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Hi! My name is Caitlin, an occupational therapist and fellow rheumatoid arthritis patient. My hope behind this guide is to assist you in your journey with rheumatoid arthritis. It can feel overwhelming and scary in the beginning, and there is a lot of trial and error in learning your body and how to best cope with this change. Because you are the most important member of your care team, I hope that I can help you to feel empowered, hopeful, and ready to take charge of your health. I believe in you, you've got this!



What is this guide?

This self-management guide will include a series of 9 modules which will guide you through creating a sustainable self-management routine for your rheumatoid arthritis. In this guide, you will learn more about rheumatoid arthritis and how it affects the body, lifestyle modifications you can include along side medication to manage your symptoms, helpful tips and tricks gathered from fellow patients, and interactive prompts to guide you through implementing these habits and routines into your daily life.

You can take this guide at your own pace. It takes time to adjust to this new change, so give yourself grace as you work toward a sustainable self-management routine. The information in this guide is meant to be a helpful resource to guide you through some research-proven self-management techniques that can help you to better manage your RA. The recommendations made in this guide are based upon recommendations from The American College of Rheumatology which cite exercise, diet, rehabilitation, and self-management programs as some impactful interventions alongside your medication to aid in managing your RA (England et al., 2023). I have gathered information from many credible sources from research articles to professionals in the field. Please refer to the references section at the end of this program to find all sources used in the making of this guide.

The recommendations in this guide do not replace regular medical

treatment with your rheumatologist.

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Module 1: What is Rheumatoid Arthritis?

Rheumatoid Arthritis (RA) is an inflammatory, autoimmune type of arthritis which means that the immune system begins to attack itself. The body loses the ability to recognize the difference between foreign cells that need to be attacked and your body's healthy cells. This causes the immune system to begin attacking everything, including your body. This inflammation in the joint space leads to symptoms such as pain, swelling, redness, and warmth. If left untreated, this inflammation can lead to irreversible damage of the cartilage and bone (Aletaha & Smolen, 2018).

Because it is an autoimmune condition, RA can have impacts to the whole body, not only the joints. The constant state of inflammation can cause some people to experience a low-grade fever, fatigue, and/or a general feeling of sickness. RA can also impact organs including the heart, lungs, skin, and eyes (Aletaha & Smolen, 2018). This is why it is so important to report any changes or symptoms you are experiencing to your rheumatologist, even if they seem unrelated to RA. You may be experiencing some of the systemic impacts of RA, and it's important to make your provider aware of those!

RA most commonly affects the small joints of the hands and feet, however, it may affect larger joints such as the knees, elbows, and shoulders as well. Usually joints that are affected will be affected on both the right and left sides of the body. Patients with RA may also develop rheumatoid nodules which are firm lumps under the skin close to bony areas, such as the elbow (Aletaha & Smolen, 2018).

Another common symptom of RA is morning stiffness of more than 30 minutes. If you are experiencing morning stiffness that lingers longer than 30 minutes, this could be an indication of inflammation in your body (Aletaha & Smolen, 2018). Be sure to make your rheumatologist aware of this!

Treatment Options:

There are several options when it comes to rheumatoid arthritis care. Our understanding of RA and how it works has led to an increase in medications and better treatments to minimize damage and increase quality of life. The goal of RA treatment is to diagnose it early and get to a state of remission or low-disease activity within 6 months (Aletaha & Smolen, 2018).

The main types of medications include:

- <u>Disease Modifying Anti-Rheumatic Drugs (DMARDs)</u>: These medications fight
 the disease to slow progression and avoid joint damage. They target specific
 molecules in the body to decrease disease activity. All patients with RA will
 use a DMARD as part of their care regimen.
 - o DMARDs can be further categorized into synthetic and biologic drugs.
 - Synthetic: These medications are commonly given orally. A common example of this type of DMARD would be methotrexate or hydroxychloroquine. Most patients will start with methotrexate to control their RA.
 - Biologics: These medications are commonly given via an injection or through IV infusion. These medications may be used together with methotrexate or after methotrexate has been found ineffective.
- Medications to assist in controlling symptoms: these types of medications do
 not stop disease progression, but can be used in addition to DMARDs to help
 control symptoms such as pain and inflammation.
 - Non-Steroidal Anti-Inflammatory Drugs (NSAIDs): these medications assist with decreasing inflammation and managing symptoms such as pain and swelling.
 - Steroids, such as prednisone, can be used during an acute disease process to decrease inflammation and pain. However, they are not meant to be used long term due to their side effects.
 - Pain medications



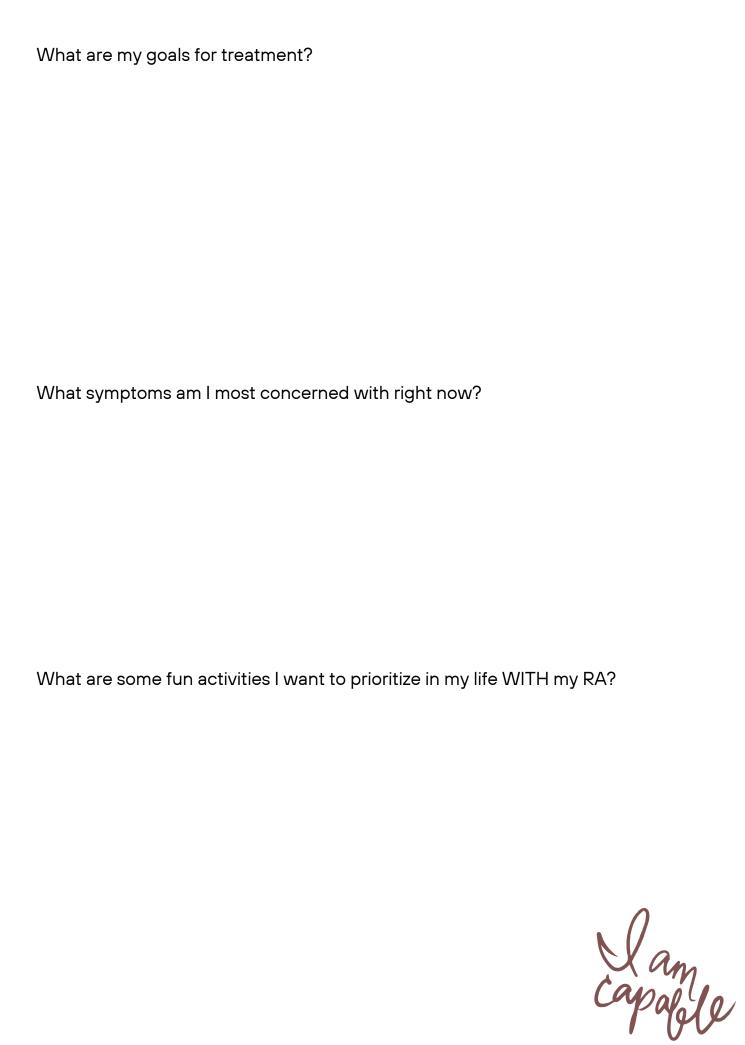
Let's Take a Time Out

Now that we've gotten a general overview of what RA is, how it works, and some treatment options, let's take a moment to breathe. It can feel overwhelming in the beginning when you are learning all of this new information and feeling the symptoms of your RA. It is completely okay to take this journey one day at a time and have an open conversation with your rheumatologist about what you're thinking and feeling. RA and its treatment is a very individualized process, so you and your doctor will have a conversation about which medications may be right for you to reach your personal goals.

I want to take a second to encourage you. You can still have a wonderful, full life with your RA. It may look a little different than it did before, but you can still find ways to do the things you love. Your rheumatologist is on your side, and they want to help you. I encourage you to keep open communication with them, and let them know your symptoms and goals for treatment. Your input and explanation of your symptoms is not a burden, it is actually an extremely important part of your care!

Below are reflection questions to consider that may help you to work through some of your thoughts on this new diagnosis and moving forward into treatment.

How can I be patient with myself as I navigate this new change?





Module 2: Joint Protection & Energy Conservation Strategies



Joint protection and energy conservation strategies can go hand in hand as you learn to listen to your body, take care of your joints, and be more mindful of your energy levels. RA can cause joints to become unstable or misaligned. It's important to protect these more vulnerable joints when you can to prevent unneeded inflammation and damage (Deshaies, 2018). RA can also have significant impacts to energy levels and fatigue in some patients. Thankfully, there are a few principles that you can incorporate into your routine to help conserve some energy for the things that are most important to you.

Joint Protection Strategies:

• Respect Pain

- Disregarding pain can lead to joint damage in the future, so it's important to learn your body and what different types of pain mean.
- Acute pain: this type of pain is sharp and is immediately triggered by an activity. If you experience acute pain with an activity, stop the activity immediately.
- Chronic pain: this is the baseline pain that you typically have in a joint. It
 is normally "achy" and may work itself out with movement. If you feel an
 increase in pain in these chronic pain areas for more than 1-2 hours
 after an activity, you should modify or stop that activity in the future.
 - Modifying could look like decreasing the length of time, reps, or amount of weight used for an activity.
 - Splints that add support and stability to joints may also be an option to help decrease pain during activities. Talk to your rheumatologist or an occupational therapist to help decide if a splint may be beneficial for you.

