Lipodystrophy United

LIPODYSTROPHY Mental Health Series: Part 1, Rest

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Welcome,

This toolkit was co-developed by Lipodystrophy United in collaboration with Give an Hour, a national nonprofit whose trauma-informed mental health frameworks informed the structure and tools included. We know how heavy the burden of mental health in lipodystrophy can be, and we hope this packet serves as a starting point and practical resource for our community members.

At Lipodystrophy United, we believe mental health is a major part of the lipodystrophy experience. We have come to this conclusion through conversations with hundreds of community members who have shared that mental health has played a significant role in their journey.

A recent community survey conducted in collaboration with Chiesi found that 76% of respondents frequently struggle with anxiety, yet more than 50% are navigating this without professional mental health support. In addition, 85% reported a moderate-to-severe impact on self-esteem and body image, and 79% reported a moderate-to-severe impact on overall enjoyment of life and health.

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The *SEVEN* Types of Rest

Understanding different types of rest can help you recharge and maintain balance in your life. Read through each type of rest below, then reflect on how you currently incorporate these into your routine and where you might need more.

Physical Rest

This involves giving your body a break from physical exertion. It includes passive physical rest, like sleep and napping, as well as active physical rest, such as gentle activities like yoga, stretching, or massages.

Mental Rest

This type of rest helps calm a busy mind. Techniques such as taking short breaks throughout the day, practicing thought diffusion, or journaling before bed can help ease mental fatigue.

Sensory Rest

In our overstimulated world, sensory rest is crucial. It involves taking intentional breaks from sensory input, such as reducing screen time, spending time in quiet environments, or practicing grounding exercises.

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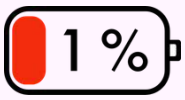
Emotional Rest

Emotional rest allows you to express your true feelings and be authentic. It involves creating space to share your emotions openly and surrounding yourself with supportive people who provide emotional peace.



Social Rest

Understanding your social energy needs is key. Whether you're an introvert or an extrovert, it’s important to recognize when to recharge your social battery, especially in interactions that drain your energy.

Creative Rest

This type of rest is especially important for those in creative fields. It involves allowing yourself to be inspired without the pressure to produce. Spending time in nature or stepping away from projects can help rejuvenate creative energy.

Spiritual Rest

Spiritual rest involves connecting with something greater than yourself. This could mean engaging in prayer, meditation, or participating in community or spiritual activities that give you a sense of purpose and belonging.

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Taking *Inventory* of My Current Rest Habits

Rest is very important for the lipodystrophy community. This thought exercise will help you reflect on your current rest habits across the seven types of rest. By identifying what you're already doing well and where there may be gaps, you can develop a more balanced approach to rest.

Physical Rest

How much sleep do I get each night? __ Hours
Do I take naps or breaks when needed? (Circle one) Yes / No
How often do I engage in physical activities (walking/yoga/workout)? __ Times per week
What physical relaxation techniques do I practice? (e.g., deep breathing, massages)
Is my body getting enough rest? What changes can I make?

Mental Rest

Do I experience racing thoughts or mental fatigue?
(Circle one) Often / Sometimes / Rarely
Do I take breaks during the day to rest my mind? Yes / No
Do I practice any mental rest techniques, like thought diffusion or journaling? Yes / No
How can I better support my mind in resting and recharging?

Sensory Rest

How much time do I spend in front of screens daily? __ Hours
Do I take breaks from sensory input (e.g., noise, bright lights)? Yes / No
What practices do I use to reduce sensory overload? (e.g., grounding exercises, quiet time)
Am I allowing my senses enough time to rest? What can I adjust?

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Emotional Rest

Do I feel comfortable expressing my true feelings?
(Circle one) Often / Sometimes / Rarely
Do I have a support system to share my emotions with? Yes / No
How often do I suppress my emotions to avoid conflict or discomfort? __ Times per week
Do I take on the emotional load of other people?
(Circle one) Often / Sometimes / Rarely
How can I create more opportunities for emotional rest in my life?

Social Rest

Do I feel drained after social interactions?
(Circle one) Often / Sometimes / Rarely
How often do I take time alone to recharge? __ Times per week
Do I feel pressure to socialize even when I don't have the energy? Yes / No
How can I balance social interactions with personal recharge time?

Creative Rest

Do I feel creatively inspired or blocked?
(Circle one) Inspired / Blocked
How often do I engage with sources of creative inspiration (e.g., nature, music, art)? __ Times per week
Do I allow myself unstructured time to rest from creative tasks? Yes / No
What can I do to better support my creative rest?

