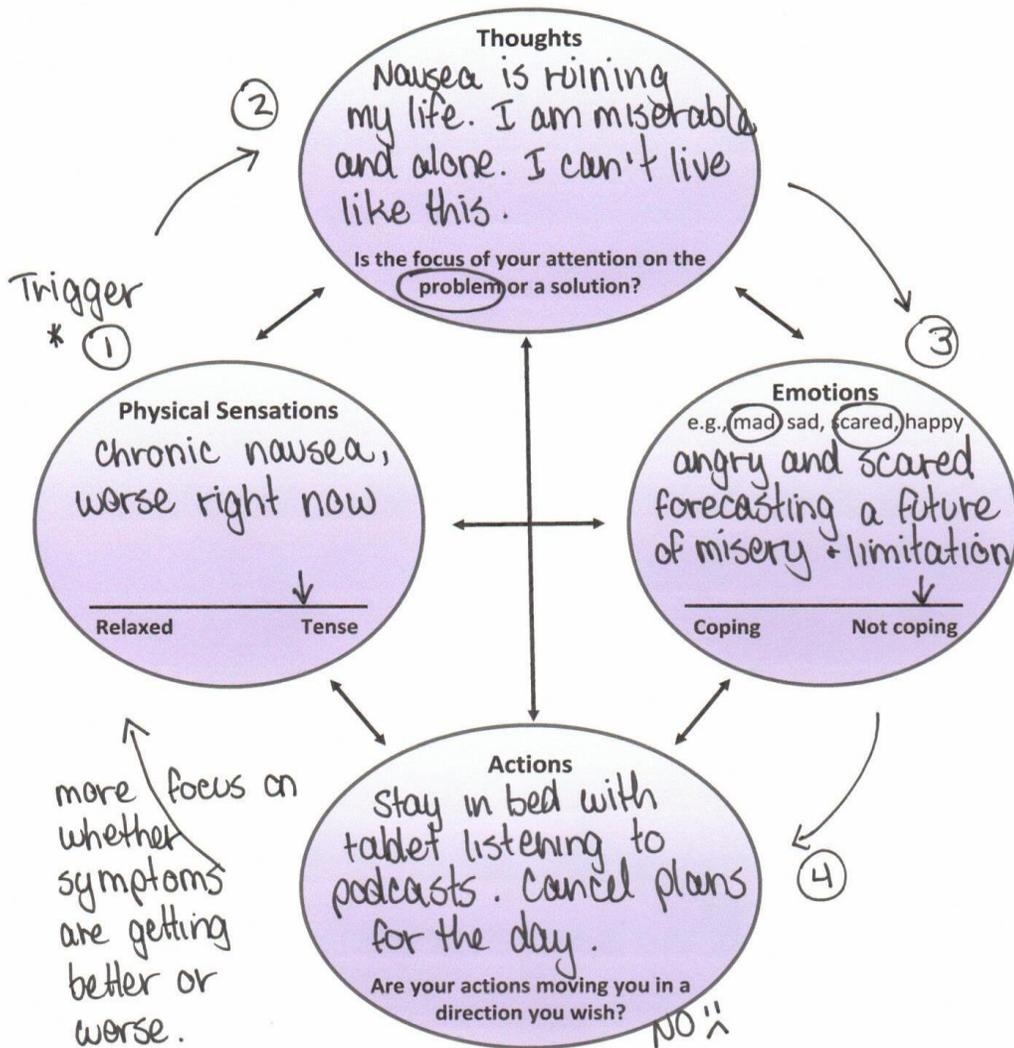


Figure 1.2 Diamond of Awareness Example: Nausea

impacts life. Examples of problem-focused thoughts are: *This nausea is the worst ever. It never goes away. Nausea is ruining my life. I'm scared to go out for fear of vomiting.*

Emotions: Problem-focused thoughts often lead to emotions, in this case anger at the unfairness of life and fear for the future. “Future-casting,” imagining what negative things will happen in the future, leads to negative emotions. Beatrice rates these emotions as closer to “not coping” than “coping.”

Actions: Feeling miserable and beaten down, Beatrice stays in bed and listens to podcasts.

