

Disability Dialogue Presents

A Do-It-Yourself Guide To Managing Your *NewLife*



Susan Schaffer, M.S.

30 W Broad St. Bethlehem, PA 18018

13Suewheels13@gmail.com

484-425-7587



Introduction

Suddenly, by some crazy act of nature or circumstance, you have a physical challenge. The first thing to remember is that regardless of what has happened, you are still you. Your life may seem as though it was turned upside down, but there are ways of dealing with this situation. I know this, because I have a physical disability myself, and I have become quite resourceful when it comes to functioning independently. I realize that not everyone is capable of the same level of independent functioning; however, with tenacity, hard work, and hope, your quality of life will improve. You will feel empowered, have more freedom, and not fall through the cracks in this big, impersonal world.

What does it mean to “fall through the cracks?” It means to admit defeat and allow others to tell you what is best for you. You will probably be inundated with “experts” who will want to give you advice to help you physically, psychologically, emotionally, and in ways you could never have imagined. Some of the help will be useful, and some of it will be medically necessary; however, don’t feel obligated to follow everyone’s advice. Just remember you are your own expert and you still have the final say in what decisions are made about your life.

What follows is a unique self-help book that addresses common issues from the perspective of a person who has a physical disability. Perhaps you have a few stories and/or solutions of your own to add. If so, visit www.pawnedcreations.com. I hope you will share this booklet so it can help others.



A special message for our troops...

The original purpose of this booklet was to reach out to the men and women who are injured fighting in the military. Once discharged from the battlefield, then the hospital, due to physical injury, the battle within you begins. The battle may seem worse than the one fought on foreign soil. There is no instruction book for learning to cope with a disability, but you have the weapons within you- your attitude. You will eventually learn to manage at home and in the community. Life can be just as rewarding as it was before your injury, and you can still reach your goals, but the route you take may be just a bit different. Fasten your seat belt and get ready for a new adventure. The first bit of advice is to keep your mind focused and face forward, don't look in the rear - view mirror.



Physical Issues

Some people think you will be fine once you schedule regular physical therapy sessions, but, unfortunately, this is not always the case. It depends on your type and severity of injury along with other factors. Of course, there is a lot to say for determination and exercise, but sometimes your body is just not going to do what it used to; however, that does not mean you should stop therapy. Do not allow negativity to take over. You can continue to have a life, regardless of how physically weak your body has become. You can compensate for your lack of physical strength in other ways.

Remember the Serenity Prayer—"God give me the serenity to accept the things I cannot change, the courage to change the things I can accept, and the wisdom to know the difference." Evaluate what you can still do and consider what kind of assistance you will need in order to manage each day. Mentally take yourself through a typical day in your previous life. The things that you struggle with now may become easier in time, so do not become too concerned. Once you figure out what kind of help you need, find someone to help you do it. Determine which agencies provide the services that will help you, and contact them. A good starting point is your Center for Independent Living. This agency is run by and for people with physical disabilities; therefore, they are familiar with typical challenges you face.

Do not become discouraged about receiving help. Able-bodied people employ others to do many daily tasks (cleaning, cooking, etc.), so do not feel badly about getting help. Contact home health care agencies or place a private ad in the newspaper or on a college bulletin board in order to find help.

Below are some questions to consider on physical functioning. Write down your thoughts.

Can I manage ... and what can I do about it?

- ... to open the front door? ... to get in the bedroom?
- ... to get into the bathroom? ... to reach the closet?
- ... to take a shower? ... to reach the dresser?
- ... to use the toilet? ... to get into the kitchen?
- ... to reach the stove, counter, and sink?
- ... to get into the living room?
- ... to sit at the kitchen/dining room tables?
- ... to work the light switches?
- ... to perform housework (clean, cook, etc)?
-to perform yard work (rake, mow, garden)?



