

LIVING WITH PBA—MY NON-MEDICAL PERSPECTIVE

BY JENNY LYNN, WHO HAS PBA

(WITH INPUT BY ANGI SCHOLTEN, WHO ALSO HAS PBA, & THE WEBSITE,
[HTTP://WWW.PBATRIAL.COM/ABOUT_PBA.PHP](http://www.pbatrial.com/about_pba.php))

I HAVE LEARNED THAT IT'S GOOD FOR OTHERS 2 HAVE EVERY LITTLE PIECE OF INFO THAT THEY CAN GET ABOUT PBA. IT HELPS THEM GET A LITTLE CLOSER 2 GRASPING THIS THING THEY SEE HAPPENING TO ME THAT THEY DON'T KNOW HOW TO DEAL WITH. PEOPLE MAY KNOW ME & CARE ABOUT ME, BUT HURT BECAUSE THEY R HELPLESS TO HELP.

DOCTORS SAY PBA GETS BETTER W/TIME. I THINK IT DOES, BUT YOUR ABILITIES 2 DEAL W/IT & RECOGNIZE TRIGGERS 4 IT, ALSO INCREASE W/TIME, MAKING PBA APPEAR BETTER W/TIME! HOPEFULLY, THIS ARTICLE WILL HELP EDUCATE OTHERS ABOUT PBA:

WHAT IS PBA?

- **PSEUDOBULBAR AFFECT** IS A CONDITION CHARACTERIZED BY EPISODES OF UNCONTROLLABLE LAUGHING AND/OR CRYING THAT MAY BE INAPPROPRIATE OR UNRELATED TO THE SITUATION AT HAND. THE CONDITION IS KNOWN BY MANY OTHER TERMS, INCLUDING INVOLUNTARY EMOTIONAL EXPRESSION DISORDER, EMOTIONAL LABILITY, EMOTIONAL INCONTINENCE, EMOTIONAL DISCONTROL, EXCESSIVE EMOTIONALISM, UNCONTROLLABLE LAUGHING AND/OR CRYING, AND PATHOLOGICAL LAUGHING AND/OR CRYING.
- PSEUDOBULBAR AFFECT IS ASSOCIATED WITH NEUROLOGICAL DISORDERS.

UNDERSTANDING PBA:

- I HAVE "NORMAL" EMOTIONS. ALL OF THEM. PART OF THE TIME, THEY GET TO LOOK NORMAL, EXPRESS WHO I AM, AND WHAT I AM FEELING. PART OF THE TIME, THEY LOOK LIKE LAUGHING, OR CRYING, OR BOTH SIMULTANEOUSLY. THE BIGGER THE LAUGHING OR CRYING REACTION, THE MORE LIKELY IT IS MY BREATHING IS OUT OF CONTROL AND I CAN'T SPEAK. AND THE EXPRESSION ON MY FACE IS USUALLY SOMETHING UNCOMFORTABLE AND EXAGGERATED AND THE DIRECT OPPOSITE OF THE EMOTION I'M DISPLAYING. THESE ARE MY "FAKE" EMOTIONS. & EVERY FAKE EMOTION THAT HAPPENS RESULTS IN A STRUGGLE TO CONTROL THESE UNCONTROLLABLE EMOTIONS
- PBA IS A RESULT OF THE STROKE, BUT NOT STROKE-RELATED. IT EXPLAINS WHY I CAN'T CONTROL MY LAUGHING/CRYING, & IF I HAVE **ANY** SMALL EMOTION, IT'S AMPLIFIED. TEARS/LAUGHTER R NOT ALWAYS PROPORTIONAL 2 HOW I FEEL. 4 EX., I CAN LAUGH/CRY WHEN I FEEL NOTHING OR DO NOT LAUGH/CRY WHEN I WANT. ANOTHER EX. IS THAT IF I MENTALLY KNOW IT'S STUPID 2 REACT, I MAY STILL LAUGH/CRY. YET ANOTHER EX. IS I CAN LAUGH WHEN I WANT 2 CRY, & VICE VERSA. PBA IS A **HUGE** PART OF MY DAILY LIFE & INTERFERES W/SO MUCH, BUT I IMAGINE IT'S ALSO HARD 4 MY FAMILY BECAUSE I CAN'T EVEN EXPLAIN IF THE EMOTION IS REAL! (IMAGINE GETTING HURT, & I LAUGH!)
- THE WORDS "I UNDERSTAND" R MEANT 2 EMPATHIIZE, BUT CAN BE FRUSTRATING BECAUSE EVEN I CAN'T UNDERSTAND IT, SO HOW CAN A PERSON W/O PBA "UNDERSTAND?" IT'S HARD 2 UNDERSTAND IF YOU'VE NEVER EXPERIENCED IT!