Spiritual Rest

Do I feel connected to something greater than myself? Yes / No
Do I engage in spiritual or meaningful activities (e.g., prayer, meditation, community involvement)? Yes / No
How often do I reflect on my values and purpose? __ Times per week
What activities help me feel a sense of peace and purpose?
How can I create more space for spiritual rest in my life?

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Journaling Prompts on Rest

Take a moment to think about your rest habits above. What did you discover?

Which type of rest do I depend on the most?

Which type of rest do I shy away from or avoid?

Which type of rest do I feel I need the most right now?

What is one small action I can take this week to improve my rest in this area?

What is one habit I already do well that I can maintain or enhance?

Action Plan:

Identify one type of rest you need more of in your life.

Write down one small action you can take this week to improve your rest in that area.

Choose one area of rest to focus on for the next week.

Write down a small, realistic action to support that area.

Revisit this resource in a few weeks to reflect on your progress.

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The *SEVEN* Types of Rest
My Self-Care Toolbox!

Physical Rest

- [ ] _____
- [ ] _____

Mental Rest

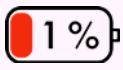
- [ ] _____
- [ ] _____

Sensory Rest

- [ ] _____
- [ ] _____

Emotional Rest

- [ ] _____
- [ ] _____



Social Rest

- [ ] _____
- [ ] _____

Creative Rest

- [ ] _____
- [ ] _____

Spiritual Rest

- [ ] _____
- [ ] _____

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LIPODYSTROPHY Mental Health Series: Part 2, Support Systems

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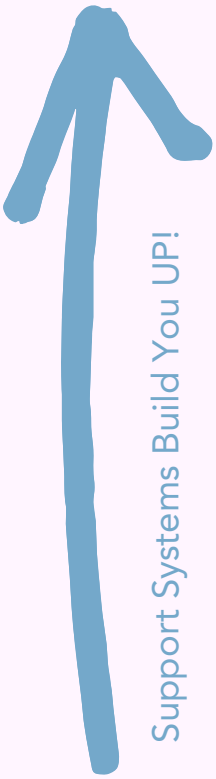
CREATING SUPPORT SYSTEMS

Our community often feel isolated and finds it challenging to connect. 51% report difficulty in maintaining friendships and 53% report feeling alone*. Since the rare care journey is often emotional and difficult, it is important to prioritize support. Research has shown that supportive relationships have many benefits. These include reducing stress, depression and anxiety; living longer; having higher levels of well-being; and acquiring better coping skills. So how do you build strong support systems? Figure out what kind of support you need then work on building and sustaining them. Yes it takes energy, but you will get so much in return.

Type of Support Needed



Different relationships check particular boxes. When you have limited time and energy, be intentional about the relationships you build & the people you surround yourself with.

Tangible — A service or a favor; reinforces that it's healthy to ask for help when needed and accept the help

Emotional — Acceptance, understanding, reliable encouragement and empathy; reminder that we are not alone

Affirmational — Feelings that build your motivation and respect your efforts

Informational — Receiving positive, supportive information or new knowledge; provides support without an emotional connection

Belonging — Belonging to a community or peer group that understands your beliefs and/or situation

Tips to Sustain Support Systems

- Respect boundaries
- Accept help
- Be available
- Be honest
- Be patient...it takes time to develop
- Stay in touch
- Reciprocate: support their successes and share appreciation
- Engage when it's healthy

