

Special Services and Resources You Should Know About

Americans with Disabilities Act (ADA)

ADA “prohibits discrimination against people with disabilities in employment, transportation, public accommodation, communications, and governmental activities.” Reasonable accommodations/modifications must be made.

You can read more on ADA (and get the full text) at: <http://www.ada.gov/>

Anti-Discrimination Clauses

Your workplace should have an anti-discrimination clause in your employment paperwork. Most workplaces also have information about what to do in cases of discrimination. Check with your employer’s human resources department if you are having difficulty finding this information.

The same should go for any contract that you sign, including rental agreements. Make sure you are able to find them.

“I have found that the more understanding my employer is, the more I feel comfortable explaining. Then, it is easier to find a solution that works for me and my employer.” - Anonymous

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RSDSA

RSDSA’s mission is to educate, support, and provide hope for all those affected by CRPS/RSD while continuing to be a driving force behind research.

RSDSA has additional resources that you may need. They also offer a database of support groups throughout the country.

To learn more, visit www.rsds.org

Social Security

Some individuals with CRPS qualify for Social Security Disability Insurance (SSDI). There is also Supplemental Security Income. These programs pay you, and sometimes certain members of your family, when you meet a certain medical criteria. While most people get denied the first time, there is the ability to appeal and/or apply again. This is helpful if you cannot work full time.

For more information on this, visit: <https://www.ssa.gov/disability/>

Service Animals

Some individuals with CRPS qualify for a service animal. A service animal is “any dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability” (adata.org). To learn more about service animals, visit

<https://adata.org/factsheet/service-animals/>

Taking Control: Gaining Independence with CRPS



Having CRPS (Complex Regional Pain Syndrome) can impact every element of life. However, that does not mean you have to give up your independence. You can go out into the world and do what your heart desires. From obtaining a job to moving out on your own, we want to help you. It may seem like an intimidating task to take on, but there are resources available that you can utilize to make the process easier!

Whether this is your first time gaining independence, or if you are trying to regain independence for the first time with CRPS, browse through this brochure. There are tips and tricks as well as a listing of potential resources for you to use. Each step towards your goal is important to us.

*“You’re braver than you believe,
stronger than you seem, and
smarter than you think”- A.A.
Milne “Winnie the Pooh”*

About CRPS

CRPS/RSD stands for Complex Regional Pain Syndrome/ Reflex Sympathetic Dystrophy. It is a chronic neuroinflammatory condition, which can become very debilitating. It is considered to be a rare disorder by the Federal Food and Drug Administration. The pain that people with CRPS live with is rated to be the worst pain on the McGill Pain Scale. The exact cause of CRPS is unknown, although there is often a trauma that triggers it (sprain, fracture, surgery). CRPS can spread throughout the body, not just the site of the trauma. While CRPS is not life-threatening, it is a life-changing event. Some of the symptoms include:

- ◇ Temperature change in the affected area
- ◇ Swelling and discoloration
- ◇ Allodynia (pain from stimuli that is not normally painful—the touch of fabric or the wind blowing)
- ◇ Burning/icy sensation
- ◇ Limited range of motion
- ◇ Flare-ups of pain (pain that is worse than every day pain)

What to Consider in the Workplace

Some of you may be going to work for the very first time. Others will be going back to work for the first time with CRPS or will be getting a new job. There are important elements of work that must be considered before you decide on a new job:

- ◇ How accessible is the environment based on your needs?
- ◇ How physically demanding is the job on your entire body?
- ◇ Travel can be taxing on people with CRPS. Commuting can be an important part of work.



- ◇ If you cannot drive, consider a workplace that allows you to work remotely or somewhere that you can take public transportation to.
- ◇ During an interview, they are not allowed to ask you if you are disabled *unless* it is a physical job that disability would impact.

Being Successful In Work

To be successful in the workplace, it is important to communicate and plan. Some suggestions are:

- ◇ Once you are hired, have an open and honest discussion with your employer about CRPS and what that means for you.
- ◇ If you are sensitive to touch, let people know immediately so you can avoid handshakes, pats on the back, etc.

- ◇ Attend work whenever possible.
- ◇ See if you can work from home if you're experiencing pain that prevents you from being able to go into work.
- ◇ Schedule doctors' appointments around work.
- ◇ Break up big projects into smaller, more manageable tasks.
- ◇ Ask for help when needed.
- ◇ Ask for accommodations, such as handicap parking spot, speech to text software, a seat to support you, etc. to help you be able to do your job.

Living with CRPS

Living on your own can be intimidating, especially when living with CRPS. It is possible for you to live a successful, fulfilling life independently. If you're heading out on your own, here are a few suggestions:

- ◇ Find an apartment complex with a first floor room available or a one floor home.
- ◇ If you qualify for section 8, you need to apply at least a year in advance for housing.
- ◇ Ideally, find a place that would be close to doctors and/or other buildings/people you would need.
- ◇ Find a local support group that you could network with. They will be your allies. They can steer you in the right direction in terms of local resources.
- ◇ Find the devices that help you the best. Whether it is mobility equipment or something like an automatic jar opener or shower chair.

"Sometimes, employers want to keep you as another number. Find an employer that thinks of you as a person." -Anonymous

Making Life Easier

Once you're settled in, here are some different services that could make your life easier. Do your research on some of the following:

- ◇ Some states have special agencies to help people with disabilities find work or go to school. Try to get into one of these programs.
- ◇ Delivery service for groceries is popular right now. See if your local store offers this. There are also other fresh food delivery services online.
- ◇ Always carry a list of your medications, emergency contacts, and list of conditions on you in your wallet/purse in case of emergency. If you have an iPhone, the Health app sets up emergency lists.
- ◇ If you don't live near public transportation, consider using a taxi-like service such as Uber or Lyft. You can book them from your phone.
- ◇ Find a relaxation technique that works for you and set time aside to do that every day. You have to take care of you!