

Practicing Self-Compassion

Patients living with chronic or rare diseases and their caregivers often carry a significant burden. Managing symptoms, appointments, treatments, and ongoing uncertainty can be stressful, alongside a sense of loss for the life they could have had. Balancing all of this with family, work, caretaking or caregiving, and everyday responsibilities can feel overwhelming, leaving little time or energy to care for themselves. **Self-compassion can play a key role in building positive emotional health.** Self-compassion is the act of treating yourself as you would treat a good friend.

3 Components of Self-Compassion

1

Self-kindness

Caring for and encouraging yourself as you would others, rather than being self-critical.

2

Common humanity

All humans are imperfect, experience difficulties and pain, and make mistakes. Give yourself a break.

3

Mindfulness

Being in the moment, present, open, and feeling emotions while they are happening.

Self-Compassion is NOT

- A form of self-pity
- What makes a person weak or vulnerable
- Self-centered and selfish
- An act of creating excuses

Benefits of Self-Compassion

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

Put It into Practice

- Take a compassion break to practice self-kindness
- Forgive yourself
- Stop competing and comparing
- Practice positive self-talk
- Develop a self-compassion mantra
- Focus on your wins
- Use a soothing gesture, like placing your hand on your heart as you breathe

Self-Care Practices

Which ones do you lean on most?

PHYSICAL

Sleep
Exercise
Yoga

MENTAL

Meditation
Journaling
Reading

EMOTIONAL

Talking
Sharing
Connecting

NUTRITIONAL

Healthy eating
Balanced meals
Staying hydrated

SPIRITUAL

Prayer
Faith counseling
Non-religious practices

FINANCIAL

Budget tracking
Emergency fund
Financial literacy

Self-Care Checklist



Exercise regularly even if only for a short time



Take time off without guilt



Disconnect from social media



Seek and accept the help of others



Seek counseling when needed



Learn and practice stress-reducing techniques



Attend to your own healthcare needs



Be mindful: identify and acknowledge your thoughts, emotions, feelings, and challenges



Set limits on your time and energy to protect your well-being



Set obtainable goals



Practice self-kindness



Get adequate rest and nutrition



Practice common humanity through shared experiences, like peer support or online groups