Let’s consider the impact of this Diamond of Awareness example. At the time of the experience, Beatrice isn’t very aware. She is worn down by chronic nausea, making it hard to enjoy life. Having experienced it so many times, she is on autopilot, repeating habitual reactions to her severe nausea experience. Afterwards, when completing the Diamond of Awareness exercise, she realizes that although this pattern of response to a chronic, disabling symptom is understandable, it is not moving her in the direction of the life she wishes for. In fact, she notices how her habitual response may be self-reinforcing. The worse she feels and the more she avoids life by staying in bed, the less she has to take her attention away from symptoms (nausea and others).

Now for the good news. The interconnectedness between thoughts, emotions, actions, and sensations means that if Beatrice can make a change in any one domain, it will have an impact on the other. Take a moment now to look at this example and identify changes in any of the four domains that may shift her experience. If she is focused on thoughts of how her symptoms are ruining her life, how could she change her thoughts? Examples of solution-focused thoughts are: *I will sit and be with the nausea for a few moments, practicing acceptance of what is. I will make an appointment with my MD to discuss whether there are any other options for the nausea. Given how I feel right now, what can I do that would be enjoyable or meaningful?* To learn more about turning problem-focused thoughts around, I recommend Dr. David Burns’s book *Feeling Good* (Burns, 2000). Although the book is written for depression, it can be adapted to any negative thought patterns.

The emotional regulation module of Dr. Marsha Linehan’s Dialectic Behavior Therapy offers many strategies to cope better with extreme moods (Linehan, 2015). One of Dr. Linehan’s suggestions is called *opposite action*. When Beatrice feels beaten down and wants to stay in bed and avoid life, the opposite action would be to get up and do something—that will move her life in the direction she wants it to go. Examples of opposite action in this case would include: taking a shower, talking to a friend, cooking a healthy meal, watching a funny program, or going outside. Opposite action won’t work immediately, but step-by-step she will create new default reactions to her symptoms and will have more positive experiences. Linehan

emphasizes the benefits of creating a life worth living. What would a life worth living include for you?

It is beyond the scope of this chapter to describe the many ways you can reverse the vicious circle of symptom-focus and pessimism. You will learn in Chapter 3: Biology of Change that we can change our biology through imagining the reality we want but don't yet have. I have created an experiential exercise, *Imagining the Opposite*, as an example of how this could work. An audio file of *Imagining the Opposite* can be found on the resource page of my website: (www.eleanorsteinmd.ca).

Diamond of Awareness Exercise: Visit with a Friend

You can also complete the Diamond of Awareness for positive experiences. The more you learn about what makes you feel well, the more you can plan for and create those experiences. Here is an example for you to try.

Actions: Your friend has just visited.

Physical Sensations: What do you notice? You may notice a mix of wanted and unwanted sensations. Overall, do you feel more relaxed or more tense? There is no right or wrong answer. The Diamond of Awareness is most useful when there is no judgment about what is good or bad.

Emotions: What emotions do you experience after spending time with a friend? You might respond that, of course, this depends on the friend. This is another factor for which awareness is helpful. Overall, are your emotions ones you can cope with or not?

Thoughts: What thoughts do you have after the visit? Write them down. Is the focus of your attention on a problem or a solution? Examples of problem-focused thoughts are: *I really feel tired. I will have to cut back on social visits. I hate PEM (post-exertional malaise), it is ruining my life. My friend noticed my brain fog; I feel embarrassed I couldn't keep up in the conversation.* Examples of solution-focused thoughts are: *I feel connected after that visit. I am a bit tired; I will rest and recover. I fumbled with some words and lost track of the conversation; it is a good thing my friend doesn't judge me and that I don't judge myself.* Are your thoughts hopeful and solution-focused or judging, blaming, and problem-focused?

Goal Setting

Once you have charted for a while, you will start noticing patterns. Maybe every time you do a certain activity, you develop a certain symptom. Maybe every time you do a different activity, you don't notice your symptoms as much. Maybe each time you have a stressful experience, you become tense and on alert. Maybe each time you have one symptom, others emerge.

These are important observations because they can give you ideas about how and where to intervene to shift your experience in the direction you want. Figure 1.3 introduces the next steps.