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My Support System

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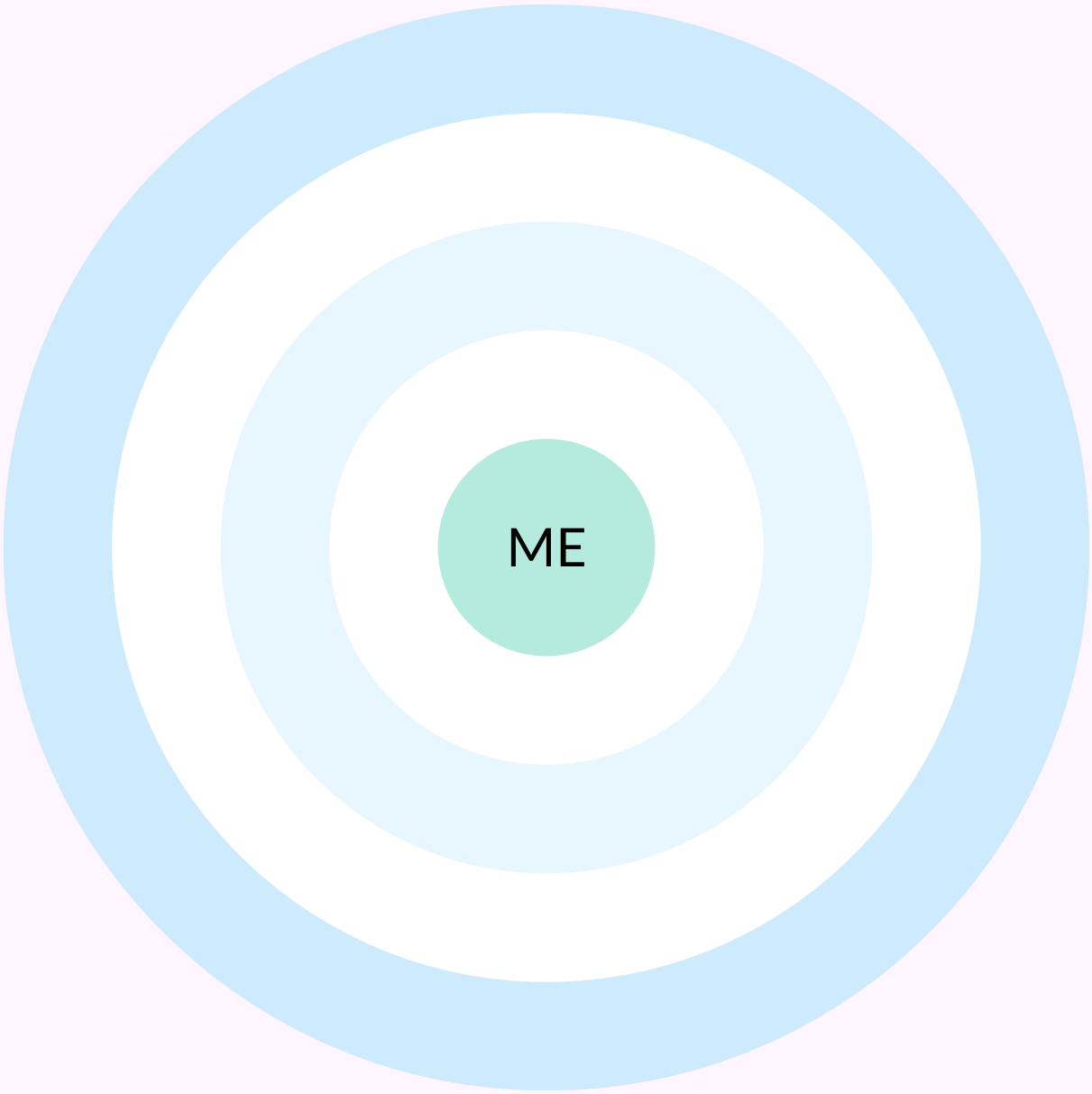
Building a strong support network is often a lifelong pursuit for many of us. According to researchers, the ability to seek support is closely tied to our mental health. it's important to emphasize that simply having access to social support is not sufficient. What truly matters is actively choosing to utilize and engage with those social supports available to us.

Write down who is in your system and make a commitment to reach out to these people and develop more relationships.



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My Support System Exercise

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3 people I trust the most:

People I can text sad/happy memes to:

Qualities that I look for in a supportive relationship:

My support needs:

People I want to invest in:

Relationships to reinvigorate:

Relationships to let go of or change:

Gaps in my support system that I need to work on:

A person who I will let see me ugly cry and talk about my feelings:

Someone I can VENT to:

An online or in-person community where I can get support:

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LIPODYSTROPHY Mental Health Series: Part 3, Rumination and Self-Compassion

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Rumination: When Overthinking Becomes a Trap

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Rumination isn't just overthinking, it's a loop of emotional distress disguised as "problem solving."
It often feels helpful, but it keeps us stuck in the past and disconnected from the present.

What It Sounds Like

- "Why did that happen?"
- "What could I have done differently?"
- "I should have said..."
- "If I could do that again, I would have..."
- "Why do I feel this way?"
- "Ugh, why am I like this?"
- "What if it happens again?"

Why We Ruminate

- We feel powerless, and thinking gives us a false sense of control.
- We're trying to make meaning out of pain.
- We believe more thinking will lead to clarity.
- We're conditioned to analyze instead of feel.
- We instinctively keep returning to the moment of distress.

The Truth

Rumination is often a trauma-informed survival skill.
If you've experienced moments where being unprepared led to pain, your brain may default to replaying events as a way to "prevent it" from happening again. But now, instead of protecting you, it may be costing you peace.

Interrupt the Loop

- Name it → "I'm looping."
- Ask → "Is this helping or hurting?"
- Redirect → Into action, acceptance, or grounding.

"You can't heal by punishing yourself. You heal by listening differently."

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Journaling Prompts on Rumination

Step 1: Name the Loop

Think of three things that make you apprehensive or anxious?
Write the ruminating thoughts exactly as it shows up:
Example: "Why didn't I speak up?" or "I should've handled that better."

Step 2: What's Underneath?

