A FREE GUIDE FOR PARENTS OF CHILDREN WITH DISABILITIES, AT ANY AGE

The Decisions That Can't Wait

The care never stops. The big decisions still need to be made.

Six decisions most families put off, and one simple way to face each one, without losing yourself in the process.

Written for you, the parent.

Patricia Pollack

GUIDE · CREATOR OF THE PAUSE IS THE ANSWER™

A NOTE FROM PATRICIA

A job I never applied for.

For 27 years I have cared for my daughter. Seizures. Suctioning. Hospital stays. Nights with no sleep. Somehow my life turned into 24/7 caregiving, a job I never applied for.

I learned something the hard way. The care never stops. And the big decisions still need to be made. Who will be her guardian. Where she will live. What happens to her when I can't be there.

I put some of those decisions off for years. Not because I didn't know what to do. Because every time I faced them, my whole body went into alarm.

This guide is the one I wish someone had given me. It names the decisions that can't wait. And it gives you one simple way to face each one, without losing yourself in the process.

> *You don't have to do it all today. You only need one step.*

WHY THESE DECISIONS KEEP GETTING PUT OFF

It is not because you don't care. And it is not because you don't know what to do. When something feels dangerous, your body goes into alarm. Your heart speeds up. Your thinking narrows. You look for a way out. That is your body trying to protect you. I call this the Pen Moment: the step is right in front of you, and your body pulls back.

The big decisions about your child feel dangerous, because they are about the person you love most, and about a time when you may not be there. So every time you get close, the alarm goes off. You get busy. You say "next month." The decision waits another year. And you are already tired, making these choices on very little sleep, in between appointments and work.

So the answer is not more information. It is getting steady enough to face the decision, one small step at a time.

Six decisions most families put off.

You do not need to make them all at once. Read the list and notice which one makes your stomach tighten. That is usually the one to start with.

01

Who makes decisions for your child at 18

WHY IT MATTERS	In many places, when your child turns 18 you lose the legal right to make medical and money decisions for them, unless something is put in place first. The rules depend on where you live.
A FIRST QUESTION	"If my child had a medical emergency the day after turning 18, who would the hospital listen to?"
WHO HELPS	A lawyer who works with families of people with disabilities.

02

Who will care for your child if you can't

WHY IT MATTERS	If something happened to you tomorrow, someone else would need to know everything you know. The medicines, the routines, the signs of trouble, what comforts your child.
A FIRST QUESTION	"Who would we trust with this, and have we asked them?"
WHO HELPS	Your partner, your family, a disability life planner, and a written letter of wishes that you keep with your will.

03

Your will, and a trust for your child

WHY IT MATTERS	Money left directly to your child can affect the benefits they rely on. A special kind of trust can protect both. In Canada, ask about a Henson trust. In the US, ask about a special needs trust.
A FIRST QUESTION	"Does our will say what happens to our child, and is it up to date?"
WHO HELPS	An estate lawyer and a financial planner who work with disability families.

04

Benefits and savings as your child becomes an adult

WHY IT MATTERS	Many supports change or start at 18, and some take months to set up. In Canada, ask about the Disability Tax Credit, the RDSP savings plan and your province's disability support. In the US, ask about SSI and ABLE accounts.
A FIRST QUESTION	"What changes for us when our child turns 18, and what do we need to apply for now?"
WHO HELPS	A financial planner, a social worker, or your child's care coordinator.

05

Life after school

WHY IT MATTERS	School ends. The care does not. Your child will need somewhere to spend their days, and one day somewhere to live. Waiting lists can be long.
A FIRST QUESTION	"What do we want our child's days to look like after school ends?"
WHO HELPS	A disability life planner, your child's school team, local disability agencies, and other parents who are a few years ahead of you.

06

Who carries what, between the two of you

WHY IT MATTERS	One of you may still be working, or running a business, often 9 in the morning to 9 at night. Over the years, the load shifts without anyone deciding it. Sometimes one of you needs to step back, and sometimes you both need help.
A FIRST QUESTION	"If we planned this on purpose, who would carry what?"
WHO HELPS	An honest conversation between the two of you, and outside help when you are stuck.

> I am not a lawyer or a financial advisor. The legal and money parts belong with professionals. What I can help with is the part they can't: getting steady enough to sit down and decide.

THE PAUSE BEFORE EACH DECISION

Two minutes, and through every step.

This comes from my method, The Pause Is the Answer™. Use it before you open the will, call the lawyer, or start the hard conversation, and again every time the alarm comes back. Most advice tells you to push through. Other methods tell you to calm down first. This one keeps you steady through the step.

Start with a pen. Pick it up and notice how light it feels. Now think about the decision. Notice how heavy the pen feels, and how strong the alarm is, from 0 to 10. This is the Pen Moment.

Pause	Stop what you are doing. Put both feet on the floor. Slowly turn your head and look left, then right, and name five things you can see. Notice that the alarm is on. You don't have to fight it.
Regulate	Breathe in slowly for a count of four. Breathe out for a count of six. Do this three times. Let your shoulders drop, and let the stress rise and fall like a wave. You don't need to feel completely calm before you act.
Do	Pick up the pen again. How heavy does it feel now, from 0 to 10? Then ask yourself: "What microstep can I take from here?" Not the whole decision. One step. Send one email. Write one name down. Close your eyes for a moment and see yourself doing it. Then do only that.
Repeat	When the alarm comes back, and it will, pause again. Steady yourself after each step, then take the next one when you choose.

> If you are doing this with your partner, do the breathing together before you talk. Two steady people make different decisions than two tired ones.

YOUR ONE STEP THIS WEEK

Five minutes. One step.

THE DECISION I KEEP PUTTING OFF

WHAT I FEEL IN MY BODY WHEN I THINK ABOUT IT

HOW STRONG IT FELT BEFORE THE PAUSE (0 TO 10)

HOW STRONG IT FEELS AFTER (0 TO 10)

THE MICROSTEP I WILL TAKE THIS WEEK

THE PERSON I WILL CALL OR EMAIL

THE DAY I WILL DO IT

- [ ] I did the pause practice before I started
- [ ] I took the step
- [ ] I told my partner, or someone I trust, that I did it

One step is enough for this week. A decision that is made stays made.

WHEN YOU'RE READY FOR MORE

You don't have to carry this alone.

My work is with parents and caregivers, never a service for your child.

Some decisions are too big to face alone, or too big to face with only each other. That is what my work is for.

FOR PARENTS · FAMILY ANCHOR

A private intensive for one or both parents. Individual time with each parent taking part, then a full day on the decision in front of you.

Begin with a private conversation at patriciapollack.com/families
In person or online, wherever you live in the world.

FOR LAWYERS, PLANNERS, SCHOOLS AND EMPLOYERS

I lead sessions for the families you serve, to help them get steady enough to act.

Learn more at patriciapollack.com/groups

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THE SMALL PRINT

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