Care Planning Guide

Supporting Families Impacted by Trisomy 18 and the Professionals Who Serve Them

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Introduction

Receiving a Trisomy 18 (Edwards Syndrome) diagnosis—before or after birth—can feel overwhelming, confusing, and isolating. Families are often asked to make difficult decisions while also processing uncertainty, grief, and hope.

This guide was created to walk alongside you—families, caregivers, and the healthcare professionals who serve you. It offers practical tools, reflective questions, and resources to support care planning and decision-making.

🔷 **Note:** This guide is not a substitute for medical advice. Always consult with your healthcare provider when making decisions about your and your child's care.

Understanding Trisomy 18

What is Trisomy 18?

Trisomy 18, also known as **Edwards Syndrome**, is a rare genetic condition caused by the presence of an extra copy of chromosome 18 in some or all of the body's cells. This extra genetic material disrupts normal development, often leading to complex medical challenges.

There are three types of Trisomy 18:

- **Full Trisomy 18:** Every cell has an extra chromosome 18 (most common and severe).
- **Mosaic Trisomy 18:** Some cells have an extra chromosome 18, others do not (symptoms may be milder).
- **Partial Trisomy 18:** Only part of chromosome 18 is extra (rare and can sometimes be inherited).

Testing & Diagnosis

Learning about Trisomy 18 often begins with testing—before or after birth. Understanding the difference between screening and diagnostic tests can help you make informed decisions and prepare for the next steps. This section explains the types of tests, what they mean, and how families and professionals can ensure results are shared clearly and with compassion.

Prenatal Testing

- **Screening Tests (Non-invasive):** Blood tests and ultrasounds may suggest a higher likelihood of Trisomy 18 but cannot confirm it.
- **Diagnostic Tests:**
    - **Chorionic Villus Sampling (CVS):** Performed in the first trimester, tests placental tissue for chromosomal differences.
    - **Amniocentesis:** Performed in the second trimester, tests amniotic fluid for chromosomal differences.

Postnatal Testing

- If Trisomy 18 is suspected after birth, doctors may confirm the diagnosis with a **blood test (karyotype or microarray)** to analyze the baby's chromosomes.

What Families Should Know

A Trisomy 18 diagnosis brings more questions than answers—and that's okay. Every family's journey looks different, and there is no single "right" way to move forward. What matters most is that you feel informed, supported, and empowered to make decisions that align with your values.

- Screening tests suggest risk, but only diagnostic tests confirm Trisomy 18.
- Waiting for results can feel overwhelming—ask your provider about emotional support or counseling during this time.
- You deserve clear, compassionate communication. Don't hesitate to ask providers to explain results in plain language, and request written summaries when possible.
- Connecting with other families who have walked this journey can help you feel less alone.

For Professionals

- Be mindful of language—phrases like "incompatible with life" can cause harm.
- Provide balanced, accurate information about possible outcomes and care options.
- Encourage families to meet with a **genetic counselor** for deeper support.

Preparing for Your Medical Appointments

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Medical appointments can feel exhausting—there's a lot of information, emotions, and decisions to process in a short time. Preparing ahead can help you feel more confident, make sure your questions are answered, and ensure your voice is heard. This section offers tips for families and professionals to work together, creating space for clear communication and shared decision-making.

For Families:

Taking a few small steps before your appointment can make the experience less stressful and more productive.

- Write down your questions in advance.
- Ask for plain-language explanations of medical terms.
- Bring a support person to help listen, take notes, and advocate with you.

Families may want to ask:

- What treatment options are available for my child?
- What specialists should be part of our care team?
- How will this condition affect growth, development, and quality of life?
- What are the risks and benefits of each medical decision?
- What support services (palliative care, counseling, therapies) are available?

For Professionals:

Creating space for thoughtful, family-centered communication helps build trust and partnership in care.

- Allow extra time for these conversations.
- Provide both verbal and written summaries to support family understanding.
- Encourage families to share their values, hopes, and concerns early in the process.

