



Taking Care of Yourself

By Laura J. Warren, TxP2P Staff

I remember how often I lied when people kindly said, “You’re taking care of yourself, right? You know Jason depends on you and you have to take care of yourself for him!” My answer was always, “Sure!” but under my breath, it was “Yeah, right!” My son was a micro-preemie and after many ups and downs was coming home after almost six months in the hospital, I was pumping breast milk every 2 hours, or at least was supposed to be. I was contracting out our dream home, and my husband and I were the finish contractors. Taking care of myself? In whose dreams?

Unfortunately, I found out the hard way what happens when I do not take care of myself – bouts of depression that can last 4 to 6 months and loss of myself – who I am, what I need, and what I want. Those kind people were right - I could not be there for Jason when I was not there for myself. It was finally when I no longer had the desire or energy to play with him, my sweet little boy who had worked so hard all those years to learn to walk and talk, and now, Mom could no longer have fun with him. I went for help.

I have read lots of “Care for the Caregiver” lists and articles and handed many out to parents in various groups I’ve facilitated. Now, I have had a little time to really read them and think about them and the following are my favorites:

- * Be gentle with yourself
- * Laugh and play
- * Identify the activities which are healing or fun for you and do one each day– it can be a quick five minutes

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TxP2P Update

By Laura J. Warren, TxP2P Executive Director

Self-care is the focus of this newsletter, and one of my favorite subjects – only because I did it so poorly for the first seven years of my son’s life. I only started taking better care of myself after I kept hearing from friends that I should. I only did went to a counselor because I found myself in a long-term depression that I couldn’t get out of alone. She turned out to be great for me and I quit going in and out of depressions. I hope you allow yourself a little time for self-care after reading these articles and understanding why self-care is so important for us as parents of kids with disabilities!

There’s also an important event coming soon to everyone’s home – the US census. I know it may sound strange for me to mention it, but the information you give on your census form can help Texans to receive additional funding for Medicaid/Medicare and even to have more representatives in the US House of Representatives. So please take the time to fill out and return your census form.

This is also the season when TxP2P will be asking you for a donation as part of our **Giving Tuesday** and End of Year campaigns. We understand that parents often have extra expenses-- and it’s the holidays, but if you make donations to nonprofits, please consider helping TxP2P this year!

Happy Holidays!

- * Use whatever method you like to gain relief – religion, philosophy, poetry, music, art, gardening, exercise, reading, etc.
 - * Schedule “withdrawal” periods during the week – limit interruptions
 - * Don’t judge your level of grief and healing by how others are grieving and healing but by your internal awareness
 - * Give yourself permission, time and space to grieve – no matter what age your child is – there is no time limit on grief
 - * Don’t pretend it doesn’t hurt at times
 - * Learn to recognize the difference between complaining that relieves and complaining that reinforces negative stress
 - * Say “I choose” rather than “I should, I ought to or I have to.” Say “I won’t” rather than “I can’t.”
 - * Understand and accept your limitations – don’t try to be all to everyone
 - * Remember that it’s healthy to laugh and cry
 - * Attempt to honestly express your feelings to people who will understand and not be
- judgmental or hurt by your honest expression
 - * Be open to meeting new friends who may share the ups and downs of your “new” life
 - * Accept your friends with all their imperfections and occasional bad advice; if they remain in your life, give them an “A” for effort
 - * Tell others what you want from them: help with _____, emotional support, just to listen, just to vent, etc.
 - * Recognize that if you decide to seek counseling, it does not mean you are weak, inadequate or mentally ill
 - * Take care of your physical needs: try to eat right, exercise, sleep – get help when necessary – a friend to walk with, medication for sleep, someone to help with meals
 - * Avoid masking the pain with drugs or alcohol
 - * Set goals for yourself, even if they are small
 - * If you never say “no” – what is your “yes” worth?
 - * And finally, give yourself permission to backslide



Early Childhood Intervention

Respite: Taking Time for Yourself

Sometimes, the best thing a parent can do for their child is take some time for themselves.

What is respite? The word respite means “break” or “relief.” Respite services are designed to offer families a break from caring for their child with developmental delays or disabilities. Respite allows parents time to take part in activities that they find relaxing, entertaining or restful while a respite provider cares for the child.

A respite break can allow a parent an hour to take a walk while the provider stays in your home to care for the child. It may be a weekend away while the child is cared for outside of the home. It can also mean time to take a

nap or see a friend while the respite provider is on duty.

How can respite help a family? Parenting is a difficult job and every parent can benefit from a break. Caring for a child with developmental delays or disabilities presents additional challenges that go beyond the everyday stresses. As a result, parents or caregivers may need longer rest periods or more down time. Respite services can provide the support families need.