Ask yourself:
1. What emotion is underneath this thought?
(e.g., fear, guilt, shame, insecurity, anger, sadness)

Step 3. What is this thought trying to do for me?

(Is it trying to protect me, prepare me, or make sense of something?)

Step 4: Reframe Your Throughts into a Reflection Prompt

Flip your rumination into a kind, helpful reflection question.
Use this structure:
"What can I learn from this..." or "What would it look like if I responded with compassion?" Write your new prompt:

Examples:
From: "Why did I mess that up?" ➔ To: "What can I learn from that moment without blaming myself?"
From: "Why can't I do more?" ➔ To: "What would enough look like if I showed myself compassion?"
How did it feel to reframe the thought?

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Reinforcing Self-Compassion

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Our community experiences a high daily health burden which can result in high levels of stress, feelings of loss of what they thought life would be like, and simply the feeling of not being able to keep up with all aspects of lipodystrophy, family, work, not to mention taking care of oneself. ***Self-compassion can play a key role in positive emotional health for our community.*** Self-compassion is the act of treating yourself as you would treat a good friend.

Three Components of Self Compassion

Self-kindness: caring and encouraging yourself as you would to others, rather than being self-criticizing.

Common humanity: all humans are imperfect, experience difficulties and pain, and make mistakes. Give yourself a break.

Mindfulness: being in the moment, present, open, and feeling emotions while they are happening.

The Stigma: Self Compassion is ABSOLUTELY NOT

- A form of self-pity
- Makes a person vulnerable and weak
- Self-centered and selfish
- Creating an excuse

Benefits of Self Compassion

- Improved happiness
- Good mental health
- A stronger immune system
- The secret to resilience
- Creates strength to face hardships
- Reinforces ability to learn from mistakes

Practicing Self-Compassion

- Take a compassion break
- Forgive yourself
- Stop competing and comparing
- Practice positive self-talk
- Develop a self-compassion mantra
- Focus on your wins

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SELF-COMPASSION STRATEGIES FOR INDIVIDUALS IN OUR COMMUNITY

Prioritizing self-care can be a challenge when navigating your disease. Self-care is essential to prevent burnout. Self-care does not look the same for every community member, you will need to find what works best for you. Try incorporating one of these tips each month and with practice, taking care of yourself will become second nature.

Learn & practice stress reducing techniques

Eat nourishing food that your dietician recommends

Give your body rest

Move your body in any way that works for you

Take time off without guilt

Participate in enjoyable activities, like reading a book

Seek and accept the help of others

Seek counseling when needed

Practice mindfulness: identify and acknowledge your thoughts, emotions, feelings, and challenges

Practice common humanity: through shared experiences, i.e. peer support, online support groups such as LU programming

Set obtainable goals

Practice self-kindness

Practice the Healthy Habits of Emotional Wellbeing

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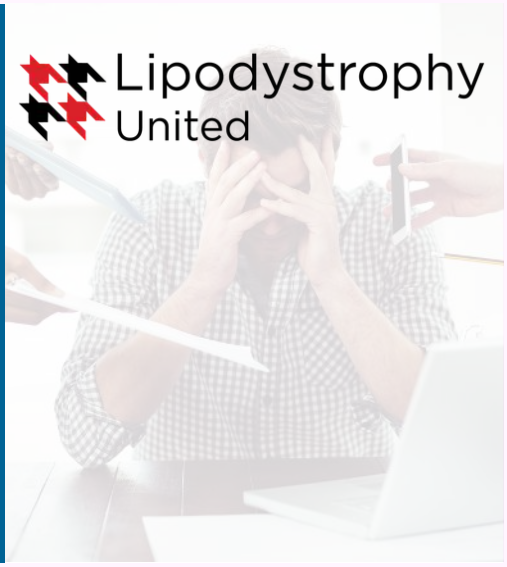
Self-Regulation: Strategies for Emotional Balance and Resilience

Emotional self-regulation is about managing your emotions and reactions in different situations. It starts with self-awareness—noticing and understanding your feelings and what activates them. Once you're aware, self-regulation helps you handle tough emotions and express them in a healthy way.



Challenge: For the next 6 weeks, practice one of these self-regulation techniques per week.

Self-Awareness: Understand and Recognize Emotions

- ☐ ***Check-In Regularly:*** Take short breaks to notice how you're feeling. Are you stressed, calm, frustrated, or content?
- ☐ ***Recognize Activators:*** Notice what sparks your emotions, whether it's a specific event, interaction, or thought. Understanding these activators helps you prepare for and manage your emotional responses more effectively.
- ☐ ***Label Feelings:*** When you feel a surge of emotion, identify it. Simply naming feelings (like anger, anxiety, or joy) can lessen their intensity and help you think more clearly.

