FANCONI™ CANCER FOUNDATION

FOR THE FANCONI ANEMIA COMMUNITY

Mental Health and Wellbeing Toolkit

Practical tools and trusted guidance for people living with Fanconi anemia and those who care for them

Developed in partnership with give an hour Mental Health. For Life.

Gratitude and Collaboration

This resource was developed in partnership with Give an Hour, an organization that provides barrier-free access to mental health care and educational resources for those in need.

We are grateful to FCF advocates Erica Williams and Faith Barbe for sharing thoughtful feedback. Their lived experience helped ensure content is relevant, respectful and responsive to needs within the FA community.

We also thank the clinical and research experts who reviewed and contributed information.

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FANCONI™ CANCER FOUNDATION

Introduction

Living with or supporting someone with Fanconi anemia (FA) can involve ongoing uncertainty, complex medical experiences, and emotional strain. This resource offers practical, compassionate support that acknowledges those realities while providing tools for everyday life.

Who This Toolkit Is For

This toolkit is designed for individuals with FA, caregivers, and care partners. Research shows that nearly half of adults with FA screen positive for symptoms of post-traumatic stress, with many also experiencing anxiety, depression, fatigue, sleep disturbance, chronic pain, and unmet mental health needs (Bogart, Voss, & Limon, 2025). Caregivers are also significantly impacted by long-term uncertainty, complex care coordination, and repeated medical stress. While FA-specific caregiver research is limited, broader caregiving studies show that caregiver mental health is closely linked to the wellbeing of the person they support, highlighting the need for mental health support for both adults with FA and caregivers.

For adults with FA who are looking for research-informed insights, data, and resources specific to mental health experiences, we recommend the Mental Health and Wellbeing Considerations for Individuals with FA and Family Caregivers lay guide by Kathleen Bogart, PhD, and Megan Voss, PhD.

Mental Health and Wellbeing Considerations for Individuals with FA and Family Caregivers: https://shorturl.at/BkTCx

What This Toolkit Includes

This is a psycho-educational resource, not a clinical guideline or substitute for medical or mental health care. It can help you:

- Notice emotional distress in yourself and others
- Navigate high-stress periods, uncertainty and crisis
- Plan for challenging moments
- Use communication tools and guided exercises
- Explore mental health support
- Share FA-informed context with providers and others in your support system

A Trauma-Informed Note

The toolkit is grounded in choice, pacing and safety. You decide what to read, use or skip, and you can move at a pace that feels right. Some topics may bring up strong emotions. It is okay to pause, step away, or reach out for support. Attending to your limits and sense of safety is an important part of care.

PACE: Quick Start

Five simple steps to pace yourself during overwhelming or difficult moments. Choose only what feels manageable right now.

1 Pause

- Take 3 slow deep breaths

2 Act on One Simple Step

- Step outside
- Drink water
- Spend time with your pet
- Write down a question or concern

3 Connect

- Reach out to someone you trust
- Family
- Friends
- FA Community

4 Engage in Self-Care

- Rest
- Move gently
- Take short breaks

5 Engage in Extra Support

- Counseling
- Peer support

US Crisis Support: Text/call 988 crisis line

Outside of US: Visit FindAHelpLine.com

How to Use This Toolkit

You do not need to read this toolkit from beginning to end. Use the sections that are most helpful for you right now. You can always return to other sections whenever you are ready.

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NOTICE WHAT YOU'RE CARRYING

Face the Five: Signs to Notice

Living with Fanconi anemia (FA), or caring for someone who does, can bring emotional strain that builds gradually over time. **Give an Hour's** "Five Signs" offers a shared, nonjudgmental way to recognize when that strain may be increasing in yourself or others in the FA community. Noticing these signs early can support well-being and make it easier to seek help when needed.

PERSONALITY CHANGES

They 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.

WHAT YOU CAN SAY:

"I've noticed that lately, you seem like you might be carrying a lot. If you ever want to talk about what's been going on, I'm here to listen and support you."

FREQUENT MOOD SWINGS

Uncharacteristically angry, anxious, agitated, or moody.

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

WHAT YOU CAN SAY:

"I know that this situation is extremely stressful, and I'd like to better understand what you're going through. If you want to share more about how you're feeling, I'm here and I'll listen."

WITHDRAWAL OR ISOLATION FROM OTHERS

They 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.

WHAT YOU CAN SAY:

"I've missed connecting with you lately. I just wanted to check in and see how you've been doing. If you ever feel like talking or just want company, I'm here."

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, poor hygiene, change in appearance, 'Depression House', significant weight gain or loss, and excessive sleeping.

WHAT YOU CAN SAY:

"I care about you and wanted to check in. If things have been feeling heavy lately, you don't have to go through it alone. I'm here to listen whenever you want to talk."

OVERCOME WITH HOPELESSNESS AND OVERWHELMED BY CIRCUMSTANCES

They 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 like "it's hopeless".

WHAT YOU CAN SAY:

"I care about you and I'm really glad you told me you've been struggling. Sometimes when people are hurting this much, they may have thoughts about harming themselves. Have you been having thoughts like that?"

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NOTICE WHAT YOU'RE CARRYING

Reinforcing Self-Compassion

Living with Fanconi anemia (FA), or caring for someone with FA, can make it difficult to catch your breath. Many people move from one medical decision, crisis or uncertainty, to the next without time to pause or recover. In the midst of that intensity, self-compassion may feel out of reach or even unrealistic. This page explores its benefits and offers small, practical ways to practice it in real life, not ideal circumstances.

Three Components of Self-Compassion

Self-kindness: responding to yourself with care and encouragement as you would for others, rather than with criticism.

Common humanity: recognizing you're not alone in struggling or feeling overwhelmed. Try to give yourself a break.

Mindfulness: noticing what you're feeling without judging it or pushing it away. This can help in responding with intention rather than self-criticism.

Self Compassion is Not

- A form of self-pity
- Ignoring real challenges
- Weakness
- Self-centered
- Giving up or lowering expectations

Benefits of Self-Compassion

- Improved happiness
- Improved mental health
- Stress reduction
- A stronger immune system
- Resilience in face of hardship
- Ability to learn from mistakes

What This Could Look Like for Caregivers

- Letting go of doing everything perfectly
- Recognizing the weight you carry
- Offering yourself the same understanding you give your loved one
- Noticing burnout without blaming yourself

What This Could Look Like for Those Living with FA

- Resting without needing to justify it
- Not comparing your body or path to those of others
- Acknowledging frustration without minimizing it
- Regonizing the effort it takes to navigate daily life with FA

Self-Compassion Micro Practices

- Take one slower breath while waiting or in a stressful moment
- Try a mantra: "This is hard, and I'm doing what I can"
- Acknowledge a win: Notice one thing you handled today
- Ask: "Would I say this to someone else in my position?"
- Focus on the next step, not everything at once
- Don't be afraid to ask for help

*Neff, K. D. (n.d.). What is self-compassion? Self-Compassion.org.

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CARE AND CONNECTION

Caring for Yourself While Caring for Your Loved One

Caring for someone with Fanconi anemia (FA) can bring emotional, practical, and psychological challenges, often requiring sustained attention to another person's needs. Many describe it as a "full-time job," and for caregivers and care partners alike, personal wellbeing can easily slip into the background. Limited access to mental health care, especially from providers familiar with rare disease, may add to isolation or uncertainty about where to turn for support. Even so, many in the FA community describe resilience, hope, and the healing value of creativity and community connection.