Celebrate small wins to remind yourself of your strength and resilience

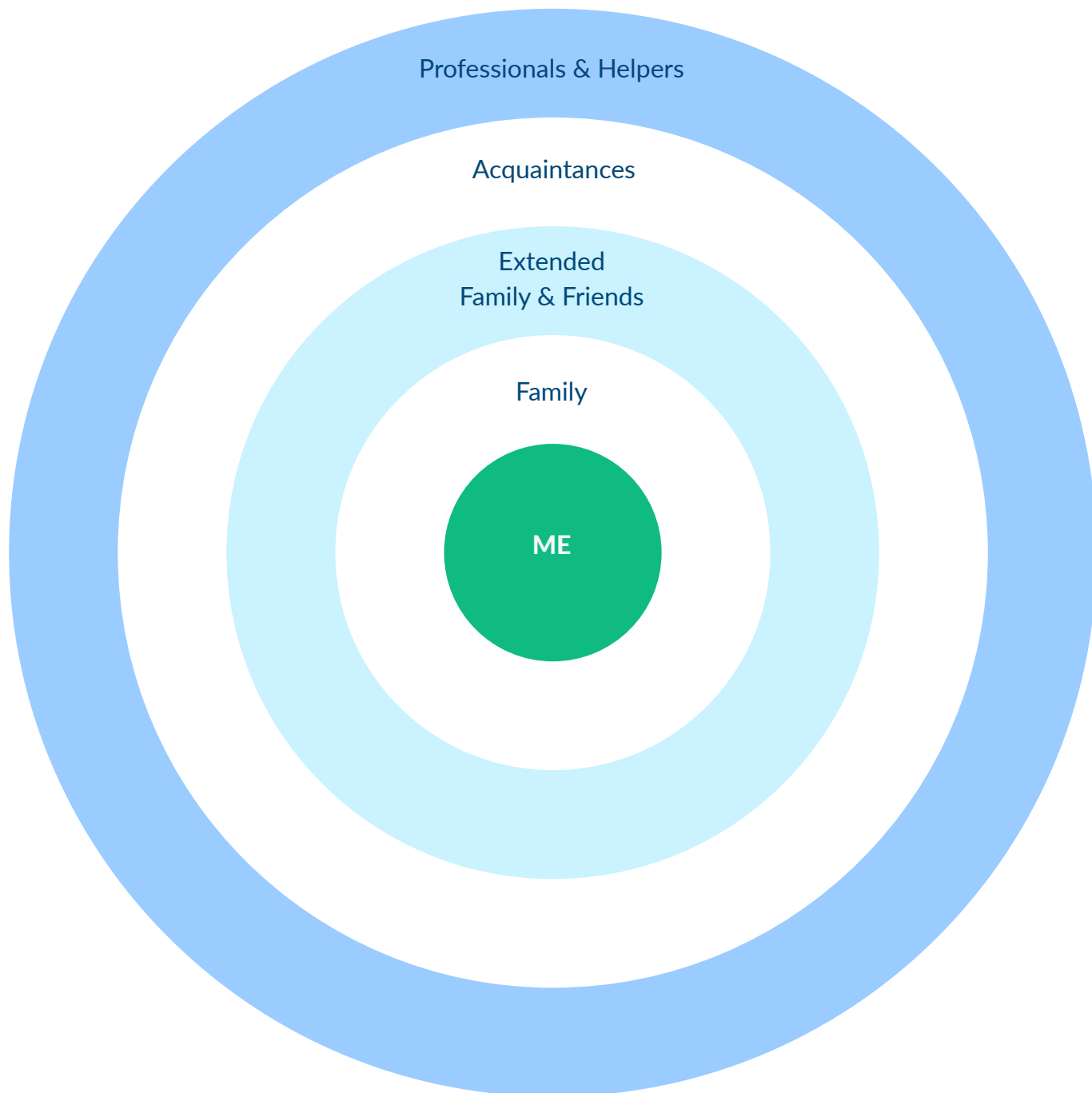


Express yourself through any activity that allows emotional release

My Support System

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 commit to reaching out to them and building more relationships.



My Support System

1. Who's in my corner

3 people I trust the most:

Someone I can VENT to:

People I can text sad/happy memes to:

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

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



2. What I need

My support needs:

Qualities I look for in a supportive relationship:

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

3. Where I want to grow

People I want to invest in:

Relationships to reinvigorate:

Relationships to let go of or change:

Creating Support Systems

Patients with chronic or rare diseases, and their caregivers, often feel isolated and find it challenging to maintain connections or form new ones. Since the journey is often emotional and difficult, it is important to prioritize support. Research has shown that supportive relationships have many benefits, including 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 those relationships. Yes, it takes energy, but you will get so much in return.

Types of Support Needed

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



Tangible

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



Emotional

Acceptance, understanding, reliable encouragement, and empathy; a 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
- Ask for and accept help
- Be available
- Be honest
- Be patient; strong relationships take time to develop
- Stay in touch
- Reciprocate: support their successes and share appreciation
- Engage when it's healthy

FACE *the* FIVE | Signs to Notice

Living with a chronic or rare disease, or caring for someone who is, can take a real toll on mental health. These “Five Signs” offer a common language for noticing emotional struggle and responding with compassion, especially when someone may not have the energy to ask for help.

THE 5 SIGNS

WHAT IT CAN LOOK LIKE

WHAT CAREGIVERS CAN SAY

1



PERSONALITY CHANGES

May seem different, showing behaviors that don't match their usual self.

- Stressed-out or checked-out
- Often anxious or depressed
- Acting unlike their usual self
- Eerily “at peace” or joyful after a hard stretch, which can be a warning sign

“I’ve noticed that lately when we talk or hang out, you seem distant and not like your usual self.

Can you tell me more about what’s going on? I want to find ways to support you.”

2



UNUSUALLY ANGRY, ANXIOUS, OR MOODY

May struggle with frequent mood swings.

- Lashing out or angry outbursts
- Panic attacks
- Always in “crisis mode”
- Strong reactions, with or without a clear trigger

“I can’t imagine how stressful that must be. It sounds 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?”

3



WITHDRAWAL OR ISOLATION

May pull away from family and friends, a sign they need support and understanding.

- Not answering texts or calls
- Needing to be alone
- Sleeping much more than usual
- Skipping plans or rarely leaving home
- Avoidance when questioned

“I’ve noticed you haven’t been answering my texts like you used to, and you’ve been spending more time alone. It’s okay to take time for yourself, but you don’t have to do this alone. I’m here if you need someone to talk to.”