Use Positive Self-Talk

- ☐ ***Reframe Negative Thoughts:*** If you're feeling overwhelmed, change your inner dialogue. For example, replace "I can't do this" with "I'm finding this hard, but I can take it one step at a time."
- ☐ ***Affirmations and Encouragement:*** Remind yourself of past successes, and use affirmations to build confidence, like "I am capable" or "I have managed challenges before."

Practice Gratitude and Self-Compassion

- ☐ ***Focus on Positives:*** Spend a few minutes each day reflecting on things you're grateful for, as this can shift your mindset toward positivity.
- ☐ ***Forgive Mistakes:*** Be kind to yourself when you fall short. Accept that setbacks happen, and focus on learning from each experience.

Develop a Healthy Routine

- ☐ ***Establish Regular Sleep and Nutrition Habits:*** Adequate rest and a diet that works for you play a big role in mood and resilience, helping you stay as regulated as you possibly can given the circumstances. For people with extreme hunger, speak to your doctor about what is best for you.
- ☐ ***Set Time for Reflection:*** Daily or weekly, take time to reflect on what went well and where you could improve, allowing you to make adjustments with intention.

Pause Before Responding to Others

- ☐ ***Use a Cushion Before Responding:*** When emotions are activated, your rational brain needs time to catch up. Responding in the heat of the moment can escalate conflicts. Instead, create a "cushion" by pausing—take a brief walk, sip some water, or give yourself a moment to cool down—before you react.
- ☐ ***Don't Feel Pressured to Respond:*** When our buttons are pushed, we might need some time to percolate before we respond. Sleep on it (if you can), what seems critical in the moment can seem like no big deal after a good night's sleep.

Build a Support Network

- ☐ ***Talk It Out:*** Find a trusted friend or mentor you can turn to for advice or a listening ear. Sharing challenges helps you find solutions or see.
- ☐ ***Encourage Accountability:*** Having someone who knows your goals can help you stay on track and offer encouragement. Find an accountability partner!

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LIPODYSTROPHY Mental Health Series: Part 4, What to Expect if you Choose Therapy

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What to Expect if you Choose Therapy

Beginning therapy can bring up a mix of feelings, concerns, and uncertainty. These are common Q&A's about what to expect in your first session. Remember, you won't feel better right away; healing takes time and often requires multiple sessions. Use an initial meeting to ask questions, set goals, and share your expectations with your therapist.

What happens in the first therapy session?

In your first therapy session, your therapist will get to know you by asking about your background, current challenges, and goals. You should leave with a clear understanding of how therapy works, including confidentiality, session structure, and what to expect moving forward.

The first session is about building rapport and understanding your needs, so don't be disappointed if you can't cover everything right away—that's normal! You'll have plenty of time to explore and work through things in future sessions.

How do I know if a therapist is the right fit for me?

Finding the right therapist is about feeling comfortable and understood. You should feel safe, respected, and listened to during sessions. Pay attention to whether their approach and communication style resonate with you.

While it's normal for progress to take time, you should begin to feel some sense of improvement or connection as you move forward. If after a few sessions you don't feel a good fit, it's okay to try someone else. The right therapist will help you feel supported in your journey.

How many therapy sessions will I receive?

There is no fixed limit on the number of therapy sessions you will receive. The duration of therapy is determined in collaboration with your therapist, based on your goals and individual circumstances. Sessions can continue until you and your therapist mutually decide it's time to conclude therapy.

What types of therapy might I experience?

We offer a variety of therapy techniques to suit different needs and preferences. Our therapists are trained in approaches like Cognitive Behavioral Therapy (CBT), Dialectical Behavior Therapy (DBT), and others, including mindfulness-based therapy, trauma-focused therapy, and more. Your therapist will work with you to determine the best approach for your goals and needs.

Will therapy "fix" me?

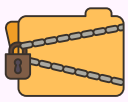
Therapy isn't about "fixing" you, but rather supporting you in understanding yourself better, managing challenges, and building healthier coping strategies. It's a process that helps you gain insight, develop skills, and make meaningful changes at your own pace.

While therapy can lead to significant improvements, it's a journey, and progress may look different for everyone. The goal is to empower you to live a more fulfilling and balanced life.

What if I don't know what to talk about?

It's completely normal to feel unsure about what to talk about, especially in the beginning. Sometimes just talking about how you're feeling in the moment can be a good starting point. Your therapist is there to guide the conversation and help you explore whatever is on your mind, whether it's a specific issue or something you're struggling to put into words.

Is therapy confidential?



Your therapist will explain the limits of confidentiality at the beginning of your sessions to ensure you understand how your privacy is protected. The goal is to create a safe, trusting space where you can be open and honest.

What if I don't like my therapist?