Reduce force and effort

 Create an environment that is as efficient as possible to decrease unneeded use of energy. Gather all your needed materials before you get started, and ask for help if you need it. Adaptive equipment can also be great tools here!

(Deshaies, 2018; Hall, 2018)

- Maintain muscle strength and range of motion
 - Maintaining muscle strength around joints can help to increase stability of the joint.
 - Range of motion, or flexibility, of a joint can be impacted by RA.
 Stretching and doing other range of motion exercises with in a pain-free range each day can help to make sure your joints are staying flexible and do not stiffen up. See Module 5: Exercise to learn more!
- <u>Use the strongest, largest joints available</u>
 - Examples may include:
 - Pick up grocery bags with your forearm instead of your hands to protect the small joints of the hand
 - Push open a door with your body weight rather than your fingers
 - Lift objects by scooping them up with your palms facing up, rather than using your fingers around handles
 - Slide objects when available
 - Close doors with the palm of your hand
 - Close drawers with your hip or side of your hand
- Ensure good body mechanics
 - Good body mechanics look like:
 - Keep your back straight and lift with your legs when picking things up off the ground, or use a reacher!
 - Carry heavy objects close to your body
 - Maintain good posture throughout the day
 - Try to keep your back straight, feet on the floor when sitting, and elbows and knees at 90 degree angles.
 - Limit the need to bend, reach, and twist by placing items within easy reach in your environment.
- Avoid staying in one position for long periods of time
 - Try to change positions or how you're gripping something periodically and take breaks. Plan to take a 10-15 minute break per hour.
- Avoid a tight grip
- Avoid pinching items between your thumb and fingers
 - Hold books, plates, or mugs in the palm of your hands
 - Try using a book holder
 - Use a purse or backpack with a shoulder strap rather than a clutch

- Avoid pushing your fingers toward your little finger
 - Patients with RA are prone to ulnar drift, which is when your knuckles start to drift toward the pinky side of your hand. Avoiding motions that push your fingers toward your pinky can help to protect against this.
 - Examples:
 - Don't rest your chin on the side of your fingers
 - Add levers to keys, handles, or door knobs
 - Hold a hairbrush or toothbrush across your palm rather than pinching it between your fingers
- Balance rest and activity
 - Make sure to plan plenty of time to complete an activity, so you aren't rushed.
 - Take regular breaks throughout the day, even if you don't feel tired yet. By resting before you become overly fatigued, you will actually increase your overall endurance.
 - When starting an activity, plan ahead for rest areas or options for breaks if needed.

Energy Conservation Principles:

Energy conservation principles can be remembered by the 4 Ps:

Plan

- Plan your day, week, and month to spread out tiring tasks.
- Try alternating between light and heavy work tasks during the day.

Prioritize

• Choose the most important tasks/routines to you and then let others help you with the tasks that aren't as important to you.

Position

• Choose less tiring positions for tasks when available. This could look like sitting down to put pants, socks, and shoes on. You may also try having a stool in the kitchen to sit while chopping vegetables.

Pace

Make sure to incorporate breaks throughout the day to avoid overexertion.
 Pace yourself and do a little at a time with breaks sprinkled in as needed.
 Try to take a 10-15 minute break each hour.



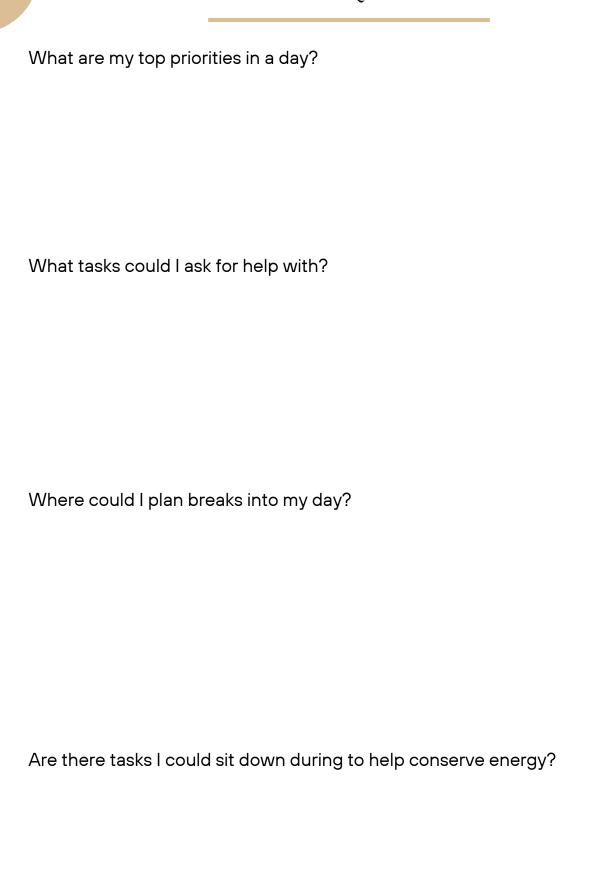
One part of having rheumatoid arthritis is that we tend to need more rest than our peers without chronic illness. This is a valid need, and it's important to try to plan ahead to make sure you are getting enough sleep at night. Deshaies (2018) recommends 10-12 hours of rest daily. This includes sleep at night and naps/rest breaks during the day. We will talk more about sleep and naps in Module 7: Sleep & the Importance of Rest. Listen to your body to learn the right amount of rest that your body needs!

Let's take a break

See what I did there? Breaks and ensuring that you get enough rest is a big part of taking care of your health and helping to avoid flares. It can be a frustrating transition to learn to slow down and take extra breaks throughout the day. We aren't used to having anything slow us down, and our culture does not naturally incorporate rest time into our days. That's why it's so important that you learn your own body and your rest needs, and you learn to advocate for those needs. I will admit that it is intimidating at times to advocate for your own needs. However, you are worthy of rest. You are worthy of advocating for, and receiving, the things you need to feel your best.

I want to clarify here that these joint protection and energy conservation strategies aren't meant to be restrictive rules. They are helpful tools you can use to build out your own self-management tool box. Make these things work for you and your life! Self-management strategies are meant to help you reduce pain and manage your symptoms the best you can to enable you to do the things you love. It's impossible to follow all of these things at all times because sometimes life just happens. And that is okay! You can choose the things you want to prioritize and then plan to add in a little extra rest and recovery time afterwards. Your rheumatologist is also a great resource to talk to when planning out trips or events if you're worried about extra pain or a flare.

Reflection Questions:



What are some tasks I could do differently to better protect my joints?
Are there tasks I currently do that are painful? How could I modify those tasks to make them less painful?
When I need a break, what will I say to advocate to friends and family to slow down and take a rest?





Module 3: Adaptive Equipment



Adaptive equipment is truly one of the most fun parts of being an occupational therapist because it gives the opportunity to help people be able to do the activities they love with more ease. Adaptive equipment can range from simple tools to more complex pieces of equipment. The options are truly endless, and the key is to be creative! If there is a task that is more difficult or painful for you, brainstorm what could help make that task easier. If you're having a lot of trouble with daily tasks, consider talking to your doctor about getting a referral to an occupational therapist. We specialize in helping people regain independence and function in their daily lives!

Some general principles to look for in adaptive equipment for RA is to look for items that have a larger, rubbery handle to make it easier to hold (McDonald et al., 2021). You may also look for items with electric options or longer handles to provide leverage. Examples of these items could be one touch electric can openers, jar openers, bottle openers, or other items with extra long handles.

There can be some stigma around using adaptive equipment. Some people may see it as "giving up" or "not trying hard enough", but that's not true! The goal of adaptive equipment is to provide the user with increased quality of life and ease during their day. Adaptive equipment can also be great tools to assist you in joint protection as discussed previously. Many of us could power through and get things done, but that may result in unneeded pain or possible damage over time. I personally use many pieces of adaptive equipment during my day that I have slowly collected over the years as I need them.

On the next pages, I will have a list of a few of my favorite pieces of adaptive equipment. I will also recommend some of my favorite internet/social media based resources for you to explore at the end as well. Think of this as a fun shopping catalog full of gadgets to help you in your day!

Bathroom

Long-handled bath and body scrubber

 This tool is helpful for people with limited shoulder range of motion, ability to bend over, and/or hand pain to scrub shampoo. This double-sided, long handled scrubber is able to be used for shampoo and body wash.



Handheld shampoo brush

 People with hand pain or decreased strength may find this helpful. This tool allows you to hold the massager with the handle in between fingers for added stability to massage shampoo into hair.



Silicone body scrubber

 This product replaces a traditional loofah. You are able to insert fingers into straps on the back to secure and wash your body without the need to grip a loofah. This could be helpful for people with hand pain or decreased grip strength.



Handheld shower head

 A handheld shower head allows you to sit on a shower seat and bring the water to you to aid in decreasing fatigue.



Wiping aid

 This can be used for someone with limited range of motion or decreased ability to twist. The wiping aid allows for better reach to be able to wipe more fully. Wrap toilet paper around the open end and close. When finished, press button on the opposite end to release.



