

FSG NATIONAL SAFETY MONTH MEETING GUIDE

June is National Safety Month. RSDSA's Facilitator Support Group¹ (FSG) has developed this National Safety Month Meeting Guide to promote living safely with CRPS/RSD. We invite all RSDSA support groups to join together as a community by making National Safety Month their topic during the month of June. We encourage all members of our community to take advantage of these resources.

If you are a support group facilitator and would like to join FSG or apply for a grant, please contact Jim Broatch, 877-662-7737 or info@rds.org.

If you are interested in joining a support group you can find a list of RSDSA registered support groups at: <https://rds.org/find-a-support-group-near-you/>.

National Safety Month generated many ideas, from topics specific to managing our condition, to practical emergency and safety preparation. We have covered four broad areas:

- Medical Records and Medical Preparedness Page 2
- Household and Personal Safety Page 5
- Disaster and Emergency Planning Page 6
- Crisis Management and Suicide Prevention Page 7

Any one of these subjects could be the centerpiece of your next support group meeting.

MEETING PREPARATION:

- Review and select one or more of the resources to share with your support group.
- Consider contacting an organization with expertise on your topic for local information and/or to find out if they can send a speaker to your meeting.
- If you don't have a speaker, select a video or printed resource as a starting point.
- Write down a few questions to get the conversation started.

¹ The Facilitator Support Group (FSG) is a resource for new and existing RSDSA group leaders. We offer a monthly support call, a Facebook page, and a grant program. We are developing a library of resources for facilitators including how-to publications and meeting guides, and are planning a leader's conference. We invite you to become a member of FSG and let us know how we can help you.

TOPIC 1: MEDICAL RECORDS and MEDICAL PREPAREDNESS

Imagine a situation in which you are unable to speak, no one knows you, and you end up in the back of an ambulance. What do you want emergency professionals to know about you? If you have CRPS/RSD, you need them to know what medications you take, if you have a spinal cord stimulator, which areas of your body they can use for procedures, and importantly - what areas to avoid!

In addition, many of us have coexisting conditions or other health needs. On top of that, we face the frustrating reality that many of the medical professionals we rely on have never heard of CRPS/RSD and we are called on to educate the doctors who care for us.

How can we prepare ourselves to interact effectively with medical professionals whom we may need to educate? What can we do ahead of time to ensure that we get the best care possible in the case of an emergency?

Here are a few tips on keeping your medical history accessible, and some recommendations for planning for the future.

RESOURCES:

- **Medical History and Medical ID**

Whether you go digital or prefer to carry a paper copy with you, keeping your medical records at your fingertips can be critical in an emergency. A wallet medical card placed next to your ID alerts first responders to your emergency contacts, physician, medications, medical conditions, and where to find additional information.

Use your phone to store “in Case of Emergency” (iCE) contacts and to store your medical records. Check your phone – your profile may be accessible by emergency professionals and is a good place to put the information you want them to know before treating you.

Give your emergency contacts a copy of your medical history so they can pass that information on in case you are unable to.

Medical IDs allow emergency responders to quickly identify your medical condition. Medical jewelry can be discreetly engraved with limited information such as your name, phone number, and condition. Comprehensive medical IDs link to a medical record your emergency team can access by phone or digitally depending on the service.

Here are some resources for having your medical information handy.

- AHIMA: *Quick Guide to Starting a PHR*
http://www.myphr.com/StartaPHR/quick_guide.aspx
- The Backup Plan: *How to Keep Your Medical Records at Your Fingertips*
Step by step instructions and downloadable Medical History form.
<https://rnn10.wordpress.com/2014/06/08/medicalhistory/>

- The Backup Plan: *Shortcut Sheets*
Instructions for placing medical records on your phone
<https://rnn10.wordpress.com/free-resources/>
- Google: Phone App for iCE Medical Information
https://play.google.com/store/apps/details?id=app.medicalid.free&hl=en_US
- **Emergency room treatment** for acute flares of CRPS/RSD can be a nightmare so many of us avoid it. If you do need to go to the E/R for CRPS/RSD, here are some tips to help you communicate with E/R staff.
 - Carry RSDSA publications: [Emergency Department and Urgent Care Guidelines](#) and [Hospital Guidelines](#) and [I Have CRPS](#) wallet card. You can print RSDSA content from the web page, or call 877-662-7737 for paper copies.
 - Plan ahead by having your doctor write a letter explaining that you are his/her patient and giving instructions about what care they recommend for you in an acute flare and/or how to reach them in an emergency.
 - Carry validated information about CRPS with you such as the National Institute of Health's brochure "Complex Regional Pain Syndrome Fact Sheet" which you can order free online.
 - Bringing information about CRPS written by emergency professionals for emergency professionals may help doctors who do not recognize the seriousness of CRPS/RSD better understand your situation.