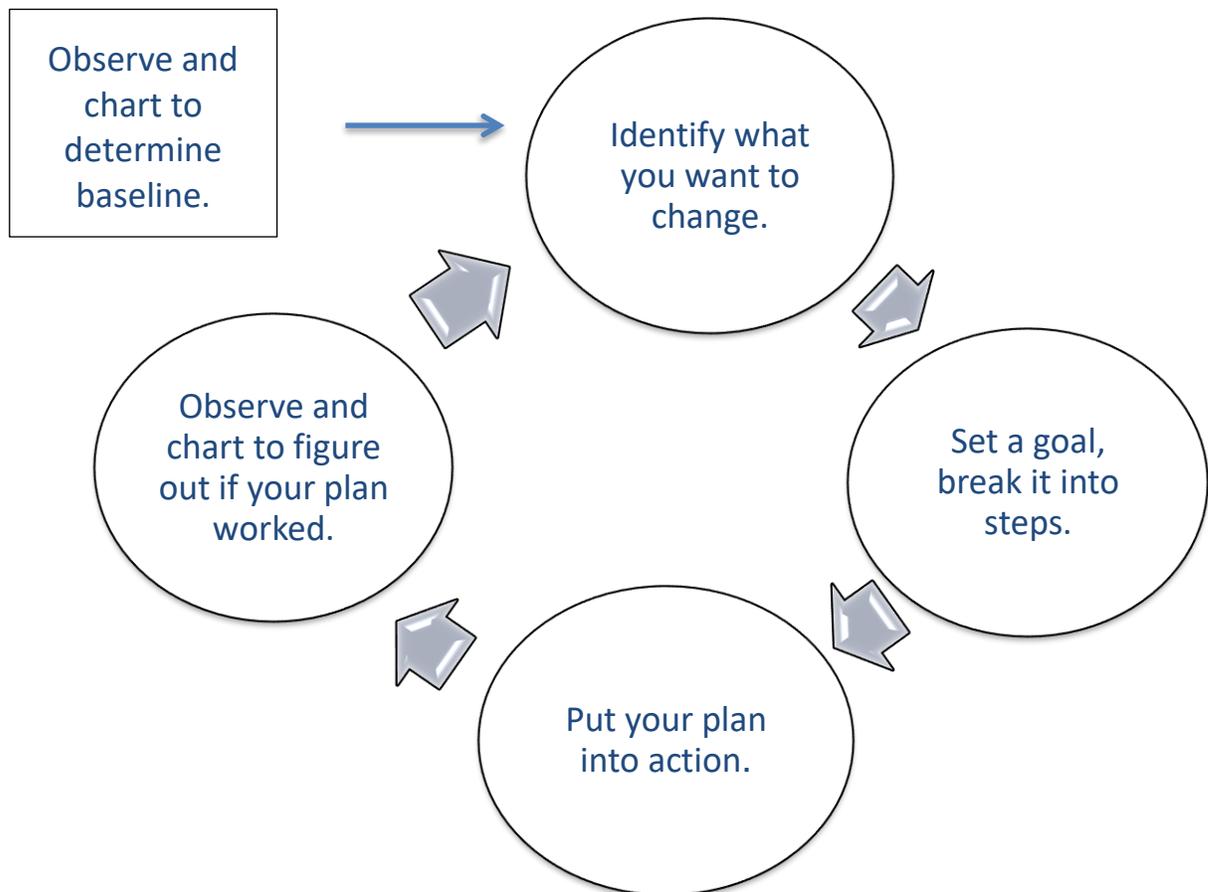
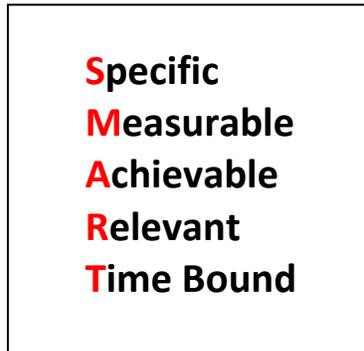


Figure 1.3 The Steps of Self-Management

1. Start with careful observation of symptom patterns (charting) to notice connections between thoughts, feelings, behaviors, and symptoms.
2. Develop hypotheses (informed guesses) about what might improve a problem you have identified.
3. Try the new ideas out.
4. Assess how the plan has worked and change your action plan if needed.