Handheld bidet

 This is beneficial if you have limited range of motion or decreased ability to twist which causes trouble with wiping fully. This electric, portable bidet allows for cleaning with only pushing one button.



Extended handle hairbrush/comb set

 If you have limited shoulder range of motion and/or strength, this may be helpful for you. The extended handle allows for easier reach, and the handles are built up with a rubber covering to increase grip.



<u>Brush straightener</u>

 This can be used by someone with decreased grip strength or hand pain when styling hair. The brush style allows for a full hand grasp rather than prolonged squeezing with the thumb as in a traditional straightener.



Pump tops for larger bottles

 These pump tops can be added to most 1 liter sized bottles of shampoo or conditioner to decrease pain by eliminating squeezing. They are also a great tool for joint protection!



Electric toothbrush

 People with decreased grip strength or hand pain may find this helpful. This type of toothbrush typically has a larger handle and provides a deeper clean without using a lot of force or brushing motions from the user.



Mounted nail clippers

 These are used for people with decreased dexterity, strength, or pain in hands. Nail clippers are mounted onto a block, so you can use the whole hand to clip nails rather than pinch strength. You could also DIY this one by attaching nail clippers to a wooden block (Crowe, 2024)!



Shower tub bench

 If you have decreased balance and/or standing tolerance in the shower, this may be helpful for you. Allows people with a tub shower to sit on the bench and slide into the shower without stepping over the side of the tub.



Shower chair

• Allows people with a walk-in shower to sit to decrease fatigue and protect from loss of balance.



Raised toilet seat

 This is used for people who have difficulty standing up from lower surfaces, decreased range of motion, or pain at the hips. The raised toilet seat attaches to your toilet, and the rails on the side assist with standing back up.



Grab bars

 Grab bars provide stability and safety in the bathroom for standing up at the toilet and shower transfers. These are a safety feature helpful to all adults. I recommend grab bars that attach to the wall, not suction cup. The suction cups are more likely to disconnect from the wall with pressure.



Kitchen

Electric can opener

 People with decreased strength and pain in the hands may find this beneficial. The Kitchen Mama electric can opener is a one touch can opener that opens cans from the side, so there are no sharp edges for potential injuries. This is one of my personal favorite kitchen tools!



Handheld jar and bottle opener

 This tool provides increased grip and an extended lever arm to open jars if you struggle with decreased strength or pain. This still requires enough hand strength to use the tool with one hand, and it can be a wide opening when opening large jars. I like this set because it also comes with a tool for opening small bottles, cans, and bottle caps.



Under cabinet jar opener

 This jar opener is mounted under the cabinet which allows for use of both hands to turn the jar if you have decreased strength or pain. The triangular design also allows for bottles of all sizes to be opened.



Electric jar opener

 If a manual jar opener is difficult for you, this could be a good option! Place on top of a jar and press the button to automatically open jars. Works better for medium and large jars, does not work as well for small bottles.



OXO Good Grips line

 The good grips line has built up rubber handles for easier use. These are great for people with decreased grip strength and pain in hands affecting meal preparation activities.



Adaptive cutting board

 People who have decreased strength to be able to stabilize meat or vegetables while chopping may find this helpful.
 Steal prongs hold food in place to chop and corner boards allow you to corral foods or bread to spread on toppings.



Vertical rocker knife

 The vertical grasp allows for a neutral wrist placement which protects joints, decreases pain, and increases strength with cutting. This knife is also small enough to take with you on the go!



90 degree angle knife

 This is another option for a neutral wrist placement when cutting to protect joints, decrease pain, and increase strength.



Vegetable chopper

 The vegetable chopper has different attachments for dicing, slicing, and spiralizing of vegetables. This allows for full use of the arm to press down on chopper to decrease pain and conserve energy.



Electric drink dispenser

 Automatic drink dispensers can be attached to most standard sized jugs and containers for automatic pouring.
 *Doesn't fit soda sized 2 liters



Dressing

Button hook

 This is helpful for people with decreased dexterity and strength in their hands to aid in buttoning. You insert the metal end through the button hole, put it around the button, and then pull through. The small hook on the opposite end is to hook zippers.



Zipper pulls

 These attach to zippers to create a longer and larger surface to hold on to. You may also try tying a hair tie through the zipper well (Crowe, 2024).



Shoe horn

 People with decreased range of motion at the hips, pain when bending over, or pain in the hands may find this helpful to aid in getting shoes on. Slide shoe horn into the back of shoe and guide heel down into shoe.



Sock aid

 The slightly flattened, curved side of the sock aid goes toward your body, then pull socks over the opposite end.
 Pull socks all the way to the end so they are flat across the bottom, slide foot into sock aid, and pull on handles.



Front closure bra

 Front closure bras may be helpful if you have decreased range of motion, dexterity, and/or pain in the hands or shoulders. There are different brands and types of closures on the market, so shop around to find one that is right for you! The bra pictured here is by Spring Rose and features velcro closure and an attachable O ring to aid in grasp.



Adaptive closure clothing

 Adaptive clothing includes velcro closures and magnetic buttons which may be helpful if you have decreased dexterity, strength, or pain in the hands. You can research and find the clothes that you like by searching "velcro close shorts" or something similar! Shorts pictured here are by MagnaReady.



IV friendly jacket

This is a comfort item for patients who receive IV infusions.
 This jacket allows for zipper access to both sleeves for IV placement. These are available on Amazon, or a small business called BeWell.



Elastic shoe laces

 These are used for people with decreased hand dexterity or pain that causes trouble with tying shoe laces. These can make any shoe into a slip on.



Medical

Push button pill organizer

 This pill organizer has a small button you can push to open the lid for easy access if opening manual pill boxes is challenging.



Push top pill organizer

 This pill organizer has a push in top and silicone lids, so it is easy to open and there is no danger of spilling pills. It's also magnetized, so you can take each day with you on the go.



Droppy eye dropper

 This eye dropper goes over the eye assisting with aim of drops and has longer handles which requires less force to squeeze eye drops.



Figure 8 splints

 Splints are used to protect and rest joints that may have deformities, be unstable, or painful. Figure 8 finger splints can be used for swan neck deformities, boutonniere deformities, trigger finger, mallet finger, or crooked fingers. Talk with your doctor to determine if these may be helpful for you.



Thumb spica splint

 Thumb spica splints provide immobilization at the thumb to provide stability and rest at the joint while still allowing function of the hand. Talk to your doctor about if this splint may be helpful for you.



Thumb CMC splint

 CMC joint thumb splints provide stability to the base of the thumb while still allowing function of the hand. Used for painful thumb joints or to provide protection during repetitive tasks. Talk with your doctor about if this splint may be helpful for you.



Pain Management

Heating pad

 These are helpful for many people with chronic pain that is eased by heat. Heat is most often recommended for chronic pain to help loosen joints. See Module 4: Pain Management for more information on heating pads.



Heated blanket

 The heated blanket is a classic that provides heat for pain management to multiple areas of the body at once. Again, heat is most recommended for chronic pain, but you can find what works best in your body!



Heated slippers

 These heated slippers could be used to help ease morning stiffness or chronic pain in the feet. They are not made for walking in most cases. The ones pictured here are electric, but they make microwavable ones as well.



Compression Gloves

 Compression gloves are used for people with pain in the hands. Compression provides gentle sensory input to decrease pain and provide increased support to unstable joints. These gloves are not available on Amazon, but come from a brand called Grace & Able online.



Office Supplies

Spring scissors

 Spring scissors automatically open for you which takes stress off of your thumb. These are great for home as well, not just the office!



Ergonomic keyboard

 There are a lot of options on the market for ergonomic keyboards. The main two are a "wave" design and a split keyboard design which allows for a neutral wrist placement rather than turning your hands in to reach keys. These are helpful for people with pain in the wrist and fingers when typing.



Vertical mouse

 A vertical mouse allows for a neutral alignment at the wrist which will help to decrease pain.



Cleaning

Long handled dust pan

 The long handled dust pan allows for minimal bending over for sweeping tasks. People with decreased range of motion, pain with bending over, and/or decreased balance may find this helpful.



Swiffer

 The swiffer can be used with a microfiber cleaning cloth attached to use as a long handled cleaning tool to reach mirrors and windows as well as floors. Get creative and use your tools to your advantage!



Long handled bath scrubber

 This long handled tool decreases the need for bending or kneeling, and it gives more leverage for scrubbing. I use this, and I find it super helpful!



Miscellaneous

Reacher

This reacher has a large, rubber handle for easy grip. The
rounded part can be used horizontally for cups, cans, or
other rounded objects. The end comes to a tight point for
small objects on the ground and for helping with dressing
tasks such as putting on pants.



<u>Dycem</u>

 Dycem is a two sided non-slip material that can be cut to any shape as needed. Great for adding grip to hands, or placing objects on top to stabilize and use one handed. This material is very versatile!



Key turner aid

 This is helpful for people with decreased pinch strength, thumb arthritis, or pain in hands that affects ability to turn keys. These rubber aids fit over your key and give a larger surface area to turn.



Foam tubing

 These can be put onto utensils and other small objects to build up handles for easier grip.