There are several resources to support a families’ respite needs. The [Take Time Texas \(https://www.dads.state.tx.us/taketimetexas/\)](https://www.dads.state.tx.us/taketimetexas/) website provides many tools and a searchable provider database to access help and support for all families.

If a family is receiving Early Childhood Intervention (ECI) services, their ECI program may have funds to help pay for respite services. ECI families should ask their service coordinator about:

- the availability of ECI respite funds,
- levels of funding based on level of care needed,
- process for prioritizing requests,
- wait list policy,
- annual hourly limit and
- annual total dollar limit.

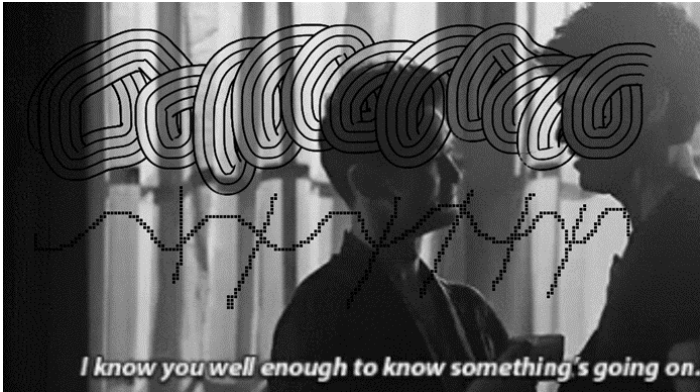
Respite can help strengthen the whole family. It can help decrease stress and increase a family’s health and well-being. In addition to giving parents a rest, it may help free up time to spend with other members of the family.



Self-Care for Caregivers: Observations from the Other Side— written by a Self-Advocate

Written and illustrated by Amy Litzinger, Self-Advocate and TxP2P Staff

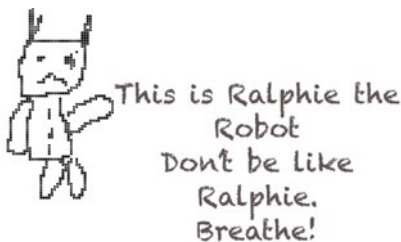
I hear so often, “I spend hours a week with my kid. I know when something’s wrong and they need a break.” We spend time with you, too. We notice, and we care.



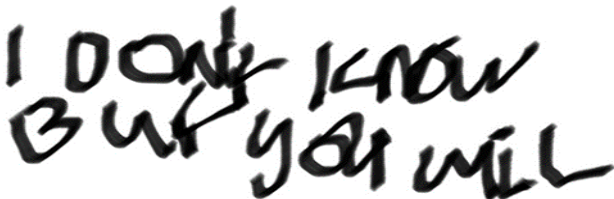
Please take 5 minutes. It doesn’t always have to be some big planned event. Self-care shouldn’t create more stress to make space for it.



We understand that sometimes you need alone time. But also think about some stress free activities we can do together, so we see what it’s like to take care of ourselves. Also we love watching you relaxed.



Take a breath. Show us your feelings. You’ll be less stressed, more open.... And we get to learn that being an adult doesn’t mean we have to be superhuman robots. Even if you’re still our heroes.



But don’t just take my word for it. Go figure out what works for you!

Self-Care Apps

By Amy Litzinger, TxP2P Staff

As parents, many of us get stressed-out at times and wonder, “How do I stop worrying and find a calmer way to live? And how do I keep from feeling like NOT worrying is just another chore to add to my list?” Maybe an app on your phone or watch can make a difference in your busy life. Here are some suggestions:

These apps have a free version:

Breathe (default on Apple Watch) – reminder style app

IbisPaint – to create art



Simple Habits Daily Meditation –
for sleep and anxiety related guided meditations

Jour – guided journaling

Motivation – daily motivational quotes

Self-checkout – mental health and mood tracking



This app costs \$54 per year:

Calm -- several categories of professionally guided meditations

Hope you can find one that helps!



Working toward Peace of Mind

By Rosemary Alexander, TxP2P

Parenting is stressful, especially parenting a child with disabilities or special health care needs. We worry a lot! What’s coming down the road? Will my child have the resources she needs? And more immediately, this treatment is too expensive! What is going on with these new behaviors? Is she safe today? These thoughts lead to big-time anxiety!

On my 37-year journey as a parent, I’ve discovered that I do not want to live ANXIOUS! I crave peace of mind. And on that journey, I have discovered a few tools that really help me get to peace.