It looks great on paper, right? But how do you actually come up with an achievable goal? SMART is a commonly used acronym to remind people of the components of achievable goals.



Example SMART Goal: React Less to Stressors

Say that in your awareness recordings you have noted that each time something goes wrong in your life, even small things, you immediately feel worried and tense. And you notice that when this happens, pain increases, sleep is disrupted, and you are more tired and cranky, causing a vicious circle. You decide that your goal is to be less affected by stressors. So where to start? Of course, there are so many ways to go about this. Here is one.

You have heard that meditation can help. You search online for the best free meditation apps. You download the app that appeals to you most and try it.

Now, create your SMART goals.

Specific – Practice meditation using the app of your choice.

Measurable – 10 minutes every morning, before starting your day.

Achievable – OK, maybe four out of seven days to start.

Relevant – You really want to learn to be calmer, so you are very motivated to try something new.

Time Bound – You commit to trying the chosen app for two weeks and then re-evaluating.

Developing a Self-Management Plan

Right now, start thinking about what you really want in your life. Spend some quiet, reflective time.

- What do you most enjoy?

- What makes it worthwhile to get up in the morning?
- Who makes you laugh?
- Where and with whom do you feel most yourself?

You likely have many goals and wishes, and not all have equal priority. Your time and energy are precious and you may want to spend them doing the things that are most important to you. The illness experience may have shifted your priorities and you may not want to return to how things were before. You may have new values and ideas of what makes a life worth living. Session #4 in *Let Your Light Shine Through* discusses this in more depth.

As you reflect on what you want, you may find a tug of war in your head between what you think you *should* work on and what you want for yourself. And because of what you hear from society, family, or medical practitioners, it will be hard to distance yourself from the *shoulds*. The most common example of this for people with ME/CFS and FM is the common belief that increasing exercise will make you feel better. Session #4 in *Let Your Light Shine Through* and Chapter 4 in this book discuss how to manage activity if you have ME/CFS and FM. Sometimes in order to set goals that are right for you, you have to examine your beliefs and do some fact checking.

As you progress through *More Light*, I recommend slowly adding to your self-management plan each time you read new information that is relevant to you. For some chapters, there may not be any information that passes your relevancy test. Remember: this is for you and no one else.

As you read each chapter:

1. Make a List of Symptoms or Situations You Want to Lessen

They could be physical or mental health symptoms or life problems. Put the problems causing you the most grief that you most want to change at the top of your list.

2. Make a List of Activities You Enjoy

It is common to think that medical goals are the most important. But as I observe patients, I notice that those who spend time doing things they enjoy seem to cope better than those who spend the whole day doing things they *should* do to get better. Fun, laughter, meaning—it is said that laughter is the best medicine. We now know that feeling better emotionally impacts our physiology for the better. Even the conservative National Institutes for Health is promoting positive emotion for the health impact (<https://newsinhealth.nih.gov/2015/08/positive-emotions-your-health>).

You might be thinking that having fun is an unrealistic suggestion, especially if you are severely ill. You may believe that your symptom burden is too overwhelming to feel anything but misery.

I would challenge you to find some way to frequently experience positive emotions. Even if overall function is decreased, people with ME/CFS, FM, and ES retain their strengths. For example, if you were creative and enjoyed making art before becoming ill, creativity will still be a tonic for you. Even though your capacity may be decreased, doing some creative activities may boost your mood, confidence, and sense of identity. On the other hand, things you were not strong at before becoming ill may be even more difficult now. Focusing on improving skills you were never good at may be an exercise in frustration.

Many of my patients find ways to adapt their interests and skills to their decreased energy. Maybe you can still enjoy art but need help purchasing, transporting, and setting up supplies. Maybe you are no longer able to attend large (noisy) workshops but can invite one or two friends over to create with you. If even this feels out of your grasp right now, take heart. Several of my former patients have written books while they were severely ill. They wrote them while horizontal, mostly in bed. So, don't give up on your passions.

3. What Makes Each Symptom Better or Worse?

Refer to Figure 1.3 as you identify the circumstances or variables that make your problem better or worse. *Variable* is the term given to events that cause something else, such as a symptom or mood, to vary—to get better or worse. It may take several weeks of observation or longer to recognize them, since many variables don't happen every day. For example, noticing the effects of menstrual cycle or season of the year is a long-term project. At first, you don't know what you are looking for.