Sometimes it takes time to build a connection, but if you still don't feel like it's the right fit, that's okay and completely normal. We encourage you to reach out to the Give an Hour staff, and we can help match you with another therapist. It's all part of finding the right provider to support you, and we're here to help you keep trying until you find the best fit.

Can therapy help with specific issues like anxiety or trauma?

Yes, therapy can help with specific issues like anxiety, trauma, and more. We have therapists who specialize in working with a variety of concerns, and we also provide ongoing training to ensure our providers have the tools and techniques needed to support the people we serve.

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What to Expect if you Choose Therapy

How much does therapy cost, and is it covered by insurance?

If clients use their insurance, the insurance will cover the majority of the cost, but the client is responsible for paying the copay or coinsurance amount set by their insurance provider. It is up to the therapist to decide whether to require the full copay/coinsurance amount or to offer a discounted rate. In some cases, providers may waive the copay entirely, allowing clients to avoid out-of-pocket costs.

What if I want to quit therapy?

It's normal to question whether therapy is right for you at any point in the process. If you're thinking about quitting, we encourage you to talk to your therapist about how you're feeling—they can help you explore why you're considering stopping and discuss any concerns you have.

Sometimes taking a break or adjusting the approach can make a big difference. If you still feel like therapy isn't helping, we can support you in finding other resources or options.

Do I have to do homework or exercises?

Some therapists may assign homework or exercises between sessions if they think it will be helpful for your progress. If you think this would be useful for you, feel free to let your therapist know. However, if you don't feel that homework or exercises would be helpful, it's important to share that as well. Therapy is a collaborative process, and your therapist will work with you to find what works best for your needs.

How do I prepare for my first therapy session?

To prepare for your first therapy session, think about what you hope to achieve and any specific challenges you'd like to work on. It's helpful to be open and honest about your thoughts and feelings, and don't hesitate to jot down any questions or concerns beforehand.

You might also be asked to discuss your background, so reflecting on that can be useful. Most importantly, come with an open mind, as it may take time to build rapport and feel comfortable with the process.

What's the difference between therapy and talking to a friend?

While talking to a friend can be supportive, therapy offers a professional, structured environment focused on your well-being. Therapists are trained to listen without judgment, provide evidence-based techniques, and help you work through challenges in a deeper, more constructive way.

Unlike friends, therapists maintain confidentiality, offer objective guidance, and create a safe space for personal growth. Therapy is a dedicated process aimed at helping you understand yourself better and make lasting changes.

What if I miss a session?

If you know you'll miss a session, we strongly encourage you to reach out to your provider as soon as possible. Missing an appointment without notice may result in a small fee or, in some cases, losing the opportunity to continue seeing that provider. Communication is key to maintaining your therapeutic relationship.

What if my provider has different beliefs than me?

Therapists are trained to respect and honor your beliefs, regardless of their own. If your provider's religious beliefs differ from yours, they will focus on understanding and supporting your perspective without judgment. If you ever feel uncomfortable, it's important to discuss it with your therapist or let Give an Hour staff know so we can help match you with a provider who better fits your needs.

What if I struggle to open up?

It's completely normal to feel nervous or embarrassed about sharing personal things in therapy. Remember, your therapist is there to provide a safe, nonjudgmental space to support you. You can start by sharing what you're comfortable with and take your time—there's no pressure to open up all at once. Therapy is a process, and your comfort is a priority.

Can I talk about anything in therapy?

Therapists are required by law to break confidentiality if you disclose plans to harm yourself or others, report abuse of a child, elderly person, or vulnerable adult, or if mandated by a court order. Otherwise, your sessions are a private and safe space for you to discuss anything openly. If you're unsure about what's confidential, your therapist can clarify at the start of your work together.

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LIPODYSTROPHY Mental Health Series: Part 5, Creating Healthy Boundaries

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Healthy Care *Boundaries*

Maintaining healthy boundaries is crucial for balancing support for others without shouldering their emotional burdens. These boundaries help define the extent of care you can offer while preserving your own mental well-being. Supporting others in their time of need doesn't mean self-abandonment. Setting clear boundaries helps you understand the limits of your care and empathy, preventing the shift into shouldering behaviors that can lead to resentment, overwhelm, and burnout.

Where do you sit on the scale between caring too little and caring too much?

