



The E.WE
FOUNDATION
EQUIP. EMPOWER. ELEVATE.



DIGITAL GUIDE

A RESOURCE FOR
FAMILIES & CAREGIVERS



CARE PLANNING GUIDE

Support for Families
Impacted
by Trisomy 18

Practical tools.
Compassionate guidance.
You are not alone on
this journey.



FAMILY-CENTERED
PLANNING



PRACTICAL TOOLS
& TEMPLATES



EMOTIONAL &
SPIRITUAL SUPPORT



RESOURCES &
CONNECTION



COMPASSIONATE
GUIDANCE



TOOLS. RESOURCES.
HOPE.

Planning today
for the care and
compassion your child
deserves tomorrow.



You are not alone. We are here for
you—every step of the way.



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.



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:



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.



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.

Preparing for Your Medical Appointments



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.



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?



You are not alone. Preparing together leads to better conversations, stronger partnerships, and care that honors your child and your family.





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**.

Care Plan A ROADMAP FOR YOUR CHILD



Medical Needs



Developmental Goals



Emotional Well-Being



Social Support



Together, we can create a plan
that honors your child and your family.





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.



For Families:



Peer Support & Community Groups



Respite & Wellness Programs
(The Pause Project)



Mental Health Resources



Financial Literacy & Assistance
(STRIPE Charitable Assistance Program)



Care Planning & Education



For Professionals:



Educational Modules & Training



Clinical Collaboration Tools



Awareness & Advocacy Campaigns



Research & Policy Engagement



You don't have to navigate this journey alone.
We are stronger together.





Caring for Yourself



Caring for a child with Trisomy 18 can be physically exhausting, emotionally intense, and spiritually challenging.

You cannot pour from an empty cup.



For Families:

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



Practical Self-Care

Prioritize rest, nutrition, hydration, movement, and moments that bring you joy.



Emotional Well-Being

Allow yourself to feel all the emotions. Seek counseling, join support groups, and give yourself grace.



Community & Connection

You don't have to do this alone. Lean on other families, friends, faith communities, and resources that uplift you.



Taking care of yourself helps you show up for your child with love, patience, and strength.



For Professionals:

Caring for others starts
with caring for yourself.



Recognize Compassion Fatigue

Acknowledge the signs—emotional exhaustion, detachment, or feeling overwhelmed. It's okay to not be okay.



Build Supportive Practices

Set boundaries, take breaks, and engage in activities that recharge your mind, body, and spirit.



Sustainability in Caregiving

Seek peer support, supervision, and ongoing education. A sustainable caregiver is better equipped to provide compassionate care over the long term.



Your well-being strengthens your ability to make an impact and support families on their journey.



Self-care is not selfish.

It's necessary.

When we care for ourselves,
we create a stronger future
for our children and our
communities.





Self-Care Toolkit



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.



You deserve care, too.
When you care for yourself, you are better able to care for others.





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.



1 Feelings Check-In

How are you feeling today?
Check the box that match how you feel:

☐

Happy

☐

Sad

☐

Frustrated

☐

Tired

☐

Confused

☐

Brave

All feelings
are
okay!



2 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 _____.



3 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.

4 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.



You are strong. You are loved. You are not alone.





Final Thoughts



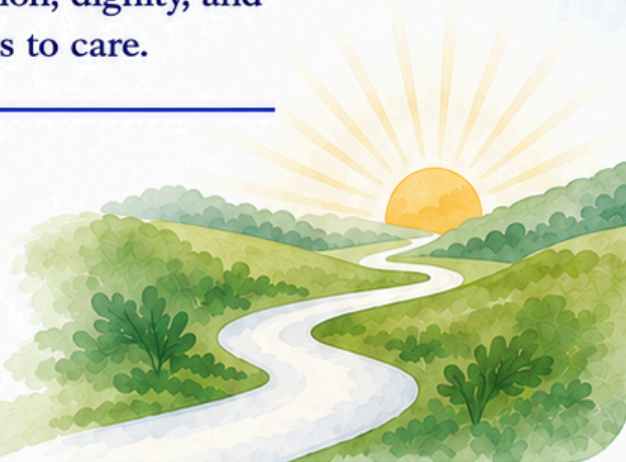
At The E.WE Foundation, we believe that *families* and *professionals* are care partners.

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.*



We're Here for You

The E.WE Foundation offers programs, resources, and support for families and professionals caring for children with Trisomy 18.



Community Support

Connect with families who understand.



Education & Resources

Access trusted information and tools.



Financial Assistance

Explore help through our STRIPE program.



Mental Health & Wellness

Find support for you and your family.



Advocacy & Awareness

Join us in creating a better future for all.

Let's stay connected.

We would love to hear from you!



Visit Us

www.theewefoundation.org



Email Us

info@theewefoundation.org



Follow Us

[@everyoneiswe](https://www.instagram.com/everyoneiswe)



Together, we can make a difference—today and every day.

COMPASSION • CONNECTION • COMMUNITY • HOPE





The
E.WE
Foundation®
Everyone Is We



*Reshaping medical perspectives through advocacy,
education and policy for rare disease families.*



Patient Advocacy | Community
Education | Health Literacy



ZEBRA
PROGRAM

Mental Health | Peer Support |
Bereavement



STRIPE
PROGRAM

Charitable Giving for
Trisomy 18 Families



A *Global* Advocacy Network

Connecting families, professionals and communities around the world.



The E.WE Foundation

A 501(c)(3) Nonprofit Organization



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