Start by noting things you observe even if you are unsure if they are related to anything important or not. Charting over time will ensure that you don't miss important variables. Keep a look out for the things that make you feel better, even if only a little bit and for a little while. It may be more beneficial to spend time doing the things that make you feel well than to focus only on alleviating symptoms.

Write each goal in a circle. Around the circle write words describing the variables that impact the problem. Add a plus sign (+) if this variable makes the problem worse and a minus sign (-) if it makes the problem better. Do this for your top 3–5 problems.

4. Look for Patterns

As you complete a better/worse diagram for each symptom, see if you notice any patterns. You might notice that one experience, such as laughter, affects many symptoms. If this is the case, it is worth identifying this variable as a suitable target for which to develop an action plan because the possible benefits could be large. An example of this might be the impact of a good sleep. You may notice that this elusive animal (sleep) leads to decreases in pain and fatigue and

improved mood. If this is the case, then working to improve sleep could have many benefits. Alternatively, you may notice that social connection improves mood, which leads you to be more hopeful and notice your symptoms less. None of these examples may be true for you. The connection between variables and symptoms is different for everyone.



Figure 1.4 What Makes Fatigue Better or Worse?

The boxes with + are the variables that make the fatigue worse.
The boxes with - are the variables that make the fatigue better.

Don't rush your analysis. The quality of your action plan depends on the quality of the information that goes into it. You might have incorrect beliefs about what makes your symptoms better and worse. Be prepared to be wrong. This is when you will learn the most!

5. Brainstorm What You Can Change

Once you have identified the variables that impact you and your symptoms, consider what you might be able to do to influence these variables. If you are short on ideas, do some research and get input from others. Look at the problem from different perspectives.

This could include:

- Talking to others whose opinion you value.
- Talking to someone with expertise in the area.
- Reading to learn more.
- Use inquiry during meditation—sometimes ideas come when we get still.

If you have ME/CFS, FM, and/or ES, you likely struggle with fatigue. Most patients I have worked with have repeatedly tried increasing their activity level but keep developing post-exertional malaise and relapsing. They feel stuck because they really, really want to do more and have not been successful. When people attend my groups, they often hear some little tip they hadn't thought of or tried before from another participant. They go home, try it, and may notice a change. Even small changes lead to increases in hope. Hope keeps motivation alive and experiencing small successes leads to more small experiments.

What about those of you who are reading this book and aren't able to attend one of my groups in Calgary, Canada? Where can you get new ideas? There are many online groups that offer support. If you are struggling, I urge you to keep searching and learning. You never know when you will happen upon an idea that will work for you. One such resource is ME/CFS & Fibromyalgia Self-Help: (www.cfidselfhelp.org). An online education session developed by experienced patients is offered through Action CIND. Go to (www.actioncind.org) to get on the email list for upcoming events. You can also find a paid online coach at the CFS Health website: (<https://cfshealth.com/>).

Be aware that you may have beliefs that impede change. The most common of these is the belief that you already know and have tried everything and that there is nothing more you can do. In Buddhism, it is recommended to have a beginner's mind. Observe yourself as if seeing for the first time and you may notice something you didn't before. Try to catch and change repetitive negative thoughts. Regardless of your previous experience, it is usually possible to improve most situations, even if only a little bit. The steps I have outlined may help you with this.

Sometimes it is difficult to change a physical or social reality such as severe illness or financial challenges. But it is always possible to change attitudes and expectations. I will discuss acceptance more in Chapter 9. Wanting things to be different than they are in the moment is a recipe for misery. Decreasing misery is a goal we all share. And decreasing misery is within our

control. Sometimes this goal of acceptance rises to the top of the list and may supersede the biomedical goals temporarily.

6. Make a Plan

Once you have some ideas for change, make a plan to put your ideas into action. Say you have identified several concerning symptoms such as fatigue, pain, and brain fog. Your analysis reveals your symptoms are all made worse by the same variables: over-activity, being upright, thinking about your finances, and broken sleep. Some of your symptoms feel temporarily better when you do watercolors, rest in a horizontal position, and laugh.