Eazy Hold

 This is a silicone handle which can be attached to most items including tooth brushes, utensils, cups, hair dryers, etc. to create stability of the item across the palm. The user can use a full hand grasp or not have to grasp at all. Note, you may need assistance getting these placed initially.



Foam covered twist tie

 This is a creative fix for larger objects that an EazyHold or foam tubing can't fit. You are able to wrap the tubing around to fit whatever object you need to add extra grip or a small handle (DeLong, 2021).



Counter height stools

 These stools, or any counter height seat you have, can be used in the kitchen or bathroom during cooking or getting ready to sit to conserve energy.



Door knob levers

• These levers attach to door knobs to convert a traditional door knob into a lever for easier opening.



Unbuckle me

 The Unbuckle Me aid presses into the small buttons on car seats and provides larger handles to push to decrease pain.



Car door assist handle

 This handle attaches to the safety latch inside the car door to provide a stable handle to push down on to assist with standing up. Window assist handle can also be placed in a rolled up window to provide a second handle.



Gas cap wrench

• This attaches to the gas cap in the car to assist in getting it on and off properly. Note: compatible with gas caps that are 5/8 inch wide and 5/8 inch deep.



Buddy Helper table clamp system

 These clamps hold paper (such as wrapping paper) in place on a table and have a tape dispenser. You can easily cut across without having to bend over or hold paper in place if tasks requiring two hands are difficult.



<u>Note</u>: Ideas for this list were gathered through a combination of my own knowledge and online resources created by Cheryl Crowe and Lindsey DeLong who are cited in the reference list.

Community Resources

EquipMeOT

- EquipMeOT is a website, YouTube channel, and Instagram page owned by occupational therapist, Lindsey DeLong. Her content focuses on home and community based occupational therapy and adaptive equipment to assist you in thriving in your community!
- Website: Equipmeot.com
- YouTube: EquipMeOT
 - She has a playlist dedicated to arthritis on her YouTube channel which has some great helpful ideas!
- Instragram: @Equipmeot

<u>Arthritis Life</u>

- Arthritis Life is a website, podcast, YouTube channel, and Instragram page owned by occupational therapist, Cheryl Crowe. Cheryl has RA herself, and she specializes in self-management of RA. She facilitates an online selfmanagement course called Rheum to Thrive that walks you through an online educational curriculum and an online support group over Zoom.
- Website: Arthritis.theenthusiasticlife.com
 - Rheum to Thrive link: Arthritis.theenthusiasticlife.com/rheum-to-thrive
- YouTube: Arthritis Life
- Podcast: Arthritis Life
- Instagram: @Arthritis_Life_Cheryl

Reflection Questions

<u></u>
What are my current thoughts on the use of adaptive equipment?
How may adaptive equipment help to incorporate more ease into my day?
What is my script for explaining to family members or friends the benefits of using adaptive equipment in my life?



Module 4: Pain Management



Chronic pain due to inflammation and/or joint damage is one of the most challenging aspects of rheumatoid arthritis. A large piece of pain management includes having a conversation with your doctor to discuss medications or other treatment options that may be able to help. However, there are also some lifestyle and non-medication based treatments that can be used alongside medication as well.

Pain can be impacted by several factors. According to Breeden & Rowe (2023) these may include:

- Biological factors: inflammation or joint damage
- Cognitive factors: how you think about and understand your pain
- Social factors: lifestyle, support of family and friends, and how you communicate your pain to others.

All of these factors impact each other, and combined they can have a large impact on the pain that you experience.

The function of pain is to alert the body to danger, or potential danger, of damage. This happens by cells within your skin, muscles, bones, and organs called nociceptors being activated due to actual or potential damage to your cells (Breeden & Rowe, 2023). These signals are then sent to your brain and are interpreted as the pain that you feel. The interesting thing about pain is that because there are so many other factors that also play a role, each person experiences pain in their own unique way.

A large part of what makes your experience of pain unique is your perception of pain. How you recognize, or feel, pain correlates with pain intensity. This recognition of pain can be impacted by many factors including:

- The amount of attention you give to pain
- Expectations of how much pain you should be feeling
- · Coping strategies you are currently using
- Increased stress
- How you think about pain
 - Negative thoughts: thinking of the worst case scenario
 - Ex. "my pain is never going to get better"
 - Fear avoidance: decreasing your movement or engagement in activities because you are afraid they may cause pain.

(Breeden & Rowe, 2023)

The amount of focus and attention you give to your pain can have an impact on the pain you feel by magnifying it in your mind (Breeden & Rowe, 2023). Tying into this concept are pain behaviors which are non-verbal forms of communication we use to communicate pain to others around us. These could be things like grimacing, wincing, grunting, or using medical equipment. In some instances, it can feel like we must "prove" to those around us that our pain is real, so we use pain behaviors to help communicate that. Interestingly, using these pain behaviors as a primary means of communicating can actually contribute to increasing pain and maintaining disability in some cases (Breeden & Rowe, 2023).

I am not saying that you should not communicate pain when you are hurting. Rather, I want to encourage you to advocate for yourself by expressing your needs clearly through words. Relying on pain behaviors to communicate your needs could lead to miscommunication or an unintentional hyperfixation on your pain that could lead to increased feelings of pain and disability over time. Instead, it could be more beneficial to clearly state what you're feeling and what you need to those around you.

Now that we've learned more about pain, how it works, and the different factors that can play a role, let's talk about some non-medication based strategies we can use to help manage pain. These tips are taken from the European League Against Rheumatism (Geenen et al., 2018) and occupational therapy resources by Breeden & Rowe (2023) and Hall (2018).

Relaxation Techniques

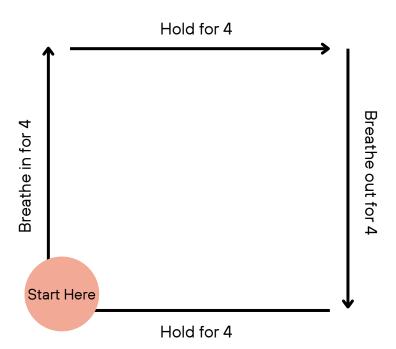
- The purpose of these techniques is to help you to find any tension you're
 holding in your body and work to let it go. Holding tension can contribute to
 increasing pain, so learning to relax those tense muscles or areas of the
 body can help.
- A few ideas for relaxation are: gentle stretching, deep breathing, and progressive muscle relaxation. Let's dive deeper into these techniques!

Gentle range of motion stretches: Complete gentle stretches in areas that feel tense to assist in helping those areas relax. Examples could be stretching the neck by bending the left ear over the left shoulder, then right ear over the right shoulder. You may also make gentle circles with the wrists or ankles to work through their range of motion.



<u>Diaphragmatic Breathing</u>: this is a deep breathing technique with the goal to focus on breathing down into your stomach first, then filling the chest with air. To learn this technique, sit up tall with one hand on your stomach and one hand on your chest. As you breathe in, focus on sending the breath down, so you feel your hand on your stomach move outward first. Then, you should feel your hand resting on your chest rise second. Once you learn this technique, you can incorporate it into breathing exercises like the one below.

 Box Breathing: this is an exercise which helps you to slow down your breathing as you trace the box. Start with your finger placed on the circle at the bottom left of the square. Then, follow the instructions on the square as you trace each side with your finger. Repeat this 3-5 times.



<u>Progressive muscle relaxation</u>: this technique is used to help you learn to recognize tension in your body. You will tense up one set of muscles and then relax them, working from the top of your body down. For example, you could begin my pulling your shoulders up toward your ears then relaxing them all the way down. Then move to making fists with your hands, then relaxing. Continue this all the way down your body until you have fully relaxed all muscles (Thorn & Andrasik, 2007).

• Caution: if you have an injury, pain, or strain in a muscle group, skip that muscle group when completing this exercise.

Heat/Cold Therapies

- Heat: Heat is recommended to be used with chronic pain and to warm up muscles and joints before exercise. Heat increases circulation to the area, helps to loosen stiff joints, and relax muscles (Hall, 2018).
 - Precautions:
 - Do not use heat for more than 20 minutes at a time.
 - Do not apply heat to acute injuries or swelling.
 - Do not apply heat if you have trouble feeling temperature.
 - If you use a menthol gel (such as Biofreeze), remove it before applying heat.
 - o Example of heat: heating pads, warm bath or shower, electric blanket
 - Place a towel between the heating pad and your skin for protection. Do not sit or lie down on a heating pad, and do not use if you think you may fall asleep.
- Cold: Cold is recommended to be used with acute injuries or swelling to decrease inflammation. It is also helpful for arthritis and post-exercise soreness (Hall, 2018).
 - Precautions:
 - Do not use cold for more than 20 minutes at a time.
 - Do not use if you have poor circulation or temperature recognition.
 - Cold decreases flexibility, so make sure to warm up that area for at least 20 minutes before engaging in exercise or activity.
 - o Example of cold: crushed ice in a plastic bag, ice gel pack, frozen peas
 - Place a towel between the cold pack and your skin for protection. If using peas, mark the bag "for therapy" and do not eat.