	UNHEALTHY Not Caring	HEALTHY Not Caring	HEALTHY Caring	UNHEALTHY Caring
What it Looks Like	Completely Detached Emotionally Distant Numb Dismissing	Practicing Self-Care Emotionally Detach from Toxic Situations Practicing Healthy Boundaries	Showing Empathy Empowering Others Setting Healthy Boundaries Prioritizing Self-Care	Compassion Fatigue Overwhelm Problem Solving Taking on Vicarious Trauma Burnout
Statements	"It's NOT my Problem" "You're Overreacting" "You're always complaining." "Suck it up"	"I can't take this on at the moment." "I don't have the capacity to help with this, but I encourage you to seek help."	"It sounds like you're going through a tough time. Let's talk about it." "Let's figure out some steps you can take to feel better."	"You don't need to do anything; I've got it covered." "Just lean on me, and I'll carry the weight for both of us."
Actions	Turning a Blind Eye Disengaging from Tough Conversations Downplaying or Overlooking Challenges Dismissing/Criticizing Concerns	Prioritizing Personal Recovery Asserting Strong Boundaries Acknowledging Challenges	Active Listening Resource Sharing Promoting Self-Care and Seeking Help Creating a Safe and Open Environment	Overcommitting Yourself Fixing/ Problem Solving Neglecting Self-Care Blurring Personal Boundaries

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Supporting vs. Shouldering: Understanding the Difference

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Understanding the difference between showing support and shouldering is crucial in setting boundaries; ensuring we can provide effective emotional support without compromising our mental health.

Supporting

Supporting is being empathetic and showing concern for others without taking on their burdens. Supporting EMPOWERS the other person, and when you support, you maintain healthy boundaries to protect your own mental health and well-being, preventing you from becoming overly involved or affected by the other person's problems. Supporting doesn't mean it's YOUR job to FIX or find solutions; instead, it is to show care and compassion to the other person so that they can find their own solutions. Supporting is a BALANCED approach that shows commitment to helping without sacrificing yourself.

Shouldering

By comparison, Shouldering refers to taking on responsibility for someone else's problems. Shouldering is when you get SO involved in helping someone that their issues begin to weigh you down. Shouldering can lead to a sense of feeling OVERLY responsible for someone else's well-being, to the detriment of your own mental health. You can feel drained of energy, empty, or as though without you, everything would fall apart. Shouldering can lead to controlling behaviors, burnout, and can cross a line from support to dependency.

Is It Supporting or Shouldering?

Aspect	Supporting	Shouldering
Empowerment	Empowers others	Overly responsible for others
Boundaries	Maintains healthy boundaries	Sacrifices personal wellbeing
Role	Shows care, not fixing	Feels the need to fix others' problems
Mental Health Impact	Positive, balanced approach	Draining, leads to burnout
Behavioral Outcome	Encourages self-reliance in others	Can lead to controlling behaviors
Respect, Empathy, and Compassion	Shows respect, empathy, and compassion	Self-serving, micromanaging

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Lipodystrophy United

LIPODYSTROPHY Mental Health Series: Part 6, Self-Care for Lipodystrophy Caregivers and Peer Supporters

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SELF-CARE FOR LIPODYSTROPHY CAREGIVERS:

ESTABLISHING HEALTHY HABITS OUTSIDE OF CAREGIVING

Prioritizing self-care can be a challenge when providing lipodystrophy caregiving to others. Self-care is essential to prevent burnout as the healthier you are, the more energy you will have to care for others. Self-care does not look the same for every rare caregiver. Try incorporating one of these tips each month and with practice, taking care of yourself will become second nature.

Learn & practice stress reducing techniques

Attend to your own healthcare needs

Get adequte rest and nutrition

Exercise regularly even if only for a short time

Take time off without guilt

Participate in enjoyable activities, like reading a book

Seek and accept the help of others

Seek counseling when needed

Practice mindfulness: identify and acknowledge your thoughts, emotions, feelings, and challenges

Practice common humanity: through shared experiences, i.e. peer support, online support groups

Set obtainable goals

Practice self-kindness

Practice the Healthy Habits of Emotional Wellbeing

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FACE the FIVE

Signs for Rare Caregivers to Notice

Being a caregiver for someone with a rare disease presents unique challenges that significantly impact mental health. Over 70% of caregivers experience high levels of stress, with 65% reporting depression and 53% anxiety. Many caregivers feel guilty prioritizing their health, with 72% experiencing self-care guilt. Give an Hour's "Five Signs" provides a common language to understand how emotional struggle can show up for rare caregivers, along with ways to show support and respond. Recognizing these signs is crucial for family members and loved ones, as it enables them to provide timely support, reducing the risk of burnout and promoting a healthier caregiving environment.

PERSONALITY CHANGES

Your loved one may seem different exhibiting behaviors that don't align with their usual self.

Stressed-out, checked-out, frequently anxious or depressed, acts differently than 'normal', eerily "at peace" or joyful when previously stressed/depressed.

UNCHARACTERISTICALLY ANGRY, ANXIOUS, AGITATED, OR MOODY

Your loved one may struggle frequent mood swings.