Caregiving experiences vary widely, and access to time, energy, and financial resources can differ. The strategies below are meant to be flexible and adaptable. Even small, brief moments of care can be meaningful.

Broad Evidence-Based Strategies

At the individual level (your own wellbeing)

Practice Mindfulness & Stress Reduction

Short breathing exercises, guided imagery, and body scans can calm your nervous system and help you cope with daily stress.

Gently Move Your Body

Try yoga, stretching, walking, or even dancing, adapted to your energy level, to lift your mood and support resilience.

Creative Expression

Journaling, music, voice notes, or crafts can give your feelings an outlet and help you find meaning in difficult times.

Integrative Therapies

Acupuncture, aromatherapy, or healing touch like massage or self-massage, can ease tension and restore a sense of calm and safety.

Quick, No-Cost Ways to Reset

Take 3 slow breaths: slow inhale through the nose, long exhale through the mouth

Use your senses: name 5 things you see, 4 you feel, 3 you hear, 2 you smell, 1 you taste

Hold something grounding: a favorite photo, a piece of fabric, a pet, or a small object that feels comforting

Step outside: even a few minutes of fresh air can calm your nervous system

Mini-pause: listen to a song, mindfully sip water, or stretch your body for one minute

Caring for loved ones with complex needs increases daily demands. Focusing on small, flexible moments of care, rather than longer activities, may feel more manageable. Even brief pauses or shared routines can offer support.

Caring for Yourself While Caring for Your Loved One, pt. 2

Finding Support and Connection

Join Peer Spaces
Connecting with other caregivers via online forums or virtual meetings, or attending FA community gatherings can help reduce isolation and stigma.

Create Shared Rituals
Memory books, family art projects, or storytelling can honor your loved one's journey and strengthen bonds.

Advocate Together
Engaging with other rare disease caregivers can validate your experience and give you tools to advocate for your family's needs.

Working With Your Care Team

Seek Trauma-Informed Care
Providers who recognize the psychosocial impact of caring for someone with FA can help identify distress and support wellbeing over time. FCF can help connect you to resources or clinicians familiar with FA.

Embedded Healthcare Support
When available, access to counseling or psychosocial services can be a helpful part of comprehensive FA care.

Build a Broader Support Team
Alongside your existing support, you may consider caregiver coaching services, peer groups, caregiver hotlines, respite care programs, the Fanconi Cancer Foundation, and other caregiver support organizations like The Negative Space.

Emotional Challenges Caregivers May Experience

Guilt or Self-Blame
Caregivers may 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.

Hyper Vigilance
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 when possible, can help mitigate these feelings.

These challenges are also experienced by individual living with FA, though they may show up differently.

CARE AND CONNECTION

Navigating Anticipatory Grief and Loss

As you focus on your wellbeing, you may notice deeper emotions surfacing, especially around uncertainty, change, and future-oriented worries. Living with FA, or supporting someone who does, involves ongoing uncertainty and repeated adjustments. Many in the FA community experience anticipatory grief: a complex mix of sadness, fear, and mourning that can arise when facing the possibility of future loss or change.

This guide offers compassionate and trauma-informed strategies to support caregivers and those living with FA as they navigate these complex feelings and find steadiness amid uncertainty.

What is Anticipatory Grief?

The process of grieving ***before a loss happens.*** It may oscillate over time and change as circumstances shift.

It may show up as ***worry about the future***, sadness about milestones that might not be reached, or often ***feeling "on edge."***

It may include both ***emotional and physical reactions,*** *such as* changes in sleep, irritability, fatigue, difficulty concentrating, or withdrawal.

Experiencing anticipatory grief is normal; it does not mean you are giving up hope.

You Might Try

Grounding: Slow breaths, notice 5 things around you, hold a comforting object, write your feelings.

Presence: Gently bring attention to present and try to focus on meaningful moments as they arise for you or with your loved one.

Meaning-Making: Creative expression, shared rituals and/or memory-keeping can offer comfort (e.g., memory book or a weekly tradition).

Support: Reach out to peers, counselors, chaplains, or grief specialists to walk alongside you.

Guiding Principles

For choosing what feels supportive

Safety & Stability: Creating small moments of calm and routine can help during periods of uncertainty (e.g., reflection, journaling, music, walks).

Trust & Choice: Permission to set boundaries, say "no," and make choices about your time and energy.

Connection & Community: Feeling understood by trusted people or communities can ease feelings of isolation (e.g., trusted friends, support groups, counselor, FA peer networks).

Emotional Regulation: Noticing, naming, and allowing emotions (without judgement) can help when feelings are intense or overwhelming. Sadness, anger, guilt, and relief are all common to experience.

When to Seek Professional Help: if grief feels unmanageable, such as constant overwhelm, panic, strained health or relationships, or trouble with daily life and activities.

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CARE AND CONNECTION

Finding Connection: Navigating Isolation

For Caregivers and Care Partners

Caring for someone with Fanconi anemia (FA) can quietly narrow a caregiver's world, leaving less time and energy for connection with friends, family, and community. Over time this could lead to feeling misunderstood, left out, or alone, even when surrounded by others. Research shows that isolation is one of the most common challenges caregivers face, yet connection itself is protective, helping reduce distress, strengthen resilience, and restore a sense of belonging.

Note: Many of these experiences are also shared by those living with FA.

Why Isolation Happens

National Organization for Rare Disease (NORD) research shows that up to 70% of rare caregivers report high levels of social isolation compared to the general population.

- Time and energy demands leave little room for social life
- Stigma or misunderstanding from others who don't "get it"
- Medical trauma and grief may contribute to "shutting down"
- Feeling different from peers as daily life centers around care
- Ongoing hardship may contribute to compassion fatigue and emotional numbness

Why It's Hard to Reach Out

Many caregivers want support but hold back for real reasons:

"I don't have time." *Caregiving can feel like a 24/7 role, leaving little space for connection. Low-effort connection counts, even a text, five-minute call, or meme can make a difference.*

"I feel guilty." *Many caregivers worry that time away is selfish. Caring for yourself strengthens your capacity to care for your loved one, but reaching out after time away can feel hard. You might say: "Things have been a lot lately, I'm feeling ready to reconnect now."*

"I don't want to burden others." *It's common to hold back. Often, people want to help but don't know how; being specific gives them a way in. You might say: "I don't need solutions, just someone to listen for a few minutes."*

"I'm too exhausted." *Fatigue can make reaching out feel overwhelming. Low-effort connection, such as watching a show together or joining an online group at your own pace, still counts.*

"I didn't realize I was isolated." *Isolation can build gradually and may be hard to recognize when it becomes your normal.*

CARE AND CONNECTION

Finding Connection: Navigating Isolation, part 2

Ways to Combat Isolation

Strengthen Everyday Connections

- Small, consistent moments of connection matter. A brief call, text, or coffee can help you stay connected without adding pressure. Choose connection that fits your energy.
- Let trusted people know when you're available (and when you're not) so expectations feel manageable.
- When it feels safe, sharing honestly, even in small ways can deepen connection.