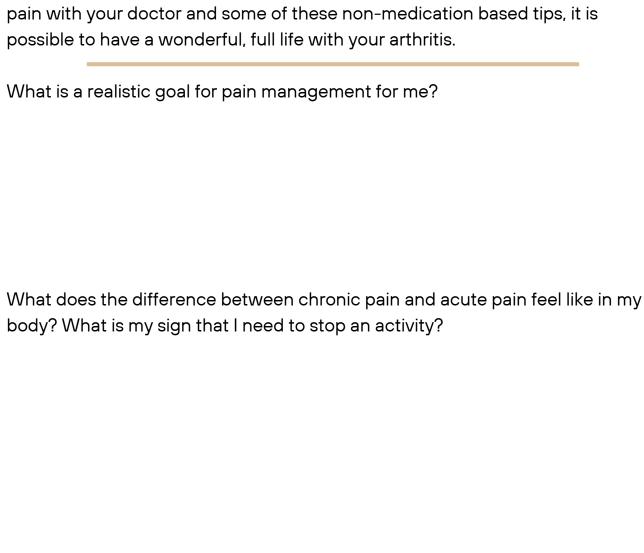


A few other helpful tips:

- Time your medication to be in full effect when you plan to exercise and/or engage in activity.
- Use pillows, back supports, or splints to better position in sitting or sleeping.
 - More information will be in Module 7: Sleep & the Importance of Rest.
- Create a "Relapse Prevention Toolbox" to help manage your pain when you are in a flare.
- Decrease negative thoughts surrounding pain by replacing them with more positive thought patterns.
- Respect your pain
- Learn to differentiate between acute and chronic pain
- Advocate for yourself and your needs!
 - o Create a script of what you will say when you are in pain and need help.

Wrap Up

Overall, the goal of pain management is to help you to function and engage in activities you want to do <u>despite</u> your pain. The goal is not to completely cure your pain (Breeden & Rowe, 2023). Unfortunately, some pain is an inevitable part of having rheumatoid arthritis. However, we don't have to let that stop us from doing the things we love to do. By combining the medical management of pain with your doctor and some of these non-medication based tips, it is possible to have a wonderful, full life with your arthritis.



How can I better advocate for myself to friends and family when I am in pain?

Relapse Prevention Toolbox

What are early warning signs of a flare?
What are activities I need to do daily to prevent a flare? (Examples: take my medications, get enough sleep, do not over-exert myself)
What are activities I can do when I feel early signs of a flare to control it?
What activities can I do when I am in a flare to manage my pain?

Automatic Thought Patterns

How we think about situations around us has a powerful impact on how we see and experience the world (Therapist Aid, 2024). Many of us have automatic thought patterns that happen before we even realize it, and those thought patterns have an impact on how we think and feel. The goal of this exercise is to help you decrease negative thought patterns and create more positive thoughts surrounding pain management (Breeden & Rowe, 2023). The following questions will guide you through that process. You can repeat this with as many negative thought patterns as you would like!

Situation: describe the event in detail that triggered the dysfunctional thought. Write down the negative thought it triggered.

Challenge:

Evidence to support the negative thought:

Evidence to disprove the negative thought (try to use the information we learned in this module here!):

Create: Create an alternative, positive thought to replace the negative one.



Module 5: Exercise



Regular exercise is the American College of Rheumatology's (2023) strongest recommendation for lifestyle interventions due to the extensive amount of research that proves the effectiveness of exercise for patients with RA. Regular exercise has been shown to improve physical function, cognition, sleep, quality of life, and decrease pain in patients with RA (Bjork et al., 2022; England et al., 2023; Shadick et al., 2019; McKenna et al., 2024).

The recommended amounts of exercise for adults is 150 minutes of moderate intensity aerobic activity (ex. brisk walking) a week or 75 minutes of vigorous intensity aerobic activity (ex. biking at 10 mph) per week (CDC, 2022). It is also recommended that you include strength training 2 times per week (CDC, 2022). The Arthritis Foundation (2024a) recommends a mixture of flexibility, cardio, and strength training exercises. Some examples of low-impact exercises that are great for RA are walking, yoga/tai chi, water aerobics, swimming, biking, and strength training (with the guidance of a professional familiar with RA). However, if you aren't able to reach this level of activity right now, that is okay! Any amount of physical activity is more beneficial for you than none at all.

Here are a few tips to get you started with exercise with RA:

- Start slow and increase the amount of exercise slowly as your body adjusts.
- Exercise with friends or in a group. This can provide accountability and fun!
- Choose shoes that fit well and provide support.
- Some discomfort during exercise is normal, however, aiming for a 2 out of 10 or lower is recommended. If you feel pain higher than this or a sharp pain, stop the activity.
- Modify as needed. You may even break up exercise into small sessions throughout the day instead of one long session.
- Warm up for 5-10 minutes at the beginning of exercise. This may include marching in place, light arm circles, and stretches. Cool down at the end of exercise. This should include lowering your heartrate and stretching.
- Make sure to breathe! Do not hold your breath. If you find yourself holding your breath, count out loud.
- Explore different types of exercise to find the one that you enjoy!

Community Resources

There are many great resources both in-person here in Chattanooga and online that can help to support your journey to incorporating exercise into your routine. Some of the best community resources that I have found so far are listed below.

<u>In-person:</u>

- The YMCA: the YMCA is an amazing community resource which provides
 exercise classes, educational programming, and individual exercise
 equipment to use. They have several exercise class options which are lowimpact and appropriate for arthritis including water aerobics classes, gentle
 yoga, chair yoga, tai chi, cycling, barre, and low-impact strength training
 and cardio classes. Whether you're looking for a low-intensity or highintensity workout, the Y has a class for your needs.
 - To learn more about membership and classes offered at each YMCA location in Chattanooga, contact these numbers for more information:
 - North River YMCA (Hixson): 423-877-3517
 - Downtown YMCA: 423-266-3766
 - Cleveland YMCA: 423-476-5573
 - Hamilton YMCA (East Brainerd): 423-899-1721
 - Website: https://www.ymcachattanooga.org/

Online:

- Arthritis Foundation: The Arthritis Foundation has a great website where
 you can explore many topics related to arthritis. Included in these is
 information on physical activity appropriate for arthritis. Your Exercise
 Solution is a section of the website with strengthening workouts as well as
 video demonstrations of exercises to ensure you are exercising properly.
 - Search "Arthritis Foundation Your Exercise Solution" to find the website
- Walk with Ease Program: This is a program which helps guide you through incorporating walking into your regular routine. This program was created through the Arthritis Foundation. There is not currently an inperson group in Chattanooga, but you can do the program on your own by purchasing the guidebook through the Arthritis Foundation's website.
 - Search "Arthritis Foundation Walk with Ease" to find the website

Let's Chat

Exercise with arthritis can feel daunting, especially if you haven't exercised regularly before. Taking it slow and exploring different options of exercise that you are interested in can be great ways to slowly build a new habit into your routine. Begin to think about what types of exercise you may be interested in and plan in a specific time that you are going to try them. Creating an event in your calendar that is set and purposeful can be a great help in actually following through with your plan.

I want to encourage you to stick with it for a few months before giving up. It can take some time to work out the hard parts and for your body to adjust.

Remember to celebrate the small wins. Every time you show up for yourself on this journey is a reason to celebrate!

What are the types of exercise that I am interested in trying?

When can I plan to exercise this week?

How will I celebrate the small wins?

• Some ideas may be to check off each day you exercise, have an accountability partner to text, or work toward a larger reward!



Module 6: Diet



While there is not a special diet that will cure arthritis, the foods that we eat can have an impact on our inflammation, how we feel, and our weight. In a survey of patients with RA, 24% of patients reported that food does impact their RA symptoms (Tedeschi et al., 2017). From a big picture stand point, choosing to prioritize fresh fruits and vegetables and decreasing the amount of fried foods, fast foods, or foods high in sugar is helpful in decreasing inflammation (Husni, n.d.). If you're looking for a specific style of eating that is most helpful, the Mediterranean style diet is most recommended for people with rheumatoid arthritis due to its anti-inflammatory properties (Paturel, n.d.).

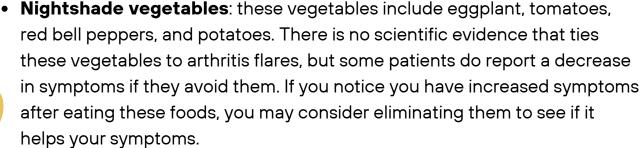
What is the Mediterranean style diet? Here's a list of the main food groups that are emphasized in this style of eating according to Paturel (n.d.):

- **Fish**: the Academy of Nutrition and Dietetics recommends 4-6 ounces of fish twice a week. However, more may be better for people with arthritis.
 - Good sources: salmon, tuna, sardines, herring, scallops, and other coldwater fish
 - You may also take a fish oil supplement. Talk to your doctor before starting any supplements if you are interested in trying this!
- **Nuts and seeds**: it is recommended to eat about 1.5 ounces of nuts per day. One ounce is equal to about one handful.
 - o Good sources: walnuts, almonds, pine nuts, and pistachios
- **Fruits and vegetables**: at least nine servings of fruits and vegetables are recommended per day. One serving is equal to one cup of most fruits or vegetables or 2 cups of leafy greens.
 - The
 - Good sources: try to get as many colors on your plate as possible! The more dark or rich in color, the more antioxidants that food has.
 Blueberries, cherries, spinach, kale, and broccoli are all great options.
- Olive oil: two to three tablespoons per day of olive oil is recommended.
 - o Good sources: extra virgin olive oil
- Beans: recommendations include one cup or more of beans twice a week.
 - Good sources: small red beans, kidney beans, and pinto beans



- **Whole grains**: a total of 6 ounces of grains per day with at least 3 ounces coming from whole grains is recommended. One ounce of whole grains would be equal to about half a cup of cooked brown rice or one slice of whole grain bread.
 - Good sources: whole wheat flour, oatmeal, brown rice, and quinoa. If you have celiac disease or a gluten sensitivity, make sure to be careful of which whole grains you are choosing to avoid gluten.