Professionals may ask families:

- What matters most to you right now?
- How do you define quality of life for your child and family?
- What kind of support would help you feel less overwhelmed?

Personalized Care Planning

A care plan brings together your child's **medical, developmental, emotional, and social needs** into one coordinated document. It serves as a roadmap for families and professionals, ensuring everyone is aligned around the child's goals, values, and priorities.

Why It Matters

- Families can feel confident knowing their wishes are clearly documented.
- Providers can deliver care that is consistent, compassionate, and family-centered.
- Everyone on the care team—across different specialties—can stay connected and informed.

What a Care Plan Might Include

1. Family Goals and Priorities

- My hopes for delivery are: ______________________
- What matters most to us right now: _______________
- Our definition of quality of life is: _______________

2. Medical Care and Interventions

- Primary diagnosis: ____________________________
- Other medical needs: _________________________
- Treatments/procedures we want to pursue: __________
- Treatments/procedures we do not want: _____________
- Pain management preferences: ___________________

3. Emergency & Crisis Planning

- In an emergency, we want providers to: ____________
- Do-Not-Resuscitate (DNR) status or advanced directives: ____________________
- Preferred hospital/ER: ________________________
- Emergency transport plan: ______________________

4. Developmental & Therapeutic Services

- Therapies we want to explore (PT, OT, speech, feeding): ________________
- Developmental goals we have for our child: _________
- Community resources we are connected to: _________

5. Emotional, Mental Health, and Spiritual Needs

- Our biggest emotional challenges right now are: _______
- Mental health support we would find helpful: _________
- Our spiritual or faith-based needs include: ___________
- People who bring us emotional strength are: _________

6. Care Team and Communication

- Primary pediatrician: ________________________
- Specialists (cardiology, genetics, neurology, etc.): ______
- Care coordinator/case manager: ________________
- Family spokesperson/advocate: ________________
- Best way to contact us: ______________________

7. Long-Term Hopes and Wishes

- Our long-term hopes for our child are: ____________
- What we want others to know about our child: ________
- Legacy or memory-making activities we'd like to include: ____________________

For Professionals

- Use the care plan to guide **shared decision-making**.
- Revisit and update regularly, especially after hospitalizations or major interventions.
- Respect family language and priorities in all documentation.
- Encourage families to bring their care plan to every appointment.

∗The care plan is a **living document**—it can change over time as the child's needs, medical options, and family goals evolve.

Advocacy & Support Resources

Navigating Trisomy 18 is not only about medical care—it's also about having access to **education, advocacy, mental health, financial tools, and community support**. At The E.WE Foundation, we are committed to walking with both families and professionals by providing resources that empower, connect, and sustain.