Find Community That Understands

Connect with other FA caregivers through online forums, private social media groups, Fanconi Cancer Foundation (FCF) events, conferences, or virtual meet-ups. Many caregivers find it helpful to pair with another caregiver for regular check-ins and mutual support.

Create Meaningful Rituals

- Simple shared rituals, like a weekly walk, family meal, or gratitude practice, can help maintain bonds beyond caregiving tasks.
- Creating together, and finding shared meaning through things like, photos, journaling, or storytelling can also strengthen bonds.

Professional and Practical Supports

- Support doesn't have to wait until things feel unmanageable. Ask your care team or FCF about caregiver support groups, counseling referrals, respite services, or short-term practical help.
- Caregiver hotlines can offer confidential and immediate support during especially isolating moments.

Warning Signs

It's normal to feel alone at times, but reach out for more urgent support if isolation begins to affect your safety, health, or daily functioning.

Signs to look out for:

- Withdrawing from nearly all social contact
- Losing interest in people or activities you once enjoyed
- Feeling hopeless, worthless, or like a burden
- Struggling to care for your own basic needs (eating, sleeping, hygiene)
- Thoughts of giving up or not wanting to go on

Caregiver Support Resources

- Suicide & Crisis Lifeline (U.S.): Call or text 988 **(urgent support)**
- Fanconi Cancer Foundation: fanconi.org
- Caregiver Action Network Help Desk: 855-227-3640
- Family Caregiver Alliance: caregiver.org
- The Negative Space: thenegativespace.life

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Creating Support Systems

Staying connected can become harder over time for people living with Fanconi anemia (FA) and for caregivers. Ongoing uncertainty, complex care decisions, and emotional strain can make it difficult to maintain relationships, even when support is deeply needed.

If this feels familiar, you're not alone. Research shows that 51% of rare caregivers have difficulty maintaining friendships, and 53% report feeling alone.* Supportive relationships can ease stress, depression, and anxiety, and offer a sense of steadiness when so much feels uncertain.

**National Organization for Rare Disorders (NORD). Rare Caregiver Survey (2016); State of Rare Disease reports (2018–2023).*

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. One person may meet more than one type of support, and your needs may change over time.

Tangible

A service or a favor. It's healthy to ask for support! Example: *"We have a hospital stay coming up, could you help with getting the kids to school while we're there?"*

Emotional

Acceptance, empathy, and presence without trying to fix or minimize. *Someone to listen without judgement, acknowledge fear or grief, and stay through stretches of waiting.*

Affirmational

Encouragement that affirms your effort, decisions, and boundaries. *Someone to remind you that you're doing the best you can in an unpredictable course.*

Informational

Clear, reliable information or guidance without emotional expectations. *Someone to explain medical terms, care pathways, or insurance options in plain language.*

Belonging

Belonging to a peer group that understands your beliefs and/or situation. *Connection with other FA families who understand living with medical uncertainty and hyper vigilance.*

Tips to Sustain Support Systems

- Set and adjust boundaries as needs and energy change
- Accept help in forms that reduce stress
- Stay connected in low-pressure ways when possible
- Notice which relationships feel steady or restorative, and lean into those
- Be honest about the kind of support that helps most
- Be patient. Trust may build slowly as people learn what support looks like for you.
- Share appreciation

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CARE AND CONNECTION

Mapping My Support System

Individuals living with Fanconi anemia (FA) and caregivers may notice gaps in their support system; this is common in rare communities. The realities of FA, including complex care, limited time, and emotional strain, can make it hard to build and maintain connections. Support systems often grow slowly and over time. Research shows that the ability to seek support is closely tied to mental health. What matters isn't having a large network, but finding ways to use the support that is available, even if it's very limited or still taking shape.

Write down the people in your support system. If it's hard to think of anyone to list, you might include your care team, services, or organizations, ***or start by naming the kinds of support you need.*** If it feels right, choose one or two relationships you may want to nurture or reconnect with over time.

START ANYWHERE. ADD THE PEOPLE AND SUPPORTS THAT FEEL TRUE FOR YOU.

It is OK to leave a space blank or name the kind of support you need.

Family
People closest to your day-to-day life

Names, services or organizations:

- _____
- _____
- _____
- _____

Extended family and friends
People you trust or may want to reconnect with

Names, services or organizations:

- _____
- _____
- _____
- _____

ME
My needs matter

Acquaintances and community
Neighbors, coworkers, faith groups or FA community

Names, services or organizations:

- _____
- _____
- _____
- _____

Professionals and helpers
Care team, counselors, services or organizations

Names, services or organizations:

- _____
- _____
- _____
- _____

Choose one person or support you may want to reach out to next:

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Mapping My Support System: Reflection

This exercise is an invitation to notice who and what already supports you, where support feels thin, and what kind of connection feels safest right now. Remember, support can look different at different times.

Three people, services or resources I trust, if any

People I can text sad or happy memes to

Qualities I look for in a supportive relationship, service or resource

My current support needs

People or services I want to stay connected to, as able

Relationships or services I may reconnect with when I have capacity

Relationships where I need more space or boundaries

Gaps in my support system right now

This can change.

Low-pressure connections that help me feel less alone

Someone I can vent to without explaining FA

A community where FA or medical complexity is understood

COMMUNICATION

Emotions Tracker

Use this tracker to notice your emotional baseline. It is not a diagnostic tool. If feelings are heavy or persist for more than two weeks, consider reaching out to someone you trust, your care team, or a mental health professional.

I am feeling...	1	2	3	4	5	6	7	8	9	10	11	12	13	14
"Off"	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Moody	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Angry or agitated	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Always wanting to be alone	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Like I need to escape	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Like I have very little control	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Overwhelmed	○	○	○	○	○	○	○	○	○	○	○	○	○	○

If you notice patterns that feel heavy or hard to manage, you don't have to handle them alone—reach out to someone you trust, the 988 Suicide & Crisis Lifeline (call or text 988 in the U.S.), your care team, or the Fanconi Cancer Foundation for support and resources.

The Conversation Compass

Conversations about Fanconi anemia (FA) can carry a lot of weight: medical uncertainty, past trauma, shifting roles, and strong emotions on all sides. Whether you're a caregiver or living with FA yourself, it's common to feel unsure how to start, when to speak up, or when to pause. The Conversation Compass is a simple tool for navigating these moments. Like a compass in physical space, it helps you orient yourself in conversation, deciding when to engage, how to express yourself clearly and respectfully, when to listen and reflect, and when it's okay to step back and exit the conversation if it becomes unproductive.

This tool can help when: speaking with medical providers about care decisions or concerns; family or friends who may not understand FA; partners, parents, or adult children navigating changing roles; or during moments of tension or fatigue.

1) Start centered and grounded.
2) Assess the moment and choose a direction, noticing whether it feels like a good time to talk.
3) Shift, pause or step away as needed, using the prompts for guidance.