- FOR PEOPLE EXPERIENCING LABILITY, IT IS AS IF ALL OF THEIR EMOTIONS ARE SITTING AT THE SURFACE, AND THE SLIGHTEST MENTION OF ANYTHING THAT HAS EMOTIONAL OVERTONES CAN BRING FORTH A TEARFUL RESPONSE. SO, I AM ASSUMED 2 SHOW TRUE CHILDLIKE FEELINGS. AT SOME DEGREE THAT'S TRUE. WHAT WOULD BE A CHUCKLE IS NOW FULL BLOWN LAUGHTER, THOUGH. BUT A LARGE PART OF TIME, IT'S UNTRUE SINCE SOMETIMES I DON'T LAUGH WHEN I WANT 2, OR I CRY WHEN I MEAN 2 LAUGH OR VICE VERSA. I GET FURIOUS AT MYSELF IF I LAUGH AT A COMMENT I'M UPSET AT!
- ONCE I PUT A NAME TO THIS STUFF, IT BECAME A DISEASE THAT I COULD TREAT. THE ONLY WAY TO TREAT PBA IS TO LEARN TO DEAL WITH IT. THIS IS IDENTIFYING WHAT MAKES THE LAUGHING & CRYING & THE OUT OF CONTROL FEELING & EXTREME EMOTIONS ACT UP. THIS IS DIFF. 4 EVERY1, AS NO1 HAS THE SAME THINGS EMOTIONALLY AFFECT THEM. THEN U LEARN WHAT WORKS 4 U 2 DEAL W/PBA. NOTICE I SAID "DEAL" NOT "AVOID." "AVOID" LEADS 2 SECLUSION. 4 INSTANCE, I STILL ATTEND CHURCH, THOUGH I NEVER KNOW WHAT IT HOLDS, & IT IS TOUGH EVERYTIME. BUT AFTER SEVERAL WEEKS, I LEARNED HOW 2 DEAL W/PRAYERS & HYMNS. (THAT, HOWEVER, BRINGS A WHOLE NEW PROBLEM, I WON'T GO INTO RT. NOW.) IT MAY SEEM AN EXCUSE OR "CONVIENENT 4 ME" AT TIMES, BUT I'M ADAPTING. I KNOW MY LIMITATIONS, CHALLENGED THEM, BUT DID NOT CROSS THEM.
- PBA IS A REASON 4 BEHAVIORS, NOT AN EXCUSE. BEFORE, I THOUGHT IT (PBA) WAS "ALL IN MY MIND." NOW IT HAS A DEFINITION AND DIAGNOSIS. LIKE MY DAUGHTER, JESS, & DISCOVERING SHE HAD CAH (CONGENITAL ADRENAL HYPERPLASIA): THERE WAS RELIEF IN FINDING OUT SHE HAD A DIAGNOSIS AFTER 9 MONTHS, & I DID NOT WORRY THAT CAH COULD CAUSE DEATH. WE LEARNED & ADAPTED R LIVES 4 IT. THE SAME IS TRUE W/OPA.
- YOU NEED TO ACCEPT THE PBA AS PART OF WHO YOU ARE. PBA IS NOT SOMETHING THAT TRIGGERS STRANGE EMOTIONAL REACTIONS. STRANGE AS THEY SEEM, NOW, THESE ARE YOUR EMOTIONS. YOU WON'T GET WHY YOU LAUGH WHEN YOU SHOULD CRY AND CRY WHEN YOU SHOULD LAUGH. THERE IS NO SENSE IN IT. PBA IS PRIMAL EMOTION WITHOUT LOGIC. JUST EMOTIONAL RESPONSE WHEN THERE SHOULD BE A RESPONSE WITH NO GAUGE OF TYPE OF RESPONSE, OR DEGREE OF RESPONSE. YOU WON'T GET IT. IT STILL MAKES ME FURIOUS. PBA MAY NOT FIT A PERSON'S MOOD
- I HAVE HEARD THAT SOME PEOPLE'S EMOTIONS FOLLOW THE NATURAL BODY BIORHYTHM [27-28 DAY CYCLE]
- PEOPLE WHO HAVE LABILE EMOTIONS CRY OR LAUGH IN RESPONSE TO EVENTS OR PHRASES THAT OTHERS MIGHT FIND ONLY MILDLY AROUSING. A PERSON W/PBA CAN'T CHUCKLE OR GAVE A SMALL, QUIET CRY. THE EMOTIONAL RESPONSE SEEMS DRASTIC INSTEAD.
- LABILE EMOTIONAL RESPONSES ARE USUALLY EMBARRASSING TO THE PERSON AND UPSETTING TO THE FAMILY MEMBERS. THEREFORE, I OFTEN CRY OF EMBARRASSMENT, AFTER A BIG, HOWLING CRY OR NEVER-ENDING, INAPPROPRIATE LAUGHTER. I CAN BE FURIOUS, BUT LAUGHED.
- IT IS IMPORTANT TO REMEMBER THAT LABILE EMOTIONAL RESPONSES ARE A PHYSIOLOGICAL AND NOT AN EMOTIONAL RESPONSE TO A STROKE.
- THE OUTBURSTS CAN OCCUR SPONTANEOUSLY OR IN RESPONSE TO PROVOCATIVE STIMULI SUCH AS QUESTIONS OR EVENTS. IRRESPECTIVE OF ITS ORIGINS, THE SYNDROME CAN HAVE A NUMBER OF PROBLEMATIC SOCIAL CONSEQUENCES