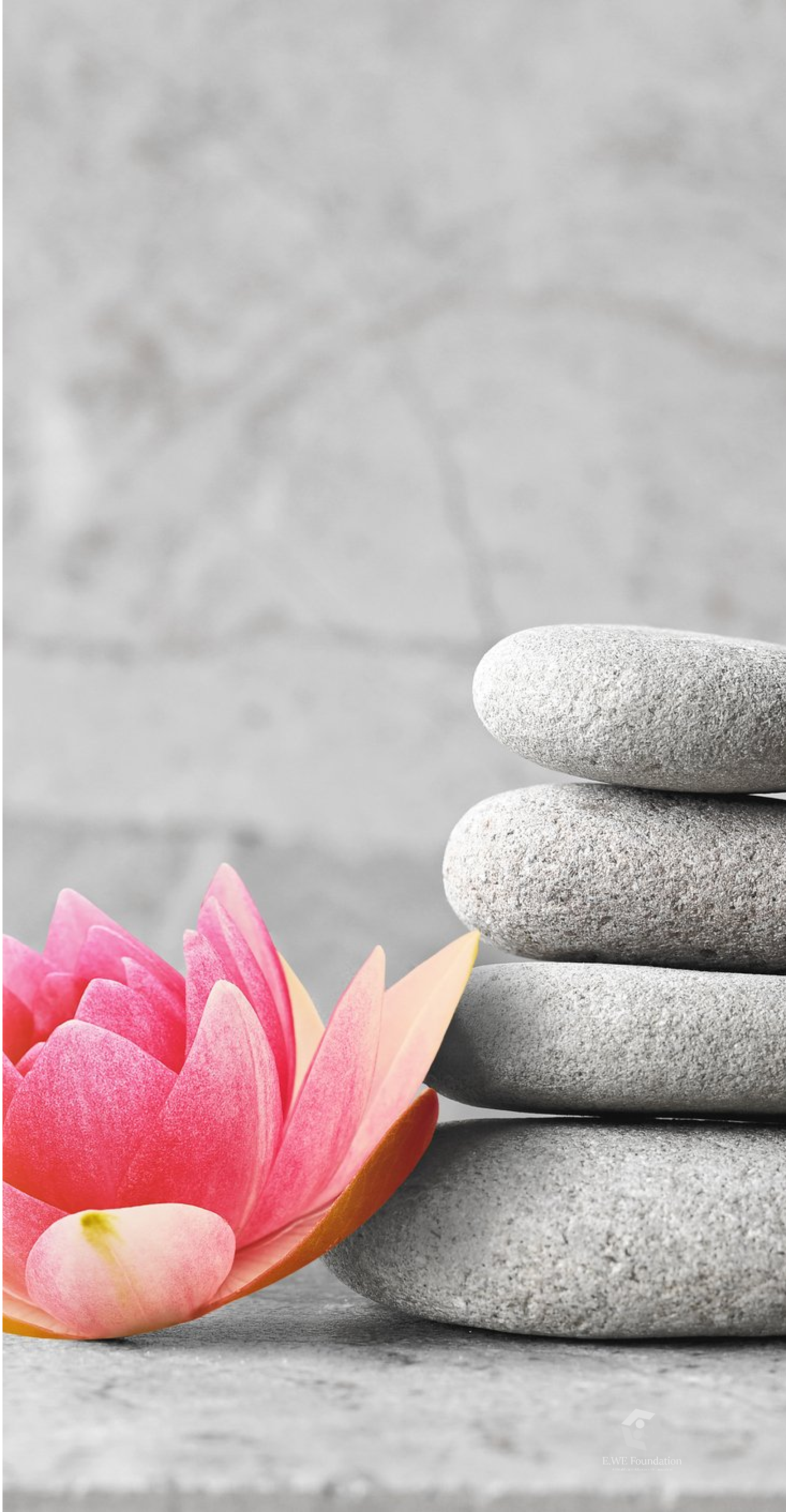
For Families

- **Peer Support & Community Groups**
  Join virtual and in-person groups for parents and siblings. These spaces offer encouragement, shared experiences, and connection.
- **Respite & Wellness Programs**
  Participate in initiatives like *The Pause Project*, which provides intentional rest, reflection, and renewal for caregivers.
- **Mental Health Resources**
  Access counseling partnerships, self-care workshops, and grief support tailored to the unique challenges of rare disease caregiving.
- **Financial Literacy & Assistance**
  Guidance on navigating Medicaid, insurance appeals, medical fundraising, and financial planning. Eligible families may also apply for support through our **STRIPE Charitable Assistance Program**.
- **Care Planning & Education**
  Downloadable guides and care templates to help structure care and track development.

For Professionals

- **Educational Modules & Training**
  Continuing education opportunities in shared decision-making and trauma-informed family engagement.
- **Clinical Collaboration Tools**
  Access care planning templates, family-centered communication strategies, and rare disease resources to support clinical practice.
- **Awareness & Advocacy Campaigns**
  Partner with us during Trisomy Awareness Month and other initiatives to amplify education, equity, and compassionate care.
- **Research & Policy Engagement**
  Collaborate with us on data collection, community-based research, and rare disease policy advancement.