N North
Engage and proceed

Check conditions before moving forward:

- ☐ Both parties are calm and receptive
- ☐ Energy levels are sufficient
- ☐ The setting is appropriate
- ☐ Mutual respect is present
- ☐ There is enough time

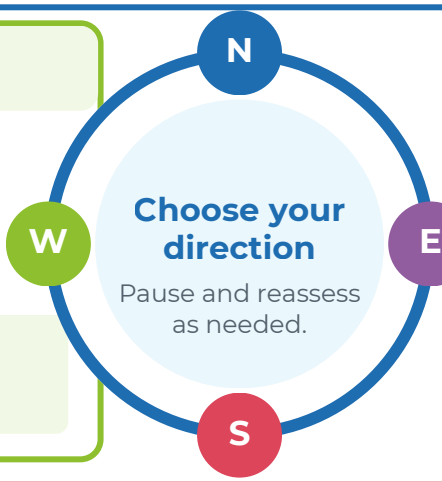
TRY SAYING
"I'd like to explore this with you."
"Let's discuss this together."
"I'm interested in your perspective."

W West
Listen and reflect

Practice active listening through:

- ☐ Clarifying questions
- ☐ Summarizing key points
- ☐ Acknowledging feelings
- ☐ Seeking understanding

TRY SAYING
"Help me understand."
"Could you explain more about that?"
"What I'm hearing is..."



E East
Express and share

Share your experience clearly:

- ☐ Express your position
- ☐ Cite clear examples
- ☐ Use "I" statements

TRY SAYING
"From my perspective..."
"My experience has shown..."
"When this happens, I feel..."

S South
Disengage and exit

Watch for signals that it may be time to step back:

- ☐ Conversation is becoming circular
- ☐ Emotions are escalating
- ☐ Personal attacks are appearing
- ☐ Energy is depleting
- ☐ Boundaries are being crossed

TRY SAYING
"Let's pause here for now."
"We should revisit this when we're fresh."
"I need some time to reflect."

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The Conversation Compass: Practice

Practice Scenarios

Use a scenario below, or a real conversation you're facing to practice orienting yourself to the discussion.

- Your partner disagrees about next steps.
- A family member pressures you to make a care decision.
- A friend says something well-intended but hurtful.
- A provider dismisses your concerns.
- You receive upsetting news and need support talking it through.

Use the compass

North: proceed and engage
South: pause or exit
East: express your view
West: listen and reflect

Move between directions as needed, while maintaining healthy boundaries.

Challenging moments

Successful strategies

Lessons learned

COMMUNICATION

Talking to Your Child About Mental Health

For Parents of Children with Fanconi Anemia

Conversations about emotions often arise after medical appointments, changes in care, or moments of uncertainty. This page offers guidance for talking with your child about Fanconi anemia (FA) and mental health in ways that are honest, age-appropriate, and emotionally safe. Children with FA may carry stress, fear, and sadness related to medical care, uncertainty, or feeling different from peers. Open conversations revisited over time and guided by your child's cues, can reduce anxiety, build trust, and strengthen coping. The goal isn't to fix difficult feelings, but to help your child feel heard, supported, and safe coming to you.

Guiding Principles

Be Honest, But Gentle

You don't have to have the "right" words or all the answers. It's okay to acknowledge that talking about FA or cancer can feel hard. What matters is being truthful in ways your child can understand and reassuring them they're not facing it alone.

Let Them Take the Lead & Meet Them at Their Level

Begin with simple, concrete explanations about FA and follow your child's questions rather than sharing everything at once. Share only as much as they're ready for, and pause when they've had enough.

Examples: *"What are you wondering about right now?" or "FA means your body has a harder time making healthy cells. That's why your doctors help take special care of your blood and your body."*

Listen Before Solving

Reflect what you hear before offering reassurance or answers.

Example: *"It sounds like you're worried about the appointment. Did I get that right?"*

Normalize Feelings

Let your child know it's okay to feel their emotions.

Example: *"I know sometimes having FA can feel hard or confusing. You might wonder why you have to go to the doctor, or why your body needs extra help. It's okay to feel sad, mad, or worried about that. You can always tell me how you're feeling. I'll listen, and we'll figure things out together."*

Model Emotional Safety & Healthy Coping

Parents can be fearful of expressing their own emotions, but showing that emotions can be expressed and managed safely helps children feel secure sharing theirs.

Example: *"I have big feelings sometimes too, and I have ways to help myself work through them."*

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Talking to Your Child About Mental Health, part 2

Practical Tips By Age

Young Children (3-7 years)

- Use storybooks, play, or drawing to explain feelings.
- Offer choices: *"Do you want to draw or talk about how you feel?"*
- Keep explanations short, simple, and concrete.

School Age (8-12 years)

- Ask open questions: *"What worries you most right now?"*
- Encourage outlets like journaling, art, music, or movement.
- Explain that mental health is like physical health, sometimes extra help is needed to stay well.

Teens (13+)

- Respect privacy while keeping communication open: *"Do you want me to just listen, or brainstorm things that could help?"*
- Invite them into problem-solving: *"What helps when you're feeling stressed?"*
- Normalize therapy and share crisis resources clearly and calmly: *"A therapist is like a coach for your mind."*

Signs Your Child May Need Extra Support

- Frequent stomachaches, headaches, or fatigue without clear cause
- Withdrawal from friends, school, or play
- Significant changes in sleep, eating, or mood
- Repeatedly saying they feel "different" or "don't fit in"
- Talking about giving up or not wanting to live

If your child talks about wanting to hurt themselves, not wanting to live, or feels unsafe, seek immediate help.

Contact your child's care team, go to the nearest emergency room, or call or text the 988 Suicide & Crisis Lifeline (U.S.) for confidential, 24/7 support.

If you are outside the U.S., your local emergency number or health provider can help connect you to crisis resources. You may also find local resources at findahelpline.com.

Navigating Crisis Responses

Living with Fanconi anemia (FA), or caring for someone who does, often involves unique challenges and ongoing emotional demands. Here are some practical steps and considerations to help you navigate your emotions and maintain your wellbeing during times of crisis.

Crises in the FA Community

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

Diagnosis
The moment of a 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, financial stability, a friend or loved one, these changes can destabilize your sense of security.

Life Changes & Transitions
Moves, changes in care routines, transition from pediatric to adult care, or shifts in family dynamics can all be sources of stress.

Key Reminders During a Crisis

Pause, Then Respond
In crisis, urgency can make action feel stabilizing. When possible, pause, breathe, and identify what needs attention now, what can wait, and who can help before making major decisions or new commitments.

Acknowledge the Emotional Impact
Notice and validate your own responses. FA can bring overwhelm, anxiety, sadness, numbness, or fear, whether you're living with FA or caring for someone who is.

Choose Safer Ways to Cope
Alcohol, substance use, or other risky coping strategies can increase distress. Reach for steadier supports when possible.

Navigating Crisis Responses, part 2

Planning Ahead: Practical Steps for Emotional Wellbeing

Create a Crisis Plan
Have a list of trusted contacts, self-care routines, and coping strategies ready for times of crisis.

Set Boundaries
It can be hard to say no to family and friends. You don't need to "earn" or seek permission to stay home and rest.

Limit Caffeine & Alcohol
Caffeine and alcohol can make anxiety worse, so cap your caffeine and alcohol intake, and avoid them altogether after 4 PM.

Plan for Fatigue
You may experience physical, emotional, or decision fatigue. If possible, have a backup plan for additional support.

