A discussion that needs to happen.

For those with, or caring for someone with, CRPS (and other persistent pain conditions).

Everyone's pain is different just as, everyone's reaction to pain is different. However, there is one thing that remains the same; living with CRPS can be difficult for both the person living with the condition and the caregiver. It is extremely important to understand how CRPS affects all parties. Learning more about the condition is the first step in helping each other to be on the same page.

Every day can be different with CRPS. Some days are better than others. Rising to the challenges can be difficult and there are plenty of moments along the way to learn from. Our approach to solving problems, rising to challenges and learning from them will make all the difference. Whether we are the person living with CRPS, their partner, family member, friend or carer, our attitudes matter. Acceptance of your new normal may not come easily but it is important for all parties. Taking baby steps toward your goals and acknowledging each milestone along the way will help make things easier.

- Setbacks happen. Setbacks are not failures; they remind us we are human. It is all part of the journey.

Communication leads to understanding.

- Working together requires patience and understanding from all those concerned.
- Recognition that peoples' responses to events may change on a day to day basis.
- Clear communication results in less misinterpretation and less confusion.
- Choose a time you are **all** ready and willing to speak, listen, hear and discuss issues at hand, to find a resolution.
- Being able to put into words what you need to express may take a few goes, keep going until you get it done.
- Take your time and engage with each other throughout the conversation.
- Let everyone ask questions and clarify things as you go.
- Recognise when the discussion is not working. Try using a reset word, yes you read that correctly "a reset word". A reset word is a word you all agree on, example "pineapple" when either party feels like things are not going to plan or the situation is escalating, calmly say your reset, e.g. "pineapple". This is when you all take a moment or ten to refocus and regroup.
- Remember no one can read another persons' mind. (Well maybe not always).
- Always ask questions if you do not understand.
- Don't be afraid to think outside-the-box and share your thoughts.
- **Think before speaking.** If you can not say anything positive, do not say anything at all; and
- Most importantly, do not go to bed on an unresolved argument. Stress will not be kind to your sleep prospects.

Ideas that may help:

1. **Teamwork** – Finding a good balance between what can and can not be done, is an important part of learning how to share the ongoing household chores. Contributing to housework enables the person living with CRPS the opportunity to continue to embrace their feeling of "self" for as long as possible.
    a. **Communication and honesty are integral when it comes to teamwork.**
2. **Choice** – Everyday life feels less restrictive when people can exercise choice in activities. This aids in maintaining self-image.
3. **Goals** – Set **SMART** goals. **SMART** is an acronym that stands for Specific, Measurable, Achievable, Realistic, and Timely. Setting small, achievable, safe goals is a great way to start.

4. **Togetherness -** Organise a special outing so you can be “partners”, “family” or “friends” again, if only for a moment, without the “carer” mindset.
5. **Get outside -** It has been proven that spending more time in parks and natural surroundings, reduces stress. There is a pretty good article on it here.
6. **Taking time out** – Taking time out is not, and should not, be considered a “cop-out”. Being a partner, family member, friend, or carer for someone with CRPS is often a fulltime job. If you require a full day or more of respite, there are options available.
7. **Accept others’ choices -** Sometimes family and friends disappear – Yes, this can happen. It is not your fault. It is not their fault. Sometimes shit happens and life goes on. Sometimes family and friends find it difficult to understand, and that could be because it is difficult to explain, hard to accept or too unbelievable to fathom.
8. **Find support** – You are not alone; support is available here. Being diagnosed or caring for someone with CRPS, is a lot to take in and cope with.

Staying Connected as a friend, partner or family member.

Adjusting to life with CRPS is an ongoing life-changing experience for all parties, and requires constant communication, understanding and hope.

- Treat the person as you did before they were diagnosed with CRPS – they are still the same person.
- Don’t stop asking them to participate in activities. Help to work out the best way they can be involved.

Ask what you need to bring to make their outing more comfortable.

Ask if they would like you to pick them up

Offer to drive their car if they would be more comfortable.

Assure them if they feel they need to leave early, you will take them home, or ensure they get home safely.

Assure them you have checked for

1. Wheelchair access if required
2. Easy access to seating and amenities
3. Shelter from rain and/or sun
4. Ease of parking
5. First aide access

Before leaving for an outing check you have everything they could possibly need;

- Pillows and/or cushions
- Blanket or wrap
- Medications / prescriptions / sunscreen / list of medications
- Change of clothes and/or footwear
- Hot or cold packs
- Toiletries and other personal items
- Jumper/jacket/long pants
- Wheelchair/wheelie walker/walking frame/other aids
- Emergency requirements/dressings
- Etc

- **Learn when to offer help**.

  Knowing when to step in and physically help someone living with CRPS can be confusing.

  Helping too much or too little may encourage feelings of loss and hopelessness, and/or anger and resentment. Communication once again is extremely important.