Emergency Treatment Resources:

- RSDSA "Could This Be CRPS" Brochure
<https://rsds.org/wp-content/uploads/2017/09/RSDSA-CouldThisBeCRPS-Brochure.pdf>
- National Institute of Health, "CRPS Fact Sheet" and Brochure
<https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Complex-Regional-Pain-Syndrome-Fact-Sheet>
<https://catalog.ninds.nih.gov/ninds/product/Complex-Regional-Pain-syndrome/17-4173> (free)
- American College of Emergency Physicians: *ACEP Now*
"Tips for Managing Complex Regional Pain Syndrome" 9-11-15
<http://www.acepnow.com/article/tips-for-managing-complex-regional-pain-syndrome/?singlepage=1>

- American College of Emergency Physicians: *ACEP Now*
“What Emergency Physicians Need to Know About Complex Regional Pain Syndrome” 12-14-16
<http://www.acepnow.com/article/emergency-physicians-need-know-complex-regional-pain-syndrome/?singlepage=1>

- **Advanced Health Care Directives: Protecting Your Wishes**

Have you made your emergency and/or end of life health care wishes known? Do you know what choices you can make, and have you designated someone to speak on your behalf if you are unable to make your own choices?

It’s not something we like to think about, but a time may come when we need to rely on others. To ensure that your health care directives are followed, you must fill out the required forms and follow state rules.

Information about Advance Health Care planning, DNR, Living Will and Medical Power of Attorney can be found at the following sites:

- Mayo Clinic: *Healthy Lifestyle – Consumer Health*
“Living Will and Advance Directives for Medical Decisions”
<https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303>
- Kaiser Permanente
Advance Care Planning: Frequently Asked Questions and Answers
https://mydoctor.kaiserpermanente.org/ncal/Images/011061-251CL_tcm75-185575.pdf
- Making Your Wishes Known: *Advance Directive*
An online resource which generates an Advance Health Care Directive for you. Includes educational videos and tips on talking to others about emergency or end of life care.
<https://www.makingyourwishesknown.com>

TOPIC 2: HOUSEHOLD and PERSONAL SAFETY

Home is our safe haven, where we relax, retreat, and find restoration. Sometimes the complexities of living with CRPS take center stage, and we may not notice basic home safety issues. When was the last time you did a home safety inspection? If you have a disability, have you considered home modifications to reduce your risk of injury?

Completing a safety check as part of your home maintenance schedule makes sense. This includes such items as checking the batteries in your fire alarm, making sure your stairs and entries are clear, removing fire hazards, and making sure your medications are stored safely. A small amount of time resolving any of these issues now could prevent major problems in the future. The resources listed below cover a broad spectrum of home safety topics, including a guide to national programs offering assistance to help people with disabilities finance home modifications.

RESOURCES:

- *The Safewise Report: Safety Hazards to Watch for Around the House*
<https://www.safewise.com/blog/safety-hazards-to-watch-out-for-around-the-house/>
- Atlantic Training: *Home Safety Tips a Comprehensive Resource*
<http://www.atlantictraining.com/safety-tips/home-safety-tips.php>
- Amputee Coalition of America
inMotion: Home Safety for People With Disabilities
[http://www.cdss.ca.gov/agedblinddisabled/res/VPTC2/5%20Injury%20and%20Fall%20Prevention/Home Safety for People with Disabilities.pdf](http://www.cdss.ca.gov/agedblinddisabled/res/VPTC2/5%20Injury%20and%20Fall%20Prevention/Home%20Safety%20for%20People%20with%20Disabilities.pdf)
- AARP Foundation
AARP Livable Communities: The AARP Home Fit Guide
<https://www.aarp.org/livable-communities/info-2014/aarp-home-fit-guide-aging-in-place.html>
- Home Advisor
Grants for Home Modification: 16 Resources for Homeowners with Disabilities
<https://www.homeadvisor.com/r/grants-for-home-modification/>
- American Society of Health-System Pharmacists
Safe Medication: How to Safely Store and Dispose of Your Medications
<http://www.safemedication.com/safemed/PharmacistsJournal/How-to-Safely-Store-and-Dispose-of-Your-Medications>
- *Activebeat: 8 Facts on Safe Food Handling at Home*
<https://www.activebeat.co/diet-nutrition/8-facts-on-safe-food-handling-at-home/?streamview=all>