Educate Support System
You may use resources like this to help friends and extended family understand the unique challenges of living with FA or caregiving, to foster compassion and long-term support.

Take Regular Breaks When Possible
Taking regular breaks can support rest and recharge. If it's an option, respite support may be helpful for caregivers and care partners.

Prioritize Self-Care When Possible
Engaging in even simple and meaningful activities that bring joy and relaxation can help maintain emotional balance.

FA-related crises can bring guilt, self-blame, hypervigilance, fear or emotional exhaustion. These responses are understandable, and support is available.

Text/call 988 for the crisis line, call FCF at 541-687-4658 or email communitysupport@fanconi.org.

Crisis Response Journey for Caregivers & Individuals Living with Fanconi Anemia

giveanhour® Mental Health. For Life.

Pre-Crisis — Preparedness/Awareness

Create a Crisis Plan

Develop a detailed plan with FA care, emergency and support contacts, and self-care and coping strategies.

Build a Support Network

Connect with other caregivers, peer support groups, and mental health professionals.

Crisis Detection — Anxiety, Vigilance

Recognize and Name Emotional Responses

Noticing early signs like anxiety, fear, or overwhelm, may help you manage the crisis more effectively.

Communicate Your Needs

Let your support network know when things feel hard and what support is helpful. You don't have to carry this alone.

Immediate Response — Stress, Anxiety, Fear

Hit the Pause Button

If possible, pause and focus on steady and deep breathing, and manage immediate emotional reactions.

Avoid Catastrophizing

Notice worst-case thoughts without treating them as facts.

Avoid Major Decisions

If possible, delay big decisions during this phase of crisis and when emotions are high.

Engage in Rescue Self-Care

Use simple, grounding techniques to help your body settle, like a brief walk, noticing your five senses, or box breathing.

Crisis Management — Support, Stability

Engage Support Networks

Reach out to trusted people or established FA-informed supports for assistance. This may include peers, family, or professionals.

Stay Hydrated, Nourished, & Get Rest

Support your body with water, nutrition, and rest when possible.

Take Regular Breaks

When able, taking regular breaks can support rest and recharge. If it's an option, respite care for caregivers may be helpful.

Post-Crisis Reflection — Reflection, Healing

Reflect, Don't Ruminate

Gently look back at what happened and how you responded without replaying or judging it. You showed up the best you could in an unpredictable situation.

Learn From the Experience

Notice what helped, what felt hard, and what you might do differently next time.

Engage in Deep Self-Care

When you can, dedicate some time to activities that promote deep relaxation and recovery.

Reintegration — Return to Baseline

Reestablish Routine

Gradually return to normal activities and familiar rhythms as energy allows.

Balance Focus

As intensity eases, reconnect with other parts of life at your own pace. Small shifts count.

Update Crisis Plan

Revise your plan based on what you've learned, and adjust supports or strategies as needed.

CRISIS SUPPORT

Crisis Response Plan

FANCONI™ CANCER FOUNDATION

Complete this plan when things are calmer, then keep it somewhere easy to find during an emotional or medical crisis.

Support contacts

Friends, family, professionals who can offer emotional support.

Name	Contact Information

Who can help?

- Who listens without fixing?
- Who offers tangible support?
- Who helps relieve stress?
- Who helps me feel safe or grounded?

(RESCUE) Self-Care Kit Ideas: Choose what feels supportive

- [ ] Healthy snacks
- [ ] Water bottles
- [ ] Sweet treat
- [ ] Comfort item
- [ ] Herbal tea
- [ ] Soft blanket
- [ ] Scented candles
- [ ] Stress balls
- [ ] Favorite book
- [ ] Journal
- [ ] Puzzles/apps
- [ ] Music playlist
- [ ] Photo album
- [ ] Sketchbook or coloring book & pencils/markers
- [ ] Spend time with pets/animals

Healthy Habit Checklist: Gentle Supports (not expectations)

- [ ] Take a break when possible
- [ ] Set limits and boundaries
- [ ] Meditate or deep breathe
- [ ] Hydrate and nourish
- [ ] Connect with a support person
- [ ] Take a walk or exercise
- [ ] Take a nap/ rest/ sleep
- [ ] Limit substances that increase anxiety (alcohol and caffeine)
- [ ] Communicate my needs
- [ ] Attend a peer support group
- [ ] Creative outlet: draw, paint, sketch, journal, write, bake, play music
- [ ] Engage with nature

Post-crisis reflection

What helped? Who showed up? What felt hardest? What would I keep or change?

Post-crisis checklist

- [ ] Plan a visit with someone from your support network
- [ ] Practice self-care (choose one restorative activity when able)
- [ ] Schedule health care for yourself
- [ ] Re-balance focus (reconnect with other parts of life)
- [ ] Update your crisis plan as needed
- [ ] Consider peer or professional support

Finding Mental Health Support

Living with Fanconi anemia (FA) or supporting someone with FA can bring ongoing uncertainty, complex medical experiences, and cumulative stress. Over time, this can affect emotional and physical wellbeing. Professional mental health support can help individuals and caregivers process these experiences, regulate stress, and build sustainable coping strategies.

The "right" fit looks different for everyone. Effective mental health support meets you where you are, adapts over time, and provides safety, validation, and practical tools and strategies for sustaining your well-being over time.

WHO
Choosing the Right Professional

If you're seeking emotional or behavioral support, look for:

- **Therapist, Counselor, or Psychologist:** Someone licensed and experienced with trauma, chronic illness, long-term medical stress.
- **Credentials:** Licensed mental health professionals: LCSW, LICSW, LMHC, LPC, MFT, PhD/PsyD, PMHNP
- **Approach to Care:** Uses trauma-informed practices that prioritize safety, choice, pacing, and collaboration.

If you may benefit from medication:

- **Psychiatrist or Prescribing Provider:** Seek a psychiatrist (MD, DO), or psychiatric nurse practitioner (PMHNP/APRN) experienced with medical complexity, trauma, and chronic illness.
- **Shared Decision-Making:** Explains options clearly, moves at your pace, and centers your input.

WHERE
Finding Mental Health Providers

- Ask your insurance plan or Employee Assistance Program (EAP) for in-network trauma-informed provider options.
- Search online for trauma-informed providers near you. Psychologytoday.com, is a helpful provider search tool.
- Ask trusted friends, family, or peers in the FA community for recommendations.
- Explore referrals from rare disease organizations or advocacy groups like FCF, NORD, or Global Genes
- Contact local or national mental health organizations like National Alliance on Mental Illness (NAMI) or Mental Health America (MHA) for lists.
- Ask your medical care team for recommendations. Some medical clinics offer counseling.

Finding the right provider can take time. Support is still available in the meantime:

- National Alliance on Mental Illness Helpline: 1-800-950-NAMI
- 988 Suicide and Crisis Lifeline (call or text)
- Online or local peer support groups

Developed in partnership with give an hour

Finding Mental Health Support, part 2

HOW
Questions to Ask

Before the First Session:

- Have you worked with people navigating rare, life-threatening conditions and medical uncertainty?
- What's your experience working with individuals managing both health needs and independence?
- What's your approach to trauma-informed care?
- Do you have experience with addressing caregiver strain, guilt, or burnout?
- Do you accept my insurance? Do you offer telehealth?
- Do you offer flexible scheduling when needed?