Psychological Issues

One of the most important factors in improving your independence is to have a positive attitude. You must believe that you will have a good life and remind yourself that “things will get better.” If you are focused on the task and determined to work hard, that is half the battle. This is easier said than done, especially when you remember how easy it was to function before your disability, and how much further you have to reach your goal now. In order to stay on track with your thinking, it helps to keep a journal. Record your successes, regardless of how insignificant they may seem, and vent your frustrations in writing. Emphasize the positives, and try to limit the number of negative entries because the more often you write/think the thoughts the more pessimistic you will become. You want the glass to be half full, not half empty. Every few weeks reread some of them to determine how much progress you have made - you may be surprised.

Write down a goal for yourself and once you reach it, replace it with another one. It is important to make sure that your goals are realistic. If they are too grand and you do not reach them, you may be disappointed. If you reach them within a reasonable time period, you will be ready to make another one. On the flip side, you should challenge yourself, or you will not really be making any progress. Make a time line for yourself and document your achievements. This activity should help your mindset stay reasonably positive.

One crucial point to remember is that you are still you, regardless of your new challenges. You may even have new options ahead for yourself that you would not have had if you were not injured. Speak using positive language, you are “a person with a disability” not “a disabled person.” The ‘disability’ is not a word that should be used to describe you. Words are powerful, and they can affect your self esteem. It is not merely a matter of semantics. In some instances, it may be beneficial and/or necessary to seek professional help in addition to these suggestions.

Below are some questions to consider on psychological functioning. Write down your thoughts.

What parts of my new life have I accepted, and what parts have I not?

How can I better accept my situation?

What are some discoveries I have made about myself?

How far have I come since my injury? How far do I have to go?

In what ways am I the same or different than I was before the injury.



Social Issues

The support of family and friends is crucial to coping with your disability. It may be helpful to join a support group so you can communicate with others who have experienced similar situations. It is important to be around people. If you isolate yourself, you risk falling into a depression. It is often uncomfortable at first to ask for and accept help from others to do things you used to do easily. Think of it this way: you no longer have to come up with a “pick up line” to meet people.

On the flip side, if someone offers you help and you do not want it, try to be tactful about refusing. The person meant well, and you should not bite his or her head off if you are striving to be independent. It becomes frustrating because you may encounter well – meaning people who will not take “no” for an answer. Some people will be offended by your response, regardless of how polite you are about it. It is an art to balance how you react when you are offered help.

I will not sugar – coat your situation. You will probably get unwanted attention, since people are naturally curious. Remember, strangers are looking at the body you have now; they don’t know you and never knew you before. When you see a child who seems curious, find the patience to say hello and offer the opportunity to ask a question. Encouraging questions is the best way to combat stereotypes. If a child just stares and then leaves, (s)he will have the chance to make judgments that are untrue, and this could turn into discrimination against people with physical disabilities. The simple act of smiling and saying “hello” can really leave a positive impression.

If you were married prior to the accident, the adjustment process can go either way. On the one hand, you have an immediate support system from someone who knows you well - the part that matters most. On the other hand, you and your spouse are confronted with a new set of problems, and that may or may not be too much of a strain on the relationship. If you rely too heavily on the spouse for help, it may lead to resentment. You should find a balance. It may be helpful for you to attend counseling to get some perspective from an impartial third party. The most important component of any relationship is good communication.

Below are some questions to consider regarding social issues. Write down your thoughts.

How do others perceive me? How can I act more positively?

How are friends and relatives treating me now that I have a disability?

Where can I go to meet people?

Who are the supportive people in my life?

Have I allowed others to help me? Explain.



Vocational Issues

Work gives life a sense of purpose; it makes people feel valued; it contributes positively to self-esteem. Returning to the job you held before you were injured may be your ultimate goal, but for many people, that is not an option. Before you start looking for a new job, consider your old one again. Are you able to perform the major functions? Can accommodations be made at the worksite? Are there other positions within the company for which you can apply? Speak to your boss. The Americans with Disabilities Act mandates that employers cannot discriminate based on your disability. Furthermore, the law provides tax credits to eligible companies that want to make the physical accommodations.