Recognizing this, you develop a plan to increase the variables that help you feel better and reduce the variables that make you feel worse. Working in this way may be more effective in improving your quality of life than trying to address health symptoms directly. This is one contrast between a self-management approach and a medical model. Self-management is holistic. Self-management goes beyond medical management and includes your whole self. Who are you? What are your goals in life apart from improved health? What are your strengths and passions? Self-management allows your full self to be part of the solution.

For each variable—those that help you feel better and those that cause increased symptoms—come up with as many ideas as you can to influence them. Not all ideas will work; not all will be practical. Write them down anyway. This list can be playful, full of dreams and intentions, and not limited to pressure-inducing *shoulds*. It's a road map, not a commandment. The beauty with a map is that you don't have to follow it. You can take a different path if it isn't working out.

With self-management, you are in charge. You are responsible for figuring out what works and what doesn't. As will be discussed in Chapter 3, the brain can't tell the difference between imagination and reality. Even if you can't put many of your dreams into action, imagining the future of your dreams and experiencing positive emotions may help you.

The following is an example of analysis and idea generation for each of the variables identified in Figure 1.3 as influencing fatigue.

1. Overactivity
Analysis: Overactivity is related in part to household tasks.
<ul style="list-style-type: none">➤ Hold a family meeting to discuss how to share the load of household tasks.➤ Break tasks into smaller portions and rest in between each portion.➤ If able, hire help for tasks that no one in the family wants or is able to do.➤ Work on changing your expectations about how often tasks need to be done.➤ Downsize your living space so there are fewer household tasks to be done.➤ Apply to government programs or local charities that can provide assistance.
2. Laughing
Analysis: You have two friends who are hilarious and you generally feel better when you are with them.
<ul style="list-style-type: none">➤ Make a plan with these two friends to have regular visits at intervals that fit your energy envelope. This way you always have something to look forward to.➤ In between visits, send texts or emails of funny things that happen or jokes you hear.➤ Pay attention to the humorous aspects of even the most difficult situations.➤ Record your favorite comedy and watch it as a reward when you have accomplished a task you are less keen on.
3. Being Upright
Analysis: Physical and cognitive symptoms worsen when sitting or standing upright.
<ul style="list-style-type: none">➤ Use a chair when possible. For example, for showering and kitchen work.➤ Use a recliner when possible. For example, for paperwork, watching TV, or talking on the phone.➤ Read the latter part of Session #3 in <i>Let Your Light Shine Through</i>.➤ Hydrate and add measured amounts of salt to diet.➤ Discuss support hose and medications with your physician to maintain blood volume and blood pressure.

4. Creating Beauty
Analysis: You feel better when you look at something beautiful.
<ul style="list-style-type: none">➤ Learn a new creative outlet that is easy to do and can create beauty perfectly.➤ Play with colors.➤ Make copies of pictures you enjoy.➤ Create a corner where you can go to be still and enjoy what you have created and collected.
5. Thinking about Finances
Analysis: Although finances are problematic all the time, it is only when thinking about them that your symptoms feel worse.
<ul style="list-style-type: none">➤ Meet with a financial planner or debt adviser to understand your options.➤ Downsize expenditures, as possible.➤ Designate time to problem-solve the financial problems.➤ Outside of the designated time, think of and do other more enjoyable activities.➤ Practice gratitude.
6. Broken Sleep
Analysis: Sleep efficiency is low (see Chapter 4 for more on this).
<ul style="list-style-type: none">➤ Restrict time in bed to total sleep time + 30 minutes.➤ Get out of bed when unable to sleep and do an enjoyable activity.➤ Train your family pet to sleep outside the bedroom. (Good luck with this one!)➤ Arrange sleep assessment for bed partner who snores loudly.➤ Practice meditation before bed.

Figure 1.5 Analysis and Brainstorming

If you are a person who prefers a graphic format rather than text, you could put your action plan into a diagram so you can see it all at once. Figure 1.6 Health Plan is an example of this.