  These reactions can at times be quite confronting for partners, family members, friends and carers. While distressing, it is important to not fuel this event with your own emotional reaction.

  Offer to come to them for a catch-up. You could bring coffee, a movie, lunch.

  Perhaps a trade-off; do a little housework for lunch or something.

  Call in for a chat – ask how their day is. Let them speak openly, and honestly. Hear them with your heart as well as your ears – love matters more than anything else.

Staying connected as a person living with CRPS.

- Be honest in a positive way. You can't expect your family and friends to understand and accept your condition if you do not tell them about it.
- Don't be afraid to tell people that while you won't be ruled by the condition, you don't wish to be judged by it either.
- Understand it may take time for your partner, friends and family to adjust to you living with CRPS - don't give up on them, help them to understand.
- Invite your friends or family members to call in for a coffee, lunch, or a movie.
- Ask your friends and family how their day was and let them know about your day.
- Do your best to acknowledge positives in conversations.
- When you achieve a goal you set, no matter how big or small they are, share this positive news with your partner, friends and family members.
- Don't be afraid to ask your partner friends or family members for help, keeping them in the loop will help them understand.
- When asked to participate in an outing, discuss the venue and what could possibly make the outing more comfortable for you and or them.
  - If you have concerns, discuss them with your partner, friend or family member, and try to work out an alternative if possible.
  - It's ok to decline an outing or an invitation if you feel you need to rest or just require a low noise or low activity day.
  - When you accept an invitation, be prepared with items you may need to take –
    - Pillows and/or cushions
    - Blanket or wrap
    - Medications / prescriptions / sunscreen / list of medications
    - Change of clothes and/or footwear
    - Hot or cold packs
    - Toiletries and other personal items
    - Jumper/jacket/long pants
    - Wheelchair/wheelie walker/walking frame/other aids
    - Emergency requirements/dressings
    - Etc

Other things to remember when your lifestyle changes.

- Educate yourself about CRPS, or the persistent pain condition your loved one is living with, so you all appreciate the whole picture.
- Work together to ensure a support network of family members, partner, friends and carers stay in touch.
- Remember, everyone is different. Actions and reactions will play a big roll in relationships.
    - How a person reacts to living with their diagnosis is, or can be, ever-changing. The same goes for the partner, family member, friend or carers.
- Pain changes people. It is easy to draw on past experiences with a person to gather some perception of what's happening. Before you come to any conclusions, ensure you really listen, get all the facts and reassess where your loved one is at this point in time.
- Learn and grow together, it is the only way to embrace life's new normal and make the required adjustments so things remain comfortable for all involved.
- When you think there's no hope, there isn't. When you believe there is hope, life changes!

Dr Colleen Johnston-Devin mentions on page ii of her Thesis – Battling Complex Regional Pain Syndrome (CRPS): a phenomenological study, **"people living with CRPS are facing a daily battle to live their lives. They face all the difficulties of living with a chronic pain condition alongside additional problems unique to CRPS."** Dr Johnston-Devin's Thesis is based on her research which utilised a phenomenological approach to investigate the phenomenon of living with CRPS. Read the full text here.

The Pain Scale allows you to rate your pain from zero to ten, with zero being "no pain" and ten being the "worse pain possible". Figure 1.

0	No Pain	I have no pain.
1	Minimal	My pain is hardly noticeable.
2	Mild	I have low level pain, which I am aware of, if I pay attention to it.
3	Uncomfortable	My pain bothers me but I am able to ignore it most of the time.
4	Moderate	I am constantly aware of my pain but continue most activities.
5	Distracting	I think about my pain all of the time and can't do some of my daily activities due to pain.
6	Distressing	I think about my pain all of the time and give up many daily activities due to pain.
7	Unmanageable	I am in pain all of the time, it keeps me from doing most activities.
8	Intense	My pain is so severe it is hard to think about anything else. Talking and listening are difficult.
9	Severe	My pain is all that I can think about. I can barely talk or move because of the pain.
10	Can't move	I am in bed because of the pain and need to go to the hospital - please help.

Communicating pain – honest, open & real.

Being on the same page is paramount to staying connected, or reconnecting, with family and friends, using the same language, words, and abbreviations will certainly help. While we appreciate all the words in the world won't help with emotional and psychological reactions, by learning to communicate about a person's pain on the same level as they do, enables a much better opportunity to appreciate, and accept those emotional and psychological reactions.