Possible additions:



Water

Of course we have to highlight the importance of water in any healthy diet.
The recommendation for water intake is at least 8 cups per day, and it
should be the main drink that you are consuming (Arthritis Foundation,
2024b).

Community Resources

In person:

- The YMCA offers programs aimed at helping you to create healthier eating habits.
 - <u>Eat Well. Live Well. Nutrition E-course</u>: provides information for weight loss, accountability, motivation and more. This class is led by a certified dietician. You may contact Ashley Barber for more information: abarber@ymcachattanooga.org.
 - <u>Nutrition consultations</u> with a certified dietician are available through the YMCA. Contact Ashley Barber for more information (abarber@ymcachattanooga,org).

Online:

• The Arthritis Foundation has many great nutrition-related resources on their website including information about the Mediterranean Diet.





Food for Thought

When it comes to changing the way that we eat, let's be honest. It's really hard. Food is more than just nutrition. It also has an emotional component, and it's a shared experience with our family and friends. So many happy memories and social events are tied to food, and this module is not telling you that you can't enjoy those fun, comfort foods anymore. Rather, it's an encouragement to listen to your body and prioritize foods that make you feel your best the majority of the time. You may try keeping a food diary for a couple of weeks while tracking your pain, morning stiffness, and/or swelling to see if you find a pattern in foods that may be impacting you. Inflammation will typically take about 24-48 hours to notice, so keep that in mind! Instead of feeling like you have to overhaul everything at once, think about 1 or 2 foods you could begin to add into your diet for a little more nutrition.



Are there any foods that I have noticed increase my inflammation or other RA symptoms?

What are some aspects of the Mediterranean diet that I like or could see fitting into my lifestyle?

What are one or two foods that I could add into my diet this week for added nutrition?



Module 7: Sleep and the Importance of Rest

addressing other factors that may be impacting your sleep (Benlidayi, 2018). In this module, we will be focusing on lifestyle modifications for the management

of sleep. If you're having trouble with your sleep, make sure to bring that up

Sleep and rest play a critical role in the management of rheumatoid arthritis.

Lack of sleep can cause negative impacts to fatigue, pain, and overall quality of life (Benlidayi, 2018). Yet, sleep can be a complex issue because symptoms from RA can make it harder to sleep. Therefore, the management of sleep needs to include controlling of the disease process with your doctor as well as

The recommended amount of sleep based on age is:

- Young adult (18-25): 7-9 hours
- Adult (26-64): 7-9 hours

with your doctor as well!

• Older adult (65+): 7-8 hours (Koketsu, 2018)

However, as we discussed in Module 2, sometimes our bodies need more sleep. Specifically, during an active flare, Deshaies (2018) recommends 8-10 hours of sleep with 30 minute to an hour rest periods in the morning and afternoon. During a flare, our bodies need that extra time to heal.

To help get a good night's sleep, you can practice habits called sleep hygiene. These habits aid in helping you to fall asleep better and get better quality sleep. On the following pages are recommended sleep hygiene habits taken from Koketsu (2018), Hall (2018), and the Centre for Clinical Interventions (n.d.).

Sleep Hygiene Recommendations:

- **Have a regular sleep schedule**: keep a regular bedtime and wake time every day, even on weekends. This regular routine helps your body to be able to fall asleep and wake up around the same time more easily.
- Get some sunshine every day: Light is one of the most important cues to our circadian rhythm. Circadian rhythm is our biological clock that helps our body to know when it's time to be awake and when it's time to sleep.
 Getting some sunshine in the morning and during the day helps your circadian rhythm to stay on track.



- **Exercise**: regular exercise helps to improve sleep (Mckenna et al., 2024). Avoid exercising within 4 hours of going to sleep to help your body calm down for sleep.
- Avoid caffeine, nicotine, and alcohol after lunch: avoid caffeine, nicotine, and alcohol for at least 4-6 hours before going to bed. Caffeine and nicotine are stimulants, and alcohol has been found to disrupt sleep.
- **Healthy eating**: eating a well-balanced diet (like described in Module 6!) can help to improve sleep. It is recommended not to eat 2 hours before bed.
- **Nap intentionally**: if you can, avoiding daytime naps can help you to fall asleep easier at night. However, a power nap of 20-30 minutes can be beneficial for many people with fatigue. Intentionally plan your nap into your day before 3 pm, and don't feel guilty!
- **Drink less closer to bedtime**: if you have to go to the bathroom multiple times a night, drink less as you get closer to bedtime to go to bed with an empty bladder.
- **Bed is for sleeping**: reserve your bed for sleeping and intimacy only to train your brain to associate bed with sleep.
- **Prep your space**: the ideal sleeping space is quiet, dark, cool, and comfortable. You can use things such as blackout curtains, eye masks, ear plugs, or a white noise machine to help with this.
- **Leave your cellphone**: stop using your phone, tablet, or other screens an hour before bed.
- **Bedtime routine**: have a relaxing bedtime routine you do each night to help signal to your body that it is time to sleep. A warm bath or shower 1-2 hours before sleep is great to help you feel sleepy.
- **Sleep when you're sleepy**: don't try to force yourself to sleep if you aren't sleepy. Wait to go to bed until you're actually feeling tired.
- **Get up if you can't sleep**: if you haven't fallen asleep in about 20 minutes, get up and do a calming or boring activity outside of bed until you feel sleepy. Once you are sleepy, return to bed to try again.
- **Don't watch the clock**: when you can't sleep it can be difficult not to check the time frequently. However, checking the time can wake you up even more and it can reinforce negative thoughts such as "look at the time, I'm never going to go to sleep".

Rest

Rest is different than sleep and is defined as "engaging in quiet and effortless actions that interrupt physical and mental activity, resulting in a relaxed state" (Koketsu, 2018, p. 307). For all people, a balance of work, leisure, rest, and sleep is essential to a healthy lifestyle. The goal of rest is to restore energy and calm to increase your ability to engage with more taxing activities (Koketsu, 2018).

According to Dalton-Smith (2021), there are seven types of rest. To feel truly rested, we need to engage in a balance of all 7 types. Let's talk about each one!

- **Physical rest**: this is what we typically think of as rest. Passively this could be sleeping or napping. Actively, this could include yoga, stretching, or a massage.
- Mental rest: mental rest is practicing slowing down and turning our thoughts off for a moment. One great practice is to take planned breaks every 1-2 hours to slow down your mind. You may also keep a notebook at your bedside to write down any nagging thoughts to sleep more soundly.
- **Sensory rest**: much of our day can be very over-stimulating. Try to make time for intentional sensory deprivation through unplugging from all electronics each evening (this is a great sleep hygiene tip as well), or simply take a few moments during the day to close your eyes.
- **Creative rest**: creative rest reawakens the awe and wonder inside of us. This is especially important for people who solve problems or brainstorm new ideas for their jobs. This can be done by admiring the beauty of nature, or it can be done by creating a work space that inspires you.
- Emotional rest: emotional rest allows us to freely share our emotions
 without the pressure of people-pleasing. This type of rest can be especially
 needed for people with chronic illness who may feel like they have to mask
 their true feelings to not upset others. Let me encourage you to seek out
 those people who allow you to freely share your genuine self. Be brave,
 what you have to share is valuable, and your feelings deserve to be heard.
- Social rest: tying into emotional rest, social rest comes from cultivating relationships that energize you rather than exhaust you. Surround yourself with encouraging, positive people and intentionally pour into those relationships.
- Spiritual rest: this type of rest allows you to feel a deeper connection to feel loved, accepted, and purposeful. You can practice this by connecting to something bigger than yourself. You may try adding prayer, meditation, or community involvement activities into your day.







Sleep Positioning

Pain from rheumatoid arthritis can make getting comfortable to sleep a challenge. The main principles of positioning for RA, and other types of pain, are to support your spine and neck in a neutral position and take pressure off of painful joints.

Here are some positioning tips by Dunkin (2022) by joint:

• Neck pain:

- o If sleeping on your back, use a thin pillow to keep neck aligned.
- If sleeping on your side, use a thicker pillow that can support your neck in the space between your shoulder and your head.
- Avoid sleeping on your stomach

• Back pain:

- Use a thin pillow to keep your spine aligned. If on your back, place a pillow under your knees and the small of your back.
- If on your side, place a small pillow under your waist and between your knees.

