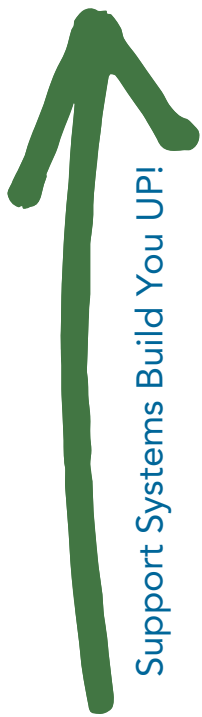


CREATING SUPPORT SYSTEMS

Rare Caregivers and patients often feel isolated and find 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



This toolkit was co-developed by Patient Health Alliance in collaboration with Give an Hour, a national nonprofit whose trauma-informed mental health frameworks informed the structure and tools included.

For more information visit
GiveAnHour.org/ContactUs

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