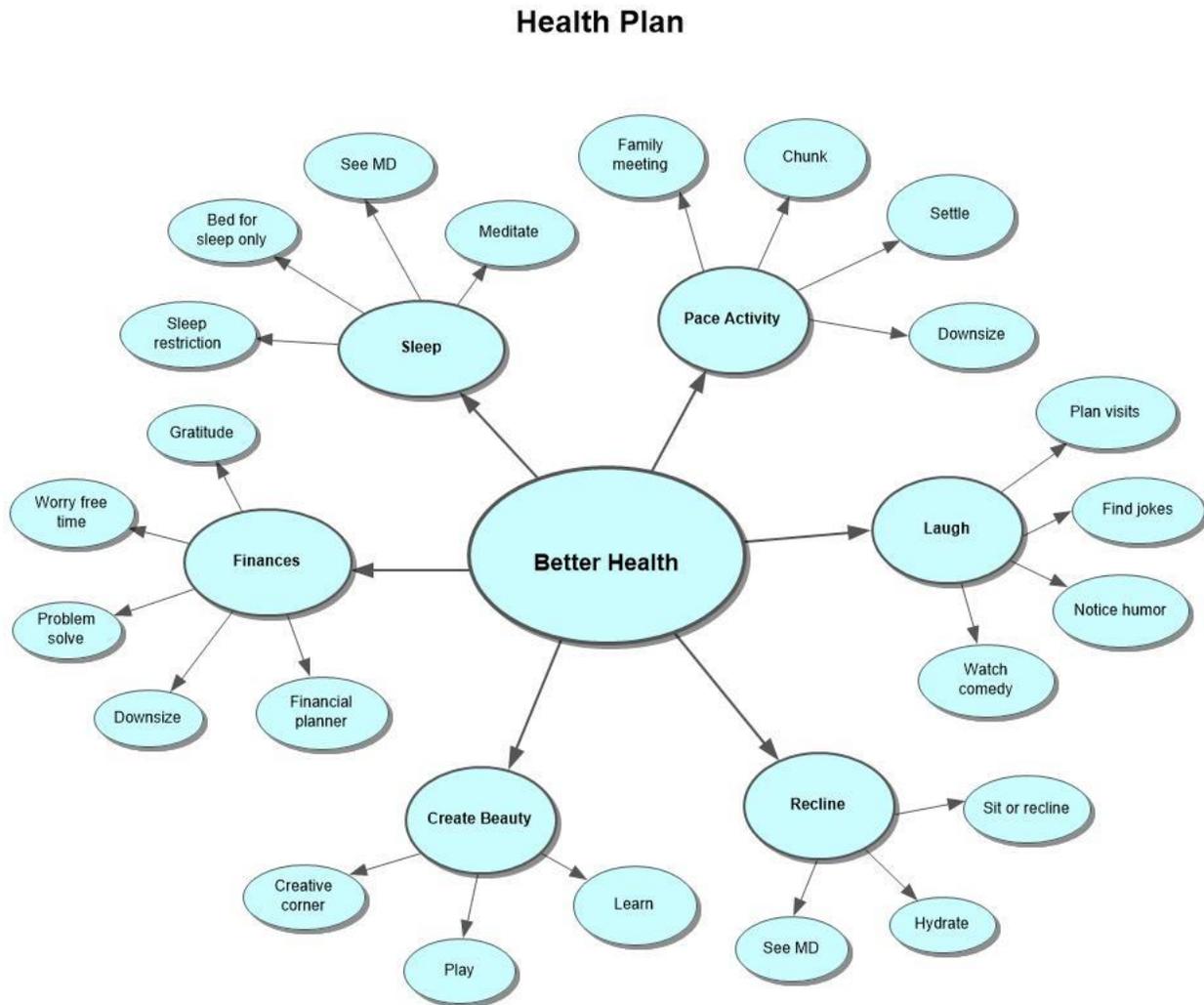


Figure 1.6 Health Plan
Designed by Melissa Ly

Whichever format you prefer, look over your list or diagram and choose one or two goals to start implementing. Start with a goal that is easier to achieve than some of the others, one that is important to you or could be enjoyable. Never underestimate the importance of keeping or reintroducing fun into your life. Having fun causes your brain and body to make molecules of fun. The more fun you have, the more easily your body is able to enjoy life. Fun should be a

prescription for everyone with a chronic condition. It is as, or more, important than medical interventions.