Caring for Yourself



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Caring for a child with Trisomy 18 can be physically exhausting, emotionally intense, and spiritually challenging. Families and professionals alike must remember: **you cannot pour from an empty cup.** Prioritizing your own well-being is not selfish—it is essential.

For Families: Your well-being matters as much as your child's care.

- **Practical Self-Care**
  - Schedule regular breaks, even short ones.
  - Keep a list of friends or family who can step in when you need help.
  - Use respite care services or programs like *The Pause Project*.
- **Emotional Well-Being**
  - I feel supported when: ____________________
  - My biggest stress triggers are: ______________
  - Strategies that help me calm down include: ______
- **Community & Connection**
  - Join peer groups where you can share honestly without judgment.
  - Talk with a licensed counselor if grief, anxiety, or depression become overwhelming.

For Professionals: Caring for others starts with caring for yourself.

- **Recognize Compassion Fatigue**
  - Notice signs of burnout: irritability, exhaustion, detachment.
  - Seek peer debriefing sessions after difficult cases.
- **Build Supportive Practices**
  - I recharge by: _________________________
  - Colleagues I can turn to are: _______________
  - Practices that help me reset include: _________
- **Sustainability in Caregiving**
  - Set healthy boundaries to protect your own energy and mental health.
  - Engage in continuing education or reflective supervision.
  - Make time for rest, hobbies, and relationships outside of work.

Remember: By caring for yourself, you strengthen your ability to care for others—whether that's your patients, your child, or your community.

Self-Care Toolkit

Practical Tools for Families & Professionals

Use this toolkit as a starting point to build intentional practices into your daily routine.

Quick Grounding Exercises

When stress feels overwhelming, try one of these techniques:

- **5-4-3-2-1 Exercise:** Name 5 things you see, 4 things you feel, 3 things you hear, 2 things you smell, 1 thing you taste.
- **Box Breathing:** Inhale for 4 counts, hold for 4, exhale for 4, hold for 4. Repeat.
- **Stretch & Reset:** Stand, stretch your arms overhead, and roll your shoulders slowly.

Journaling Prompts

Use these prompts to reflect and release:

- Today, I am grateful for: ______________________
- One thing that felt hard today was: _______________
- Something that gave me hope today: ______________
- I feel most supported when: ____________________

Self-Care Reminders

- Small steps add up—5 minutes of calm is better than none.
- You do not have to do this alone—reach out for help.
- It’s okay to rest. Rest is part of resilience.

Want more ideas? Visit our **ZEBRA Program** for mental health, emotional support, and caregiver wellness resources.

Sibling Self-Care

Because your feelings matter too.

When your brother or sister has Trisomy 18, life can feel different. Sometimes you might feel happy, sometimes worried, sometimes sad—or even all those things at once. That's okay. Your feelings are important, and taking care of yourself helps you take care of the people you love.

Feelings Check-In

How are you feeling today? Circle the faces that match how you feel:
🙂 Happy
😢 Sad
😡 Frustrated
😴 Tired
😕 Confused
💪 Brave

Try These Prompts

- Today I felt ________________________.
- Something that made me smile was ________.
- One thing I wish others understood about my family is ________.
- I feel loved when ____________________.

Self-Care Ideas for Siblings

- Draw a picture of your feelings.
- Keep a special notebook just for your thoughts.
- Play outside or get active when you feel stressed.
- Talk to a friend, teacher, or trusted adult when you need to.
- Spend one-on-one time with Mom, Dad, or another caregiver.

Coping Reminders

- It's okay to ask questions about your sibling's care.
- It's okay to have mixed feelings—you can love your sibling and still feel sad or worried sometimes.
- You are an important part of your family's care team.

Final Thoughts

At The E.WE Foundation, we believe that **families and professionals are partners in care**. Together, we can ensure that children with Trisomy 18 are met with compassion, dignity, and equitable access to care.

You are not alone on this journey. We are here to support you—every step of the way.

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