4



NEGLECTING SELF-CARE OR RISKY BEHAVIOR

Financial strain, physical limits, and distress can lead to neglected self-care.

- Reckless spending
- Drinking or substance use
- Neglecting hygiene or appearance
- Big changes in weight or sleep
- Letting daily tasks slide

“This might be hard to talk about, but I’ve noticed you’ve been drinking more [or name what you’ve noticed] lately, and I’m concerned about you.

I’m here for you. Would you feel comfortable talking about it?”

5



OVERWHELMED BY CIRCUMSTANCES AND HOPELESS

May feel extreme or prolonged grief, worthlessness, or guilt.

- Saying “There’s no point” or “It’s hopeless”
- Shutting down emotionally
- Giving things away or making end-of-life plans
- Talk of suicide or self-harm

“I know it can be hard to open up, and I want you to know I’m here for you.

I’ve noticed you’ve been really struggling lately, and I care about you. Are you having thoughts of hurting yourself or ending your life?”

For US residents: In crisis? Call or text 988 (Suicide & Crisis Lifeline) or call 911.

Finding Mental Health Support for Patients & Caregivers

Why Mental Health Support Matters

Whether you're living with a chronic or rare disease or caring for someone who is, it's an emotional marathon filled with ongoing uncertainty, crisis cycles, and grief. The daily demands can be relentless, and without the right support, burnout can set in quickly.

The “right-fit” mental health care is designed to *meet patients and caregivers where they are*, offering:

- **Safety:** A nonjudgmental space for all feelings, even the ones that feel “wrong.”
- **Validation:** Recognition of both the strength and the exhaustion of living with a demanding disease.
- **Stabilization:** Tools to regulate your nervous system, manage stress, and recover after emergencies.
- **Resilience:** Strategies for sustaining your emotional health long-term.
- **Empowerment:** Support in making choices for your well-being without guilt.

WHO: Choosing the Right Professional

If you're seeking emotional or behavioral support:

- ✓ Choose a therapist, counselor, or psychologist experienced in trauma, chronic illness, and caregiver burnout (LCSW, LPC/LCPC, MFT, LSW, PhD/PsyD).
- ✓ Trauma-informed providers will pace sessions to match your nervous system's capacity and never push you to share more than you're ready for.

If you may benefit from medication:

- ✓ See a psychiatrist, mental health doctor, or nurse practitioner (MD, DO, PMHNP, APN).
- ✓ Look for trauma-informed care that explains options clearly, moves at your pace, and includes your input in every decision.

Patients and caregivers benefit when providers are aware of:

- Medical trauma — both the patient's and the caregiver's.
- Anticipatory grief and ambiguous loss.
- System fatigue — navigating healthcare bureaucracy.
- Isolation — especially if friends/family can't relate to the lived realities of the disease.

Finding Mental Health Support for Patients & Caregivers

WHERE: Finding Mental Health Providers

- ✓ Ask your insurance company or Employee Assistance Program (EAP) for a list of in-network, trauma-informed providers.
- ✓ Search online for “trauma-informed therapist + [your city]” or “psychologist + chronic illness.”
- ✓ Ask trusted friends, family, or other patients and caregivers for recommendations.
- ✓ Check rare disease advocacy groups, nonprofits, and government websites.
- ✓ Contact your local or national mental health organizations for referrals.

You may have to wait for the “right” provider. In the meantime:

- National Alliance on Mental Illness (NAMI) Helpline: 1-800-950-NAMI (US-based)
- 988 Suicide and Crisis Lifeline (call or text, US-based)
- Patient and caregiver peer support groups (online & local)

HOW: Questions to Ask

Before the First Session:

- ✓ Have you worked with patients, caregivers, or people navigating long-term medical crises?
- ✓ What’s your approach to trauma-informed care?
- ✓ Do you accept my insurance? Do you offer telehealth?
- ✓ How do you adjust therapy when someone is under chronic stress?
- ✓ Do you have regular openings that can flex around medical appointments?

After the First Session:

- ✓ Do you think you can meet my needs as a patient or caregiver?
- ✓ How will we create my treatment plan together?
- ✓ Will our goals adapt if my health or caregiving role changes?
- ✓ How do I reach you in between sessions if I’m in crisis?

You don’t have to “earn” therapy by reaching your breaking point — you deserve support now.