There are some modifications an employer may make that cost a minimal amount of money or none at all. For example, to raise the height of a desk so a wheelchair can roll under it, put it on bricks. If you cannot reach the file cabinet, ask for permission to make your drawer into a small cabinet for files. If one of your job duties involved physical activity, switch one of your job duties with someone else. Lower a fax machine and microwave by placing it on a desk. If you must take medication at a certain time, take shorter breaks, but more frequently to get your total work hours. If you must use public transportation, come early or leave late. You can replace a bathroom door with a curtain, and if it is too low to transfer on, get a raised plastic seat.

If traveling is difficult and you cannot do the job at home, you may investigate starting a home - based business. The computer offers a myriad of programs to earn money, and sitting at a computer is a sedentary activity. This is a cheaper way to reach more potential customers, since the web is worldwide. Unfortunately, there is a lot of competition on the internet and people may scam you by making empty promises about their programs - be aware!

Below are some questions to consider on vocational issues. Write down your thoughts.

Did I enjoy the job I had before I was injured?

Could I return to my previous job?

What modifications would be needed?

If I start a home based - business what would I do?

Could I learn some new skills or get some training?



Higher Education Issues

Four – year colleges

An option to consider, if returning to your previous job is unrealistic, is to enroll in college to learn some new skills. The Office of Vocational Rehabilitation is a state agency that offers assistance with college issues. They may help you financially with tuition and footing the bill for disability needs such as attendant care. Many colleges have advisement counselors specifically for students with disabilities. This person will discuss the physical accessibility of the campus, will find students to help you with attendant care and note taking; arrange for you to have extra time for tests, and move classes to accessible buildings, if necessary.

Other options

If a four – year degree is not an option, local community colleges and trade schools may fit best into your life. These programs, offered through many types of schools, are shorter and cheaper if you need a certificate or an Associate's Degree in order to be qualified for the desired job. This is a good opportunity; especially if you have a family to take care of and must remain home. Other options include classes on the Internet or a correspondence school. You may never have to leave your home to attend class, or, if you do, it is for a very limited number of days. Class work is completed via the internet or snail mail and you may make arrangements to contact your advisor and/or professors regularly throughout your experience. Internships and scholarships are available if you qualify.

Below are some questions to consider on educational issues. Write down your thoughts.

What education would be required for you to hold a different job?

What type of work would you enjoy performing?

What type of job could you realistically perform?

Would you be able to physically endure college?

Would you be able to financially afford college?

Would financial assistance be available?



Community Issues

It is important that you venture out into the community and do something enjoyable as often as possible. Seeing a movie, going out to a restaurant, or attending a religious service are very good ways to lift your spirits. Focusing on a pleasurable activity will take your mind off of your current situation, at least for a little while. Perhaps you could join a group that meets regularly, or you might take classes on a hobby you enjoy.

There are some things you must now consider when making arrangements to leave the house. Ask if there are accessible restrooms and any steps to get through the front door. Most places do not have any problems, but it is a good practice to ask. Next, if you rely on attendant care, make sure you speak to the person ahead of time and explain your plans. You do not want to be up all night because you forgot to phone a friend to help you into bed.

Volunteering is a wonderful outlet in which you are doing something meaningful. Some places in the community that use volunteers are libraries, hospitals, churches, The Red Cross, and The United Way. A wonderful volunteer program that is found in many communities is called "Community Exchange." People help each other and their hours are tracked, so rather than receiving money for a service, they receive points. Once you accumulate points by helping others, you may receive help. For example, once Betty gets points for helping Tommy with housework, Betty is eligible to receive a ride to the store from Greta. This cycle continues indefinitely. Check your area to see if there is such a program or try to start one. "Craigslist" is a way to learn of community groups. There is an entire section for that purpose and ads are free. "Meetups" is another way to initiate groups. Check your local and community newspapers.

Below are some questions to consider on Community Issues. Write down your thoughts.

What are some interests I have always wanted to pursue?

Are these places near bus routes?

What are the hours of the events?