After the first session:

- Do you feel equipped to support my needs?
- How will we shape goals together, and as my needs change?
- What support is available between sessions if needed?

What Providers Should Know About FA

- Repeated medical trauma is common for both individuals with FA and carers
- Anticipatory grief and loss over uncertainty are commonly experienced
- Many experience healthcare system fatigue from ongoing coordination, advocacy, and bureaucracy
- Many experience systemic barriers related to education, work, disability, health insurance coverage, etc.
- Many experience stigma and isolation when social supports don't understand the realities and impacts of FA

Reflect on Fit and Safety Early On

- Does this provider feel like a safe and flexible fit for my experience?
- Do I feel heard and respected?
- Did the provider understand my FA-related context?
- Did the session feel supportive, not overwhelming?
- Can this relationship adapt as my needs change?

Feeling unsure at first is common as trust is built over time. It's okay to take some time to decide if it's a "good fit."

Mental Health Storyboard for Caregivers

This storyboard offers a brief snapshot of the physical, emotional, and mental health impacts of caregiving in the Fanconi anemia (FA) community. It helps caregivers share their experiences and support needs without retelling their entire story. This is not a diagnositic tool or complete mental health history. Consider pairing this document with the Brief Guide for Mental Health Providers and Understanding Rare handouts in the Mental Health Toolkit.

ABOUT ME

Name

Relationship to loved one

Years caregiving or time since diagnosis

Have you ever seen a mental health provider?

☐ Yes ☐ No ☐ Prefer not to answer

Previously diagnosed mental health concerns

Share only what feels relevant and comfortable.

My loved one's diagnosis or stage

Use plain language.

How caregiving has changed my daily life

Consider responsibilities, appointments, medications, care coordination or other changes.

What Others May Not See

What feels important for others to know about me right now?

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Mental Health Storyboard for Caregivers, part 2

MY PHYSICAL AND EMOTIONAL WELLBEING

Emotional challenges
Uncertainty, grief, anxiety, feeling different, isolation

Physical or medical stressors
Sleep, fatigue, side effects, body changes, new diagnoses

Significant experiences
Events that affect you emotionally or physically

Strengths and resilience factors
Perspective, humor, self-advocacy, problem-solving

Sources of social support
People, groups, services or spaces that support you

Other life stressors
Work, relationships, finances or other concerns

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FA Caregiver Storyboard: What Helps

What Helps Me

Check all that apply.

- ☐ Talking with a therapist or counselor
- ☐ Peer caregiver support or support groups
- ☐ Mindfulness or meditation
- ☐ Creative outlets, such as art, music or writing
- ☐ Movement or exercise
- ☐ Faith or spiritual practices
- ☐ Time in nature
- ☐ Journaling or reflection
- ☐ A medical team that communicates clearly
- ☐ Practical help from family or friends
- ☐ Online communities or rare disease groups
- ☐ Respite or breaks from caregiving

Other:

What I Need From a Mental Health Professional

Check all that apply.

- ☐ Familiarity with rare disease stressors (uncertainty, anticipatory grief, systemic barriers)
- ☐ Comfort discussing loss, grief and trauma
- ☐ Willingness to collaborate with caregivers and families
- ☐ Sensitivity to stigma and isolation in rare disease communities
- ☐ Practical coping strategies
- ☐ Experience with medical trauma and long-term stress
- ☐ A trauma-informed, compassionate care approach
- ☐ Flexible options, such as telehealth or evening hours
- ☐ Understanding of cultural or faith factors in my family's journey
- ☐ Emotional support

Other:

Additional Resources

Fanconi Cancer Foundation Mental Health Hub: www.fanconi.org/mental-health/

Fanconi Cancer Foundation Resource Library: www.fanconi.org/resource-library/

International FA Support Organizations: www.fanconi.org/international-support/

The Negative Space for Caregivers (support groups & resources): www.thenegativespace.life/for-caregivers/

Taking Charge of Your Survivorship (psycho-educational groups, tools/resources): www.takingcharge.csh.umn.edu

Therapist Training / Resources (PDF): https://giveanhour.org/wp-content/uploads/RARE-SERIES-ORIENTATION-PACKET-2025-3.pdf

Give an Hour Free Resources: www.giveanhour.org/rare/

If this exercise brings up difficult feelings, you're not alone. Consider reaching out to your existing care team, or if you're in the US and experiencing emotional distress or need immediate support, you can call or text ***988 for the Crisis Lifeline. If you're outside of the US, visit findahelpline.com.***

Developed in partnership with give an hour

Mental Health Storyboard for Individuals With FA

This storyboard offers a snapshot of how Fanconi anemia (FA) affects your physical, emotional, and mental health. It can help you share your experiences, needs, and priorities with others, without having to explain your full story each time. This is not a diagnostic tool or complete mental health history. Consider pairing this document with the Brief Guide for Mental Health Providers and Understanding Rare handouts in the Mental Health Toolkit.

ABOUT ME

Name

Current age **Age at diagnosis**

Have you ever seen a mental health provider?

☐ Yes ☐ No ☐ Prefer not to answer

Previously diagnosed mental health concerns

Share only what feels relevant and comfortable.

My FA

Use plain language.

What a Typical Day Looks Like

Appointments, energy level, routines, etc.

What Others May Not See

What feels important for others to know about me right now?

Developed in partnership with give an hour

Mental Health Storyboard for Individuals With FA, part 2

MY PHYSICAL AND EMOTIONAL WELLBEING

Emotional challenges
Uncertainty, grief, anxiety, feeling different, isolation

Physical or medical stressors
Sleep, fatigue, side effects, body changes, new diagnoses

Significant experiences
Events that affect you emotionally or physically

Strengths and resilience factors
Perspective, humor, self-advocacy, problem-solving

Sources of social support
People, groups, services or spaces that support you

Other life stressors
Work, relationships, finances or other concerns

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Individual With FA Storyboard: What Helps

What Helps Me

Check all that apply.

- ☐ Talking with a therapist or counselor
- ☐ Peer support/connecting with others with FA
- ☐ Mindfulness or meditation
- ☐ Creative outlets, such as art, music or writing
- ☐ Movement or exercise
- ☐ Faith or spiritual practices
- ☐ Planning ahead to reduce stress
- ☐ Time in nature
- ☐ Journaling or reflection
- ☐ Clear communication with my care team
- ☐ Practical help from family or friends
- ☐ Online communities or rare disease groups
- ☐ Taking breaks from thinking about my health
- ☐ Spending time with my loved one(s) or pet(s)

Other:

What I Need From a Mental Health Professional

Check all that apply and add your own

- ☐ Familiarity with rare disease stressors and systemic barriers
- ☐ Comfort discussing loss, grief and trauma (including repeated medical trauma)
- ☐ Understanding stigma and isolation in rare disease communities
- ☐ Respects my autonomy and includes me in decisions about my care/treatment
- ☐ Trauma-informed, compassionate care approach
- ☐ Flexibility (telehealth, evening hours, understanding of caregiver demands)
- ☐ Understanding of cultural or faith factors in my family's journey
- ☐ Ability to provide both practical coping strategies and emotional support
- ☐ Support navigating identity, independence, and life planning
- ☐ Comfort discussing topics like fertility, relationships, or future planning

Other:

Additional Resources

Fanconi Cancer Foundation Mental Health Hub

Fanconi Cancer Foundation Resource Library

International FA Support Organizations

Therapist Training / Resources (PDF)

Give an Hour Free Resources

The Negative Space for Caregivers (support groups & resources)

Taking Charge of Your Survivorship (psycho-educational groups, tools/resources) Resources

If this exercise brings up difficult feelings, you're not alone. Consider reaching out to your existing care team, or if you're in the ***US and experiencing emotional distress or need immediate support, you can call or text 988 for the Crisis Lifeline. If you're outside of the US, visit findahelpline.com.***

Developed in partnership with give an hour

Supporting FA Caregivers and Care Partners

This page is designed to support mental health providers working with caregivers supporting a loved one with Fanconi anemia (FA). Research highlights significant mental health needs among adults living with FA and underscores the importance of recognizing the experiences of caregivers.