Daily, I try to notice the stories I’m telling myself. I am really good at catastrophizing--I picture the worst case scenario first off. For example, when the phone rings, I think, oh, no, it’s Will’s attendant telling me that Will has had a terrible seizure or been in a wreck (both things have happened). But usually it’s Will’s attendant saying, “We’re running a little late today, be home at 6.”

If I wait to be terrified until I get the facts, I can usually avoid those moments of stomach-churning fear! When I feel myself going down that road of expecting the worst, I stop and retell the story to myself in a less anxiety-producing way.

I like to replace a picture of the worst with an image of the best. For example, when my head is full of negatives, I try to picture a trip to a beautiful place or an image of Will laughing so hard he can’t stand up or dancing energetically to the beat of the music.

Another help is living in the present moment. I try to focus on the now, which is usually okay, instead of

the past, full of uh-oh’s and should-of’s, or the future, full of uh-oh’s and what-if’s. I turn to the five senses: what am I hearing right now—a bird call? Seeing a tree starting to turn a fall color? Tasting a bit of dark chocolate? Smelling the new bar of eucalyptus soap? Touching a soft pillow with my head? These thoughts bring me back from worry to something tangible and positive, in the present moment.

In other words, be aware of what you’re doing to yourself with your thoughts and feelings. They can be redirected to a source of comfort or reassurance. And be grateful for what does work, what you do have, the positives in your life, that smile, hug, or faith. Take care of your head!



Advocacy Opportunities

By Linda Litzinger, TxP2P Staff

Things Would be Better if...

As parents, can you think of a change that would make life better for your child and your family? Maybe about education, waiting lists, current services or _____? Starting today through a year from now is the perfect time to visit your Legislator or State Agency representative to ask for this change, in the form of state funding or a new bill. Amy and I can help you make that appointment, attend with you (in person or by cell), to turn your great idea into legislation. Please either text, call or email me at 512-922-3810 or Linda.Litzinger@txp2p.org.

SAVE THE DATE!!! November 21st during the School Day

Mock hearing in the Texas Capitol, plus visiting our Legislators! To attend, please contact me, at Linda.Litzinger@txp2p.org or 512-922-3810.

The WACOs—17 Years and Counting!

By Linda Jones, TxP2P Texas network Connections Program

Will Alexander's network – the WACOs – is the first and oldest personal network for a person with a disability in Texas. I decided to talk with Rosemary Alexander, Will's mother, about how this network got started and to share some highlights of the network's history.

Back in the early 2000's, Rosemary discovered the book [A Good Life](#) by Al Etmanski, which describes the five essential components of a good life for a person, plus how to achieve it. According to the author, a good life includes relationships, a living situation of one's choosing, the means of contributing to society, financial security and freedom of choice. The first step to achieving these goals is to establish a personal network with the person with a disability at the center.

Texas Parent to Parent arranged for Rosemary to participate in training on personal networks at the Planned Lifetime Advocacy Network (PLAN) in Canada, which Al Etmanski helped to establish. (See plan.ca) Rosemary came back fired up to develop a personal network for her son Will, who was 20 years old at the time and just graduating from public school -- the time when many people with disabilities are at risk of becoming

isolated.

Rosemary had already formed a group to assist in person-centered planning for Will after graduation. At first, the group was comprised of family members and old friends who served as a support network for Rosemary and family. After participating in PLAN's training, it seemed natural to transition this group into an ongoing network for Will and to add some people closer to his age.

So the first personal network in Texas was born and christened "The WACOs." Seventeen years later and the group is still meeting –at least twice a year. A typical network meeting includes a fellowship hour with food and wine, then time for status reports and a discussion of Will's life.

Rosemary reflected on some of the milestones that have happened over the years and how the network has helped. Members have come and gone – a close family member unexpectedly died, another moved back to Austin and joined the network. Rosemary experienced a temporary but debilitating illness. Will broke his leg. Through these many changes, network members provided moral support as well as food and assistance.

One thing that having a network

inspired Rosemary to do was write down everything she could think of about Will. She wrote about his likes, dislikes, medications, activities, doctors and therapists, services and financial assistance, down to his shoe size. She put this information in a notebook, tabbed for easy reference, and gave it to the network members. She was also inspired to develop an annual calendar, which includes important dates such as annual physical exams, income reporting deadlines and the application due date for Will's attendance at Camp CAMP (www.campcamp.org).