• Shoulder pain:

- If on your side, sleep on the side that is not painful and place a thick pillow between your arms to keep your shoulders aligned. Try to bring your shoulders back, rather than letting them slump forward.
- If on your back, place a pillow under each arm to align shoulders. This
 can also be helpful if you have elbow pain to lessen stress on the elbow.

Wrist and hands:

- Splints can be helpful at night to position your hand in a more comfortable position. Talk to your doctor or get a referral to an occupational therapist to get fitted for splints if needed.
- When sleeping on my side, I also have used pillows between my arms (like described for shoulder pain) to lay my hands across to help support them instead of balling them into fists.

• Hips and knees:

 Place one or more pillows between the knees if sleeping on your side. If you're on your back, place a pillow under the knees.

Feet:

 Sometimes the weight of sheets or blankets on the feet is painful, so you can use blanket lifters that attach to the mattress to lift sheets off of feet. I've also used a tall pillow or stuffed animal at the foot of the bed to help with this!

Let's Chat

Sleep is such an important part of managing your RA and allowing your body that time to heal. In my own self-management journey, I have found that lack of sleep is a major trigger for me that increases my pain and stiffness. However, that may be different for you. That's why it is important to get know your own body and the amount of sleep and rest that works best for you.

I will be the first to say that needing more sleep and rest than our friends and family can be frustrating. It can feel like you're missing out or being a "party pooper". But remember, you deserve rest to feel your best! Just like with all aspects of self-management, you have the power to make these tips fit your life. Sometimes you'll choose to prioritize the late night and sometimes you'll choose to prioritize your sleep, and that's okay. You know what is best for you in that moment. I want to encourage you to listen to your body and be brave enough to advocate for what you need, whatever that may be. You've got this!

My ideal nighttime routine would look like:

What areas of rest may I need to more intentionally address?

When I need to prioritize sleep and rest, how will I advocate for myself with my friends and family?



Module 8: Mental Health



The changes that come with a new diagnosis and unpredictable symptoms can have impacts to your mental health that sometimes go undiscussed. When it comes to self-management, your mental health is just as important as your physical health. In this module, I would like to discuss some of these impacts and offer a few strategies that may help to manage the emotions that come.

Occupational therapist, Cheryl Crowe (2024), describes the expectations of the RA journey like the hero's journey. For many, when you receive a diagnosis, you are determined to fight this disease, take the medicine, and "fix" it. We expect this journey to be linear, something that we can fight and overcome. However, it typically doesn't end up looking like that. Instead, the journey tends to be an up and down journey through mountains and valleys. There will be seasons where we are feeling great. We may be in remission or low disease activity, and all of our treatments are working. Then, there will be other seasons when we may experience a flare or medications become less effective (Crowe, 2024).

It can feel like we have failed somehow by not doing "enough". I've done something wrong. That's why I'm flaring, right? Actually, not necessarily. Sometimes you can be doing everything "right" and your disease still goes into a flare. That is the unpredictability of RA, and it can be so frustrating.

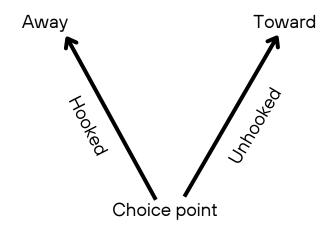
So, what do we do? We can't change the nature of RA or the impacts that it may have to our energy levels or activity limitations. Instead, we can focus on what we can control which is our mindset toward those things. It can be so easy to begin fixating on negative thoughts about ourselves. In my experience, I begin to over-rely on labeling myself as someone with RA, and I list out all the things I won't be able to do and all the ways that my life will go wrong in the future. Does that sound familiar? You're not alone in those thoughts if it does. Let's talk about some ways we can work through those things.

Acceptance and Commitment Therapy:

The goal of this strategy is to decrease the impact of painful thoughts and feelings while also taking steps forward toward a full, meaningful life (Harris, 2019). This is done by learning to accept those hard thoughts and feelings when they come, identifying our values and the type of life we want to lead, and taking action toward that life.

For many of us, when we are in pain or begin to feel anxiety over the future, we can get stuck in this loop of negativity. Harris (2019) calls this getting "hooked" by your thoughts. This leads to our thoughts dominating our actions, rather than letting our actions be guided by our values.

A helpful illustration of this is called the <u>choice point</u> (Harris, 2019). When a situation comes that triggers hard thoughts or feelings, we have a choice. We will either get "hooked", or we can "unhook". This is called the choice point. When we allow ourselves to stay hooked by those thoughts, we typically will choose "away" moves. These are moves that move us away from our values and goals. Or, we can choose to unhook from those thoughts and choose "toward" moves. These are actions that move us closer to our values and goals.



Situations, hard thoughts and feelings

A few ways we can unhook from those hard thoughts are:

- Focus on the present moment
 - Slow down and ground into the moment that you are in. What do you hear? What do you feel? What do you see? Paying attention to the sensory experiences around you can help ground you.
 - Step back and observe your thoughts
 - Try to view your thoughts as if you were an outside observer. Your thoughts can be a helpful guide, but they don't have to control you.
- Acceptance
 - It's natural to want to run or fight against painful thoughts and feelings.
 However, when we run from those thoughts it tends to make them more powerful than they need to be. Let the feelings come. You can feel your feelings, then let them go. They don't have to control you.
 - Take each day as it comes. You will most likely have good and bad days.
 You are only able to live in what is available to you today, so try not to worry about what may be in the future. Enjoy each day for what it is.
- Ask yourself, is this helping me reach my goals?
 - When you're at a choice point, ask yourself, "is this helping me to get closer to my values and the life I want?" If yes, go for it. If no, try to think of a different action that will.

Note: if you are struggling with your mental health, consider reaching out to a licensed counselor to work on some of these techniques professionally.

Breathe

The impacts to your mental health that can be caused by such a large change are real. It's okay to grieve the energy or the lifestyle you had before RA that may have changed since your diagnosis. It's hard to come to terms with the fact that you may not be able to go as far or as long as you used to.

But remember, **you are still you**. You are still the same wonderful person that you were before your diagnosis, and you are still loved exactly as you are. Just because you may have to do things a little differently or take things at a slower pace does not make you less than. Life at a slower pace is just as valuable as life at a faster one. Take your journey one step at a time, always working toward the life you want to lead. You may have to get creative along the way, but you are capable. You are brave. You can do this!

Reflection Questions

What are my values? What does the life I want to lead look like?
When I get hooked by hard thoughts and feelings, how do I typically respond?
Is that a toward or away action? If it is away, what could I do differently to make it a toward action?
Next time I get hooked by a hard thought or feeling, what will I do to unhook from that thought?
If I'm having a low energy day, what are activities I could do that I enjoy?



Module 9: Habit Formation



We've learned about many different lifestyle modifications that can aid in your self-management journey, so let's take a moment to talk about how to implement those ideas. Changing habits is definitely easier said than done, but it can be done! The key is to understand how habits work and use that information to your advantage.

Habits are controlled by a "habit loop". This loop consists of a cue, a routine (the behavior), a reward, and a craving that is driving that habit (Duhigg, 2012). This means that all habits have something that signals to you to engage in the habit, and there is a reward that is driving you to keep doing it. These cues and rewards could be any number of things, so in order to change your habits you must become aware of what your current habits are.

The 4 Rules of Habit Change by James Clear (2018):

- 1. <u>Make it simple</u>: provide yourself with an obvious cue to signal you to engage in a habit.
 - a. You can change your environment to make cues more obvious such as laying out your exercise clothes and shoes the night before.
- 2. <u>Make it attractive</u>: habits become more attractive when we associate them with positive feelings.
 - a. Try bundling a new habit with something you enjoy, or create a motivation ritual that helps you get in the mindset to complete a habit.
- 3. <u>Make it easy</u>: create an environment that makes completing a good habit as easy as possible. When you're building new habits, <u>repetition</u> is more important than perfection.
- 4. <u>Make it satisfying</u>: our brains are wired to crave immediate gratification. Give yourself a reward immediately after completing a habit, even if it's just checking off a habit tracker!

Over the next few pages, we are going to walk through how to become more aware of our habits, set goals, and use these laws of habit change to our advantage.

This exercise aims to help you become more aware of your current habits. Be truthful in recording what your typical day looks like right now. Then, after thinking about the self-management behaviors we have discussed in this program, create what an ideal day would look like incorporating new habits.

	Current Daily Routine:		Ideal Dally Routine:
6:00		6:00	
7:00		7:00	
8:00		8:00	
9:00		9:00	
10:00		10:00	
11:00		11:00	
12:00		12:00	
1:00		1:00	
2:00		2:00	
3:00		3:00	
4:00		4:00	
5:00		5:00	
6:00		6:00	
7:00		7:00	
8:00		8:00	
9:00		9:00	



Now that you've identified some habits you would like to incorporate into your day, let's walk through how to set goals and follow through. First, pick the habit that you would like to prioritize first, and write it below.