In FA, caregiving often involves long-term uncertainty, complex care coordination, and repeated medical stress. While FA-specific caregiver research is limited, broader caregiving studies* show that caregiver mental health is closely linked to the wellbeing of the person they support and that caregivers experience higher rates of anxiety and depression, pointing to the need for ongoing mental health support and further research.

What Is Fanconi Anemia (FA)?

FA is a genetic disease caused by mutations in any of the known 23 genes that play a role in the FA DNA repair pathway. Dysfunctional DNA repair in all cells of the body means that people living with FA have a very high risk of developing bone marrow failure and cancer at young ages, in addition to many other systemic issues. FA is considered a cancer-predisposition disease.

- Average age of FA diagnosis is seven years.
- Many with FA require a hematopoietic stem-cell transplant.
- People with FA require highly specialized, multidisciplinary care—frequently at distant, specialty centers, making coordination and long-term follow-up essential.
- Cancer surveillance and early detection are crucial, as traditional cancer therapies are tolerated poorly. Surgery is often the most viable treatment option if caught early.
- In a recent study*, nearly half of adults with FA screened positive for symptoms of post-traumatic stress, with many also reporting anxiety, depression, and ongoing unmet mental health needs.
- Adults with FA experience higher rates of fatigue, sleep disturbance, and chronic pain than the general population.

*Kathleen R. Bogart, Megan E. Voss & Madeleine Limon (2025): Mental health in the first generation of adults with Fanconi anemia, Psychology, Health & Medicine, DOI: 10.1080/13548506.2025.2495889

Rare Caregivers

Broadly, rare caregivers face factors beyond that of a "general" caregiver.

- 67% of rare caregivers have a higher caregiver burden on the burden of care index
- 62% help with at least one Activity of Daily Living (ADL)
- 84% provide medical/nursing care

Alongside these demands, many face ongoing psychosocial stressors, including financial strain, changes in relationships, isolation, impacts on the broader family system, and limited opportunities for self-care. Supporting rare caregivers also requires sensitivity to the fear of the unknown, difficulty finding relevant peer support, and the emotional toll of navigating complex medical and social systems across multiple diagnoses, often over many years.

*https://www.caregiving.org/guidebooks/

Rare Facts

- In the U.S., a disease is defined as rare when it affects fewer than 200,000 people
- 72% of rare conditions are genetic
- 95% of rare conditions have no approved treatments or curative options.

*Cleveland Clinic. (2024, April 30). Importance of supporting family caregivers. https://newsroom.clevelandclinic.org/2023/02/15/importance-of-supporting-family-caregivers

Developed in partnership with give an hour

PROVIDER RESOURCES

Mental Health Considerations for Adults With FA

A Brief Guide for Mental Health Providers

Fanconi anemia (FA) is a rare, inherited condition associated with bone marrow failure, cancer risk, and lifelong medical complexity. As more individuals live into adulthood, mental health needs are becoming more visible and urgent. This resource is informed by research focused on mental health in adults with FA, and reflects current knowledge in a still emerging area where additional research is needed. It is intended to provide general considerations and is not a substitute for clinical judgment or individualized care.

What to Know Right Away

- Mental health symptoms are common and often under recognized
- Experiences are shaped by chronic uncertainty, medical trauma, stigma, and systemic barriers
- Routine screening and trauma-informed care are essential
- Many individuals have limited access to providers familiar with FA or rare disease

Understanding the Lived Experience

FA is a rare genetic cancer predisposition disease that impacts nearly all parts of the body, and involves a high risk of cancer, and often bone marrow failure. It's impacts extend far beyond medical care.

Adults with FA often navigate:

- Lifelong medical complexity, surveillance, and uncertainty
- Repeated or ongoing medical trauma from procedures, hospitalizations, and cancer screening and care
- Fear of disease progression or early death
- Fatigue, sleep disruption, and physical limitations
- Fertility challenges and body differences
- Stigma, isolation, and feeling "different"
- Disruptions to education, work, relationships, and future planning

Many describe FA as "all-encompassing," affecting every area of life

Mental Health in Adults with FA

- Lower health-related quality of life across all domains, including emotional, physical, and social functioning
- High rates of mental health symptoms have been identified:
  - ~50% probable PTSD
  - ~33% anxiety
  - ~25% depression
- Many individuals report unmet mental health needs or lack of diagnosis despite symptoms

Key Risk and Protective Factors

Risk factors

- Stigma and social isolation
- Concern with death and dying
- Fatigue and sleep disturbance
- Low confidence in managing health (self-efficacy)
- Cumulative medical stress and trauma

Protective factors

- Strong emotional and social support
- Sense of meaning or post-traumatic growth
- Connection to others with shared experience
- Skills for managing health and uncertainty

Mental Health Considerations for Adults With FA, part 2

A Brief Guide for Mental Health Providers

Key Considerations Based on Reported Experiences

Understand chronic uncertainty

- Uncertainty is ongoing and often cannot be resolved
- The goal is helping individuals live alongside uncertainty, not eliminate it
- Hypervigilance, fatigue, and emotional shifts are common, and often adaptive responses to ongoing uncertainty

Recognize coping as non-linear

- Changes in coping or functioning are expected over time
- Fluctuations often reflect changing stressors, not lack of resilience

Recognize and address systemic barriers

- System navigation is an ongoing stressor, not a background issue - acknowledge this burden explicitly
- Individuals may face delays, misdiagnosis, insurance barriers, medical dismissal, and repeated need to advocate
- Access to knowledgeable providers is often limited, especially outside major centers
- Financial strain, insurance limitations, and geographic barriers can affect care engagement
- Explore barriers openly and collaborate on realistic, accessible care plans

Use a trauma-informed lens

- Medical trauma is ongoing and cumulative
- Hyper-vigilance, anticipatory stress, and grief are common and understandable responses

*Routine screening is recommended, even outside acute medical events.