In summary, Rosemary sees the network as an essential part of Will's system of care – a rich and caring community that not only enriches Will's present, but also ensures his future – no matter what. (A Good Life is available at <https://planinstitute.ca/learning-centre/publications/>)



Book Review: Peace Begins with Me by Ted Kuntz

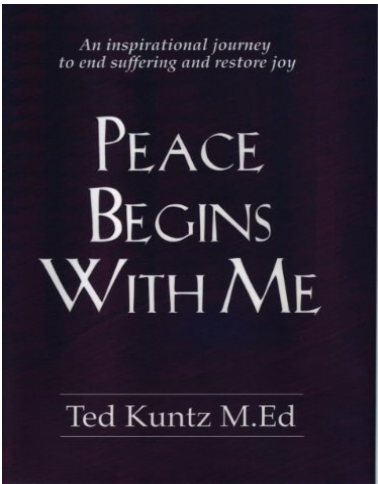
By Rosemary Alexander, TxP2P Staff

Some years ago, I attended a 5-day workshop in Vancouver hosted by PLAN, a Canadian parent organization. One of the speakers was Ted Kuntz, who talked about his book, *Peace Begins with Me*. That talk started my journey to take control of my feelings whenever possible! “Peace begins with me” became my mantra.

Ted is a therapist whose son has significant disabilities and the book follows his research into how to change the constant feelings of despair about his son to the feelings of joy and peace. That’s a tall order, but he read widely about many different cultures and talked to a wide variety of people.

In the end, he provides us with a guide for changing our thinking so that we can “end suffering and restore joy” in our lives. He

explores what he was doing to feed his negative outlook, such as



imagining the worst, resisting reality and delaying happiness. Then he proposes ways to feed his positive self, like living in the present, choosing what does the most good, accepting reality and trusting.

My favorite positive technique is “Schedule worry time”, which he says “is the simplest and yet most

powerful of the tools in my toolbox.” The first step is “to decide how long you wish to worry each day,” admitting that you will be worrying. He thinks 10-15 minutes per day is enough!

Pick a 10-15 minute block of time and during the rest of the day, when you notice that you are worrying, “gently remind yourself of your worry time and place,” and defer those worries to that appointed time. Do your worrying only during that time. “When you give your mind specific instructions and honor those instructions by being true to your word (sitting down in your worry chair at the appointed time), your mind will respond beautifully.” I hope you’ll find this book as helpful as I did!

This book is available at <https://planinstitute.ca/learning-centre/publications/>

Resorce Alert!

We have many articles from past newsletters on our website. Go to www.txp2p.org then click on Resources and you’ll see Recent Articles.

Recent articles cover 8 topics:

1. Advocacy and self-care.
2. Family Stories of their Journeys.
3. Transition Issues.
4. Medical issues.
5. Education and ECI.
6. Specific Disabilities and Mental Health.
7. Emergency Preparedness.
8. Resources.

There is also a newsletter archive, which contains newsletters from 2002 to 2019, 4 per year in most years! Please look at some of our past newsletters articles for more information and parent stories.

Great Special Education Websites

Compiled by Rosemary Alexander

NavigateLifeTexas, a great resource for any and all issues facing families of children with special needs in Texas:

<https://www.navigatelifetexas.org/en/education-schools/special-education-101>

<https://www.navigatelifetexas.org/en/education-schools/ard-process>

<https://www.navigatelifetexas.org/en/education-schools/faq>

Got questions about Special Education? SPEDTex the Special Education Information Center for Texas, can help: <https://www.spedtex.org/>

Here's a project of the Texas Education Agency committed to providing accurate and consistent information to parents and families of students with disabilities, created by parents, for parents: <http://texasprojectfirst.org/>

Partners Resource Network is a non-profit that operates the federally funded Texas Parent Training and Information Centers for Texas (PATH, PEN and TEAM): <http://prntexas.org/>

Wright's Law was created by a couple (lawyer and counselor) who wanted to help people learn about advocacy and special ed law: <https://www.wrightslaw.com/>

Upcoming conferences & this newsletter:

- TxP2P East Parent Conference, February 8th, 2020 - more information coming soon!
- **Are you getting this newsletter by U.S. mail** but you are ready to get it by email instead? Then please contact Norma at norma.castro@txp2p.org and ask her to make the change. Save a tree!

Thank you to our Statewide Conference Sponsors!!

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Texas Parent to Parent
1805 Rutherford Ln., Suite 201
Austin, TX 78754

Toll Free: 866-896-6001
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Conference Schedule

Date	Conference Title	Location	Registration Information
February 8th, 2020	TxP2P East Texas Conference	Tyler ISD Career & Technology Center, Tyler, TX	Registration will open in November 2019 www.txp2p.org
February 26-28, 2020	Texas Transition Conference	Wyndham San Antonio Riverwalk San Antonio, TX	https://tamucehd.qualtrics.com/jfe/form/SV_087ZNkFJhtpbrtb
July 10 & 11, 2019	TXP2P 16th Statewide Parent Conference	Austin, TX	Registration will open in March 2020 www.txp2p.org