Whatever you do, don't embark on the biggest, hardest goal first. Remember, you want your goals to be achievable. Each time you have success, your confidence and motivation will increase. It is better to choose very small and achievable goals than a large, difficult goal that may take a long time to achieve. If the large goal is very important to you, break it up into small enough steps that your chance of success for each step is high (at least 80%). Read this paragraph over until you are willing to set small achievable goals.

I have facilitated a diet and lifestyle group for many years that supports participants with goal setting. I have observed that the non-judgmental support of others is very helpful. No matter how expert we are at goal setting and problem-solving, not all action plans will be successful. No matter how optimistic we are, we all have periods of discouragement. There are good days and bad days. It is common on the good days to have difficulty remembering that we are so ill. Often, I think to myself, *I'm not really ill. I can do anything I want.* On the bad days, I often forget that I have ever felt better or that the symptoms wax and wane. On these days it is normal to become discouraged, even hopeless. The support of others who have been through similar experiences helps you maintain perspective on the ups and downs of chronic illness. An online support group, while not as powerful as getting to know people in person, can also serve that purpose. When searching for support online, look for groups with positive, active, solution-focused discussion. Communicating with people who complain frequently won't be helpful.

If you can't find the right group for you, consider starting your own online group to support each other in goal setting. You can have a vast store of knowledge, but if you can't put it into action, your health and life will not change.

Over time your goals and action plans may change. You might achieve some parts of a goal and then move on. Or you may learn more and decide a goal isn't possible or important and cross it off your action plan. Keep your working plan in a place where you will see it often. It will remind you of your goals and increase the chances you will work toward them every day.

Questions and Reflection

1. For you, what are the pros and cons of a self-management approach?
2. Complete a Diamond of Awareness after an experience you consider negative and another one for an experience you consider positive. Notice the connections in each of your completed diagrams between the four domains: physical sensations, thoughts, emotions, and actions.

Come up with at least one strategy you could use in future to move in the direction of solutions and a life worth living.

3. Create a SMART goal for one of your health objectives.

4. Begin developing your own health plan:

- Write down the symptoms, problems, or strengths you want to work on. Write each topic at the top of a new page. Jot down ideas for what to include in your action plan on the appropriate page.
- Using Figure 1.3 as an example, create a “what makes my symptom or quality of life better or worse” diagram for one symptom.
- Using Figure 1.4 as an example, make a list of possible actions you could take to make your symptom or quality of life better.

References for Chapter 1

- Anonymous. (2009). What is health? The ability to adapt. *Lancet*, 373(9666), 781.
doi:[https://dx.doi.org/10.1016/S0140-6736\(09\)60456-6](https://dx.doi.org/10.1016/S0140-6736(09)60456-6)
- Burns, D. (2000). *Feeling Good: The New Mood Therapy*. New York: Quill (Harper Collins).
- Derry, S., Cording, M., Wiffen, P. J., Law, S., Phillips, T., & Moore, R. A. (2016). Pregabalin for pain in fibromyalgia in adults. *Cochrane Database of Systematic Reviews*, 9, CD011790.
doi:<https://dx.doi.org/10.1002/14651858.CD011790.pub2>
- Linehan, M. (2015). *DBT Skills Training Manual*: Guilford Press.
- Luciano, J. V., Martinez, N., Fernandez-Vergel, R., Garcia-Campayo, J., Verduras, C., Blanco, M. E., . . . Serrano-Blanco, A. (2011). Effectiveness of a psychoeducational treatment program implemented in general practice for fibromyalgia patients: a randomized controlled trial. *Clin J Pain*, 27(5), 383-391. doi:10.1097/AJP.0b013e31820b131c [doi]
- Panagioti, M., Richardson, G., Small, N., Murray, E., Rogers, A., Kennedy, A., . . . Bower, P. (2014). Self-management support interventions to reduce health care utilisation without compromising outcomes: a systematic review and meta-analysis. *BMC Health Services Research*, 14, 356. doi:<https://dx.doi.org/10.1186/1472-6963-14-356>
- Van de Velde, D., De Zutter, F., Satink, T., Costa, U., Janquart, S., Senn, D., & De Vriendt, P. (2019). Delineating the concept of self-management in chronic conditions: a concept analysis. *BMJ Open*, 9(7), e027775. doi:<https://dx.doi.org/10.1136/bmjopen-2018-027775>