Address stigma and isolation

- Explore experiences of being misunderstood or dismissed
- Support identity beyond diagnosis
- Be mindful of intersectional identities and inequities in care

Make space for existential concerns

- Be open to conversations about mortality, uncertainty, and meaning
- Avoid minimizing or redirecting these topics

Integrate physical and mental health

- Fatigue, sleep, and pain are central to mental health
- Collaborate with medical providers when appropriate

Adapt care to real-life constraints

- Offer flexibility in scheduling and pacing
- Consider telehealth and lower-energy engagement options
- Recognize fluctuating health/energy levels

What to Screen For

Mental health symptoms

- Depression (PHQ-9)
- Anxiety (GAD-7)
- PTSD (PCL-5)

Quality of Life and Functioning

- Fatigue and sleep
- Pain and physical limitations
- Social connection and isolation
- impact on daily roles and independence

When to be especially attentive

- New diagnosis or major health changes
- Cancer diagnosis, treatment, surveillance
- Transplant or intensive medical care
- Periods of increased uncertainty or loss
- Loss within the FA community

Mental Health Considerations for Adults with FA, part 3

A Brief Guide for Mental Health Providers

Therapeutic Approaches to Consider

- Cognitive behavioral therapy (CBT)
- Acceptance and commitment therapy (ACT)
- Trauma-focused therapies, including EMDR
- Grief-focused therapy
- Health psychology approaches for chronic illness adjustment

What Individuals with FA Value in a Provider

- Understanding of rare disease and medical complexity
- Comfort discussing grief, trauma, and uncertainty
- Willingness to collaborate with medical teams
- Awareness of stigma and isolation
- A trauma-informed, compassionate approach

Learn More and Access Tools

For deeper guidance, evidence-based recommendations, and tools to support care visit fanconi.org.

- Mental Health & Wellbeing Considerations for Individuals with FA and Caregivers: Comprehensive report by Bogart and Voss
- Fanconi Cancer Foundation (FCF) resources
  - Mental health toolkit and worksheets
  - Community-informed guidance on rare disease experiences
  - Support resources for individuals and families

Supporting Hope in the Context of Uncertainty

- Be honest and transparent about uncertainty
- Avoid guarantees or false reassurance
- Support hope while allowing space for grief and complexity

Additional Resources

Mental Health & Wellbeing Considerations for Individuals with FA and Caregivers Report: www.fanconi.org/mental-health/
Beyond the Diagnosis: Rare Disease Training for Mental Health Providers (Give an Hour): www.giveanhour.org/wp-content/uploads/RARE-SERIES-ORIENTATION-PACKET-2025-3.pdf
Fanconi Cancer Foundation (FCF) Resources: Mental Health Toolkit, Psychosocial Research, Community Support, FA Clinical Care Guidelines : www.fanconi.org/resource-library/
Taking Charge of Your Survivorship: Psychoeducational groups, tools, and resources: www.takingcharge.csh.umn.edu
Give an Hour Free Resources: https://giveanhour.org/rare/

References:

1. Kathleen R. Bogart & Megan E. Voss (2024): Mental Health & Wellbeing Considerations for Individuals with FA & Family Caregivers. Fanconi Cancer Foundation. https://fanconi.org/wp-content/uploads/2024/10/Updated_Sharable-Version-Mental-Health-Considerations-for-Individuals-with-FA-Family-Caregivers.pdf
2. Kathleen R. Bogart, Megan E. Voss & Madeleine Limon (2025): Mental health in the first generation of adults with Fanconi anemia, Psychology, Health & Medicine, 31(1): 1-15. DOI: 10.1080/13548506.2025.2495889
3. Give an Hour. (2025–2026). Beyond the Diagnosis: Rare Disease Training for Mental Health Providers, Clinical Companion Resources (Modules 2–3). Developed in collaboration with Al Freedman, PhD, and clinical contributors.

Understanding Rare Disease

A Resource for Friends, Family, and Supporters

Rare disease affects every part of life - not just health but routines, relationships, and a person's sense of safety. For many individuals and families, it brings uncertainty, ongoing stress, and the need to adapt in ways others may not see.

Rare disease isn't as rare as it sounds. In the United States, a rare disease is defined as a condition that affects fewer than 200,000 people. Yet for each family who hears the words "We've never seen this before," the experience feels profoundly isolating.

How Do I Approach Something I Know Nothing About?

You don't need to be an expert to make a difference. You just need to be curious, kind, and willing to learn.

✓ Do this:

- Say, "I don't understand what this is like, but I'm here to listen."
- Keep showing up, even after the initial crisis fades.
- Ask questions with genuine interest: "What has this experience been like for you?"
- Ask what helps most: rides, meals, quiet company.
- Learn from the person living it. They are the expert on their condition and story.
- Respect limits: fatigue, cancellations, changing plans.

✗ Avoid this:

- Offering quick fixes or comparisons ("At least it's not...").
- Only talk about the illness or prognosis.
- Assuming it's "all figured out" once a diagnosis arrives.
- Treating someone as fragile or defined only by their illness.

Psychologist and rare parent, Dr. Al Freedman describes it as being "launched into the Twilight Zone". Life as you knew it disappears overnight, and you wake up on another planet.

10,000+ rare diseases have been identified worldwide.

300 million+ people affected globally, and about **1 in 10** Americans.

⅔ of rare diseases begin in childhood.

Most people see **7 or more specialists** before finding answers.

Only about **5%** of rare diseases have an FDA-**approved treatment**.

Behind every diagnosis is a **family** navigating uncertainty, fear, grief, hope and the ongoing work of adapting to life with FA.

What the Experience Can Feel Like

Shock and disbelief at diagnosis or sudden medical change.
Exhaustion from navigating endless appointments, systems, and advocacy.
Mistrust after misdiagnoses or medical dismissal.
Isolation when few people understand what life is like now.
Grief and guilt over lost independence, routines, or dreams.
Hypervigilance *and* always waiting for the next call, symptom, or test result.
Resilience and pride in surviving what once seemed impossible.
Hope and meaning-making through community, advocacy, or helping others.

Acknowledgments, References and Disclaimer

Acknowledgments

This toolkit was developed by the Fanconi Cancer Foundation with input from individuals, caregivers, and advocates within the Fanconi anemia community. We are deeply grateful to those who shared their experiences, insights, and feedback to help ensure this resource reflects real-world needs.

We extend our sincere thanks to Give an Hour for their partnership and foundational mental health tools and resources, which greatly informed this toolkit.

We also thank the researchers and professionals who contributed their time and expertise in rare disease and trauma-informed mental health care.

Disclaimer

This toolkit is for educational and supportive purposes only. It is not a diagnostic tool and does not replace individualized medical or mental health care. Please consult your health care team or a qualified mental health professional for guidance specific to your needs.

This resource was developed using evidence-based research, clinical and community-informed insights, and AI-assisted tools (for summarization purposes only). All content has been reviewed and edited by the Fanconi Cancer Foundation to ensure accuracy and relevance for individuals and families affected by Fanconi anemia.

While evidence informed, this resource reflects current knowledge in a still emerging area where additional research is needed.

References & Resources

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- National Organization for Rare Disorders (NORD). Rare disease data and caregiver statistics. www.rarediseases.org
- The Negative Space - resources and support groups for caregivers. Available at www.thenegativespace.life
- Taking Charge of Your Survivorship - psychoeducational tools, resources, and groups. Available at www.takingcharge.csh.umn.edu/survivorship
- 988 Suicide and Crisis Lifeline (U.S.). 988lifeline.org