TOPIC 3 – DISASTER and EMERGENCY PLANNING

We think it will never happen to us, but what if a disaster or emergency strikes? Are you prepared? Does your family know what to do and where to meet? What will happen to your pets? If your mobility is affected by CRPS, do you know how you would evacuate? Taking the time to put a plan in place, or updating your existing plan, could mean the difference between confusion and effective action. Being prepared can save lives.

Here are a few things you can do. Check national and local web sites to find out where your evacuation centers are located, and what supplies you need to bring with you. Download and follow emergency planning checklists. Review your insurance policies for covered events, and to see if you have enough insurance to cover potential losses. Consider video-taping your home to document your property. You can even do an emergency drill as a dry run so the whole family knows what to do if you ever need to implement your plan.

RESOURCES:

- Federal Emergency Management Agency (FEMA)
 - Video: *Important Things to Know Before a Disaster*
<https://www.fema.gov/media-library/assets/videos/159970>
 - Brochure: “Preparing Makes Sense for People With Disabilities”
https://www.fema.gov/media-library-data/1440775166124-c0fadbb53eb55116746e811f258efb10/FEMA-ReadySpNeeds_web_v3.pdf
Note ~ Contact RSDSA for hard copies of this brochure
 - Ready.gov Guide: *Plan Ahead for Disasters*
<https://www.ready.gov/>
- Centers for Disease Control (CDC)
 - *Emergency Preparedness: Including People with Disabilities*
<https://www.cdc.gov/ncbddd/disabilityandhealth/emergencypreparedness.html>
 - *Preparing Your Medicine Cabinet for an Emergency: A Checklist*
<https://blogs.cdc.gov/publichealthmatters/2017/10/preparing-your-medicine-cabinet-for-an-emergency/>
- American Red Cross: *Disaster Safety for People With Disabilities*
Includes preparedness guide and downloadable resources
<http://www.redcross.org/get-help/how-to-prepare-for-emergencies/disaster-safety-for-people-with-disabilities>
- National Safety Council: *National Safety Month Free Materials*
<http://www.nsc.org/act/events/Pages/National-Safety-Month-Free-Materials.aspx>
- National Fire Protection Association: *Emergency Preparedness*
<https://www.nfpa.org/Public-Education/By-topic/Emergency-Preparedness>

TOPIC 4 – CRISIS MANAGEMENT and SUICIDE PREVENTION

Living with any chronic illness is challenging, but living with CRPS/RSD and the uncertainty it brings means we are constantly adjusting to unpredictable circumstances. By trial and error we develop a toolbox to help us meet our challenges, but do we know what do we do in a crisis? Where can we get help for ourselves or a loved one?

Having well rounded habits for everyday life that address our mental, physical, and emotional needs lays a ground work for mental health. Developing a tool box for flares means we won't have to panic when they hit. Planning ahead by knowing where to turn in the event of a crisis is like knowing how to reach the fire department in the case of a fire ~ you may not need to use them, but it is reassuring to know that they are there.

RESOURCES:

- You Tube Video: RSDSA Conference: “Living with Pain”
Jill Harkavy-Friedman, PhD, American Foundation for Suicide Prevention
<https://www.youtube.com/watch?v=ZKBY56SHSIU>
- American Foundation for Suicide Prevention: Local Chapter Listing
<https://afsp.org/our-work/chapters/>
- National Suicide Prevention Lifeline
The National Suicide Prevention Lifeline 1-800-273-TALK(8255).
Connects the caller to a certified crisis center near where the call is placed.
<https://suicidepreventionlifeline.org/how-we-can-all-prevent-suicide/>
<https://suicidepreventionlifeline.org/help-someone-else/>

Note: September is National Suicide Prevention Month. Check the FSG (Facilitators Support Group) Library for an in depth meeting guide and additional resources.