To aid in simplistic communication we have listed the different types of pain as used most commonly, unfortunately, it is not uncommon to have more than one:

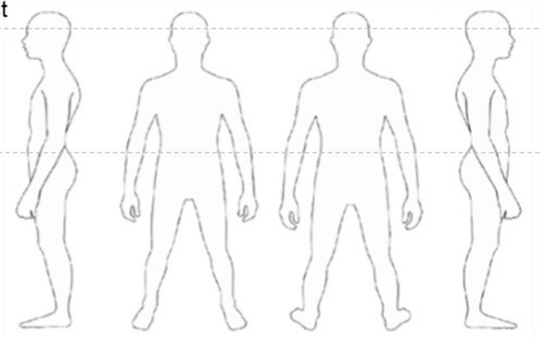
- **Acute** – pain that starts suddenly and typically lasts short term.
- **Persistent** – pain that lasts for a longer period of time, generally more than three months.
- **Breakthrough** – pain which happens between, and despite regularly scheduled pain medication.
- **Neuropathic** – pain which happens when a nerve is damaged.
- **Referred** – pain is when the pain from one part of the body is felt in another part of the body.
- **Phantom** – pain is when there is pain from a body part which is longer intact.
- **Flare-up** – pain refers to a period of intense pain which is felt more severely to the day-to-day persistent pain. A flare-up could last a few moments, a few days or much longer.
- **Total** – pain includes emotional, social and spiritual factors that affect a person's experience.

Describing pain can also be quite confusing, and again easily misunderstood. This list below demonstrates commonly used descriptions which will assist with your communication at home and with your medical team. Again, it is not uncommon to have more than one:

Figure 2

A. **Aching** – a continuous dull pain in the affected area.
B. **Tender** – sensitivity to touch, requiring tact or careful handling.
C. **Sharp** – a sudden, intense spike of pain.
D. **Shooting** – sudden severe pain that moves through the area.
E. **Hot** – warm/heated sensation in the affected area and or hot to touch.
F. **Burning** – a sensation of hot or cold burning in the affected area.
G. **Stabbing** – a sudden sharp pain.
H. **Tingling** – a tingling sensation, like pins-and-needles feeling.
I. **Stinging** – sharp discomfort/soreness on an area of skin.
J. **Throbbing** – a deep ache that pulsates or beats repeatedly, often synchronized with the pulse.
K. **Cold** – a cold sensation in the affected area and or cold to touch.
L. **Tearing** – an intense sensation of discomfort or distress that feels like the area is being torn or ripped apart.
M. **Splitting** – An intense sensation of discomfort or distress that feels like the area is being cut apart or split open.
N. **Cramping** – a sudden, involuntary, spasmodic contraction of a muscle, or group of muscles, generally with extreme pain.
O. **Heavy** – a sensation that the body, or body part, can not be moved or lifted due to its weight.

DAILY PAIN NOTES

NAME: ________________________________ **DATE AND TIME:** Time:-______am/pm Date:___/____/____	**WHERE IS YOUR PAIN?** On the diagram, shade the area where you feel pain, mark an X on the area that hurts the most 
Was there an **event** that worsened pain? Yes / No Note below: ________________________________ ________________________________ ________________________________	
PAIN INTENSITY: Rate your pain by circling the one number that describers your pain at it's worst. 1 2 3 4 5 6 7 8 9 10 No Pain *(Refer fig 1)* Severe Pain Can't Move	**TYPE OF PAIN:** Describe your pain by circling the letter or letters that match your pain description. (*Refer fig 2)* A B C D E F G H I J K L M N O
DID YOU USE MEDICATION TO REDUCE PAIN? YES / NO. If so, note medication below: ________________________________ ________________________________ ________________________________	**DID YOU USE ANOTHER METHOD TO REDUCE PAIN? YES / NO** If so, note pain relief method below: ________________________________ ________________________________ ________________________________
If using pain medication in the past 24 hours, how much **relief** has it provided. Circle % of relief. 0% 10 20 30 40 50 60 70 80 90 100% No Relief Complete Relief	If using another method in the past 24 hours, how much **relief** has it provided. Circle % of relief. 0% 10 20 30 40 50 60 70 80 90 100% No Relief Complete Relief
HOW DOES PAIN INTERFERE: Circle the one number that describes how, the pain has **Interfered** with your;	
A. General activity: in the past 24 hours 1 2 3 4 5 6 7 8 9 10 Does Not Interfere Does Interfere	**B. Mood:** in the past 24 hours 1 2 3 4 5 6 7 8 9 10 Does Not Interfere Does Interfere
C. Employment / housework: in the past 24 hours 1 2 3 4 5 6 7 8 9 10 Does Not Interfere Does Interfere	**D. Relationships with others:** in the past 24 hours 1 2 3 4 5 6 7 8 9 10 Does Not Interfere Does Interfere
E. Sleep: in the past 24 hours 1 2 3 4 5 6 7 8 9 10 Does Not Interfere Does Interfere	**F. Enjoyment of life:** in the past 24 hours 1 2 3 4 5 6 7 8 9 10 Does Not Interfere Does Interfere