Lashing out, angry outbursts, panic attacks, self-soothing. Always in 'crisis mode', feeling repeatedly triggered. May happen with or without a clear trigger.

WHAT YOU CAN SAY:

"I've noticed that lately when we talk or hang out, you seem distant, you don't seem like your usual self. Can you tell me more about what's going on? I want to find ways to support you."

"I can't imagine how stressful that must be. It's sound like you're having a really tough time dealing with all of this. I want to understand what you're going through. Can you tell me more about how you're feeling?"

WITHDRAWAL OR ISOLATION FROM OTHER PEOPLE

Your loved one might pull away from family and friends, signaling a need for support and understanding.

Not responding to texts, excessive malaise or sleeping, Needing to be alone. Not showing up for planned activities, housebound or signs of agoraphobia, avoidance when questioned.

"I've noticed that you haven't been responding to my texts like you used to, and you've been spending more time by yourself. It's important to take the time you need for yourself, but you don't have to do this alone. You can lean on me for support, I'm here if you need someone to talk to."

MAY NEGLECT SELF-CARE AND ENGAGE IN RISKY BEHAVIOR

Financial strain, physical limitations, and emotional distress can contribute to neglecting self-care or engaging in risky behaviors.

Reckless or irresponsible spending, substance use, sedentary lifestyle/lack of physical activity, hair matting from poor self-care, change in appearance, "Depression House", significant weight gain or loss. Excessive sleeping.

"This might be difficult to talk about, but I've noticed you've been drinking more lately, and I'm really concerned about you. I just want to make sure everything is okay. I'm here for you. Do you feel comfortable opening up about that?"

OVERCOME WITH HOPELESSNESS AND OVERWHELMED BY CIRCUMSTANCES

Your loved one may experience extreme or prolonged grief, feelings of worthlessness, or guilt.

Verbal expressions of distress: "There's no point in going on", shutting down, masking feelings, making end-of-life plans, suicidal thoughts, self-harm, or worrisome verbal statements, "It's hopeless".

"I understand it can be hard to open up and I want you to know I'm here for you. From a sincere place of concern I want you to know that I've noticed you've been really struggling lately. Are you having thoughts about hurting yourself?"

Navigating *Crisis Responses* for Caregivers in the Rare Disease Community

Crisis in the Rare Community

A crisis isn't always a single dramatic event. For caregivers, it can be a series of moments that evoke intense emotional responses due to:

Diagnosis

The moment of diagnosis can activate feelings of shock, grief, and fear.

Progression or Flare-ups

Worsening symptoms or unexpected medical issues can create significant stress.

Losses

Whether it's the loss of a trusted doctor, a critical medication, or financial stability, these changes can destabilize your sense of security.

Life Changes

Moves, changes in care routines, or shifts in family dynamics can all be sources of stress.

Practical Steps for Emotional Wellbeing

Create a Crisis Plan

Set Boundaries

Limit Caffeine & Alcohol

Plan for Caregiver Fatigue

Educate Your Support System

Take Regular Breaks

Prioritize Self-Care

Emotional Challenges for Rare Caregivers

Guilt & Resentment

Caregivers often struggle with feelings of guilt, especially regarding the genetic aspects of rare diseases or the level of care they can provide. Open communication and family therapy can be helpful in addressing these emotions.

Hypervigilance

The constant state of alertness and worry about the care recipient's wellbeing can lead to chronic anxiety. Strategies like mindfulness, regular exercise, and engaging in hobbies can help mitigate these feelings.

Key Reminders During a Crisis

Respond Don’t React

Taking action can feel like you’re doing something to exert control over a frightening & uncertain situation, but it can lead to impulsive decision making.

Pause Before Acting

Avoid making big decisions or offering more support during a crisis. Take time to process and stabilize first.

Acknowledge the Emotional Burden

Recognize and validate your own emotional responses. It's normal to feel overwhelmed, anxious, or depressed when dealing with the constant demands of caregiving.

Avoid Unhealthy Coping Mechanisms

Substance use or excessive drinking can exacerbate stress. Seek healthier alternatives.

Crisis Resources

United States Resources

National Suicide/Crisis Lifeline 988 (Call or text plus online chat) https://988lifeline.org
Crisis Text Line: Text HOME to 741741
https://www.crisistextline.org

National Alliance on Mental Illness Helpline: 1-800-950-6264, Text NAMI to 62640 (staffed M-F 10 am to 10 pm)
https://www.nami.org

Mental Health America: 1-800-969-6642
https://mhanational.org

International Resources

International Association for Suicide Prevention:
https://www.iasp.info/

Befrienders Worldwide: https://befrienders.org/

Lifeline International: https://lifeline-international.com/

As always, if you feel you or someone else's life is in danger, call 911 or your local emergency number.