Great! Now we are going to create a SMART goal with that habit. The SMART acronym stands for:

Specific

Measurable

Attainable

Relevant

Timely

These types of goals help us to create goals that are clearly understood and realistic to meet. Here is an example of how SMART goals work:

Non-SMART goal: I will start exercising.

• This goal is very vague. It does not specify the type of exercise you will do, how you will meet the goal, or when you will meet the goal by.

<u>SMART goal</u>: I will consistently attend a water aerobics class at 9 am at the North River YMCA 2 times per week by June.

• This goal specifies what class you will attend (water aerobics), when you will attend it (9 am), is a realistic goal, is measurable (2x per week), and sets a time frame that this goal will be met in (by June).

Write your SMART goal below:



Now that you have clearly defined your goal, let's move on to implementing the 4 laws of habit change (Clear, 2018). First, we must <u>make it obvious</u>. One technique for this is to create <u>implementation intentions</u>. An implementation intention is a plan for when, where, and how you will carry out your habit (Fritz & Cutchin, 2016). These are typically written in an if-then or when-when format, so a template could be "when [cue] happens, then I will [habit]". Example: when I finish breakfast, I will pack my bag for water aerobics class"

Write your implementation intention below:

Law 2 is <u>make it attractive</u> (Clear, 2018). It's always much easier to do a habit that is enjoyable! You may consider finding friends or family that are also interested in the same habits to create a community around you that prioritizes the same things. You may also use <u>temptation bundling</u> or create a <u>motivation ritual</u>. Temptation bundling allows you to link an action you want to do with an action you need to do (ex. make a coffee in the morning, then take your medication). A motivation ritual is a routine that helps you get in the mindset to complete a habit (ex. getting water, turning on instrumental music, and sitting at your desk to begin focusing) (Clear, 2018).

How will you make your habit more attractive? Explain the techniques you will use below, and describe how you will implement those techniques.



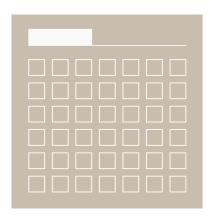
Next we need to <u>make it easy</u> (Clear, 2018). A large part of making a habit easy is creating an environment that removes obstacles. Set yourself up for success by removing unhealthy snacks from the cabinet, laying our your exercise clothes the night before, or creating a meal plan for the week. This is called a <u>commitment device</u>. It's an action you take in the present moment that will control your actions in the future. Remember, when you're creating a new habit, repetition is more powerful than perfection (Clear, 2018). Showing up for yourself makes a huge impact!

Write down how you will make your habits easy. Describe the techniques you will use and how you will implement them:

Finally, we must <u>make it satisfying</u> (Clear, 2018). Our brains are wired to crave instant gratification which means our brains want a reward for our habits immediately. You may build in small rewards for yourself to help fulfill this law of habit change. This could be as easy as checking off a habit tracker, so you have a visual representation of all your hard work. Other helpful tools for making habits more satisfying is to avoid all or nothing thinking. Don't beat yourself up if you don't do your habit perfectly every time. Instead, focus on never missing a habit twice. If you miss once, that's okay, but focus on showing back up for yourself the next time to solidify that commitment (Clear, 2018).

How will you make your habits more satisfying? Write down a small reward you will use after your habit below.

If you're interested in a habit tracker, here is a simple idea you could use. Just write in the habit you are focusing on at the top, and you can check off each day you complete it this month. There are also free printable habit trackers you can find online, or habit tracking apps you can download if you prefer digital.



A few extra tips:

Overall, choose habits that you enjoy and cater to your strengths. Don't force yourself to things that you hate because that will only lead to burnout. Explore and find healthy habits that are enjoyable to fit into your life to create a healthy, fulfilling, and fun life! To end this module, the following are a few more tips from Clear (2018) that I feel like will be helpful to you:

- <u>Habit contract</u>: this is a verbal or written agreement between you and 1-2 accountability partners. You will outline the habit you are committing to and the punishment you agree to if you do not do that habit. Having specific accountability can be very motivating!
- <u>Just right challenge</u>: this is a concept that we love in OT, and James Clear highlights in his book as well. When making goals for yourself, set goals that are realistic to your level of skill right now. It is no fun and extremely unmotivating to try to reach a goal that is way too hard. Find that sweet spot of giving yourself a challenge, but not making it so hard that it's impossible.
- Identify based goals: Clear (2018) explains in his book that identity is the
 deepest layer of behavior change. When you create identity-based goals,
 you are creating goals for who you want to be rather than what you want to
 achieve. When you begin to think of yourself as someone who is healthy
 and takes care of their body well, it is easier to begin showing up as that
 person in your habits.

Final Thoughts

Thank you for all of the hard work you have put into reading and completing the reflection activities in this program! It takes time and commitment to choose to continue to show up for yourself in this way. Congratulations on taking that first step forward into your self-management journey. I am so excited for you!

You just learned so many new ideas and tools for your self-management journey, and you may be feeling really excited to try them all. Or, you may be feeling overwhelmed by all the ideas. Both of those feelings are valid. I encourage you to choose one aspect at a time to build solid habits around to avoid burnout and ensure sustainability of that habit. Self-management is a lifelong journey that we will continue to grow in as we age with chronic illness. What works for you in this season may change in the future, and that is okay. Learning to listen to your body and choose to do the things that help you feel your best is what self-management is all about.

I am so excited and proud for you to continue this journey with the tools you've learned in this program. I know that you will create a beautiful, vibrant life with your RA. You are so brave and capable. You've got this!





Resources

Symptom Tracking

Tracking your symptoms can be a helpful tool in finding trends. It can also give your doctor a look into how your RA has been doing since your last appointment. The most important symptoms to track for RA include morning stiffness and swelling. You may also choose to track other factors related to your RA such as pain level, amount of sleep, food eaten, or other lifestyle factors. By tracking those lifestyle factors alongside your symptoms, you may be able to find a relationship between what you do and your symptoms to help you curate a personalized self-management routine that works for you.

Symptoms to track:

- Morning stiffness: is your morning stiffness over or under 30 minutes?
- Swelling: where is your swelling located, and how long did it last?
- Medication: were there any days you had to miss your medication?

Possible symptoms to track in addition:

- Pain: what is your pain on a scale of 1-10?
- Fatigue: what is your fatgue on a scale of 1-10?
- <u>Sleep</u>: how many hours of sleep did you get?
- Food diary: record what you ate at each meal

Resources to help you track:

Online:

- PatientSpot app
 - This app was created by CreakyJoints, a patient advocacy website, in conjunction with rheumatology researchers. You are able to track your symptoms and treatments, share that information with your doctor, and participate in chronic disease research if you choose through this app.

Paper:

- Symptom tracking journals
 - You can search for symptom tracking journals online to purchase
- Create your own symptom tracker
 - Write down your symptoms each day in a planner or notebook
 - You may also search for free and low-cost templates online that can be printed

Preparing for Your Doctor's Appointment

Your appointment with your rheumatologist is an important time set aside to update them on how you've been doing since your last appointment and address any concerns that may have come up. It can be hard to remember everything that has happened in the last several months or to remember all the questions you had in the moment when you start talking. That's why it can be helpful to think through your questions ahead of time, and have your points written down. Remeber that your rheumatologist is on your side, and they want to help you. Your voice is important and deserves to be heard! Below are a few prompts you can use to help you prepare for your next doctor's appointment!

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What are your main questions/concerns for your doctor?
Have you had any changes in symptoms since your last visit?
Have you had any appointments with other doctors or specialists since your last visit?

Fall Prevention Tips

Falls are a serious health concern for older adults (adults older than 65). Each year, one in four older adults will fall (CDC, 2023). Falls can lead to serious injuries, fear of falling, and decreased independence for older adults. That's why it is so important that you do all that you can to help protect yourself from falling.

Below are a few tips from the CDC (2023) that you can use to help you to prevent falls:

- Ask your doctor to <u>assess your risk of falling</u>. They can help identify some areas that you may be at risk and help you address those.
- Talk to your doctor or pharmacist to <u>review your medications</u> with you to see if any of them have dizziness or increased drowsiness as a side effect.
- Have your vision and feet checked once a year. Decreased vision or neuropathy affecting your feeling in your feet can increase your risk of falls.
- <u>Exercise</u> and stretch to maintain flexibility, strength and balance
 - Tai chi and other low impact classes discussed in Module 5 are great options!
- Wear comfortable, supportive shoes
- <u>Decrease clutter</u> and make sure that all walkways are clear of anything you could trip over.
 - Removing area rugs can help to clear walkways to decrease risk of tripping. If you do not want to remove rugs, make sure that all sides and corners of the rugs are secured to the floor, so they are not a tripping hazard.
- Install grab bars in your bathroom next to the toilet and shower
- Ensure your home has <u>a lot of light</u> by adding more light sources or using brighter light bulbs.
- Install railings on both sides of stairs or outdoor steps into the home

Community Resources:

 Matter of Balance is an 8 week program geared toward fall prevention and decreasing fear of falling in older adults. Classes are offered at several different locations in Chattanooga including the YMCA and other community sites. You can ask about Matter of Balance at your local YMCA or keep an eye out for class sign ups if you live in a senior living community.

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