If the function is at night, can I get myself into bed after I return home?

What are some volunteer programs in which I can get involved?

Can I start my own group activity? (Check "meetups" on your computer)

Now that the “lecture” is over it is time to view things from a less serious perspective. Each day you will discover new challenges and ways of dealing with them. If you’re keeping a journal, reflect on your entries and start sharing them with others who are just starting the journey.

Physical Issues- “What are my limits?”

* “Slow as molasses in January” If you are determined to use your muscles to manage your daily life, that is admirable. It is usually more meaningful to perform a task on your own. It may be slow at first, but it will get easier and soon your pace will quicken. If you get used to people doing for you, your muscles will soon atrophy and you will regress.

* “One step at a time” On the other hand, if you are too determined to be independent and your body isn’t ready yet. You may re-injure yourself. It is common for a person to overdo therapy, be over confident, and not listen to the doctor’s orders. This can result in a setback.

* “It’s how you play the game” Sports may still be a good outlet for you. There are all kinds of athletic programs for people who have disabilities. The Paralympics is a program in which people with physical challenges compete globally. Quad rugby is a very competitive program for people with physical disabilities.

Psychological Issues- “Who am I?”

* “The name game” The actual diagnosis may be important for medical billing, educational, genetic, and reimbursement purposes, but that’s the extent of it. Once you have a name for the problem, there is a major downside. Often people hide behind the word and use it as an excuse for laziness. More important than terminology is how you cope with it.

* “How do you like me now?” Those are lyrics from a song by a singer who talks about the way he was perceived in high school versus his present persona. Although he is successful now, he is still the same person inside. Society often judges people when the circumstances have changed. You must remember that regardless of your appearance, you’re still you.

* “Just do it.” That slogan is not just for Nike Sneakers. People over analyze something and then decide against it. The deck may seem to be stacked against you, but do not allow that kind of thinking to control you. Life may be challenging now, but you still have a lot of living to do.

* “Every cloud has a silver lining.” Things do not always work out the way we plan, but there is always a flip side. Regardless of how bad things are, it can always be worse. Take time to think of how something can be worse and realize that it is not so bad.

Social Issues- “You’ve got to have friends”

* “Getting to know you” These lyrics from “The King and I” musical, hold true for anyone. It is important to take the time to reach out to a person. Everyone has a story to tell, and everyone has something of value to contribute to society. Don’t just decide to overlook the obvious.

* “Lean on me” We rely on others most of the time, whether it is your boss, your grocer, or your husband. All people know other people, and I believe that life is easier when you have connections. Do not bear the burden of a disability completely alone.

*” Don’t air your dirty laundry” On the other hand, it may be best to keep some things to yourself and your immediate family. Make it a policy to share with the right people. When others ask “How are you?” they do not expect a pessimistic long answer. It isn’t that they don’t care, but they have problems of their own.

Vocational Issues- “What do people do all day?”

* “Taking care of business” Work is often considered the most important part of adult life. It not only increases your income, but it also increases your value as a human being because you are contributing to society. Everyone can do something, regardless of how mundane it may seem. It does not have to be paid employment to be meaningful. .

* “You’re hired!” Stand up for yourself, sell yourself, and apply for that job. If you believe that you are qualified, then prove it. The Americans with Disabilities Act was written to level the playing field for all job applicants.

* “Reading, Writing and ‘rithmetic” One good thing that may result from the injury is the chance to go back to school. Perhaps there has always been a field that you wished you could pursue, but you could not, since you had obligations. Now you may have the opportunity!

Community Issues- “What can I do for you?”

*” The melting pot” There are many kinds of people in this world and everyone is given the chance to succeed. You live where there are freedoms and opportunities unlike anywhere else. Do not allow your disability to take over your life.

*” Alone we can do so little but together we can do so much” Helen Keller tells us we can make a difference but we must be inclusive because everyone’s contribution matters.

*” No man is an island” We all need each other regardless of our limitations; we are all interdependent creatures. Do not feel badly for requiring help in life.