- BEING TIRED CAN BE STIMULI ENOUGH 2 TRIGGER A CRY.
- THE EMOTIONAL AND PHYSICAL STRESS CAN BE SEVERE. YOU, YOUR FAMILY AND YOUR FRIENDS MAY EXPERIENCE MANY FEELINGS ASSOCIATED WITH GRIEVING.
- OVER-PROTECTION (WHETHER BECAUSE OF GUILT, PITY OR LOVE) WILL SLOW YOUR PHYSICAL AND EMOTIONAL ADJUSTMENT.
- STUDIES SAY PBA GETS BETTER W/TIME, BUT I ALSO THINK A LOT HAS 2 DO W/THE FACT I LEARN TECHNIQUES OVER TIME 2 ATTEMPT 2 CONTROL IT!
- EVEN IF THE EMOTION IS NOT THE ONE YOU DESIRE TO BE EXPRESSED, I KNOW TH WHEN IT HAPPENS IT IS BECAUSE YOU ARE FEELING EMOTION OF SOME KIND.

HOW IT AFFECTS ME PERSONALLY:

- DURING MY STAY IN THE HOSPITAL, I WAS NEVER TOLD **WHY I WAS CRYING** SO MUCH, LAUGHING OUT OF CONTROL, ETC. I WAS LEAD TO BELIEVE IT CAME FROM NOT COPING WELL. (MAYBE SHOWING THE LACK OF KNOWLEDGE OF MY PTS & OTS). ANYWAY, IT HELPED ME TREMONDOUSLY TO KNOW IT WAS NOT DEPRESSION. THE LABILITY HAS LESSEned WITH TIME. BUT REMAINS A PROBLEM.....
- **PBA IS VERY REAL.** WHEN I AM MADE 2 CRY LOUD, LIKE I WOULD W/PUBLIC SPEAKING, I CAN'T SIGN OR THINK CLEARLY. I DON'T THINK LIKE I AM USED 2 THINKING--WORDS R OFTEN LOST & IT'S NOT UNTIL LATER THAT I CAN SAY WHAT I THINK. MY MEMORY'S ALSO WORSE, SO I CAN'T TYPE & RECALL WHAT I WROTE. I PREFER 2 TYPE & LEAVE WHILE IT'S READ--NOT 2 "HIDE," BUT SO IT'S HEARD (SINCE I'M SO LOUD). WORDS R HARDER 2 THINK OF NOW. I'M *NOT* ELOQUIENT...NEVER WAS B4! PRESIDENT THOMAS S. MONSON, IN THE LDS (MORMON) 1ST PRESIDENCY OF THE CHURCH, SAID: "YOU CAN SHARE...IN MANY WAYS—BY THE WORDS YOU SPEAK, BY THE EXAMPLE YOU SET, BY THE MANNER IN WHICH YOU LIVE YOUR LIFE." I DO IT BY HOW I LIVE &/OR EXAMPLE.
- WHEN I SIGN AT HOME, THEY R SHORT, CONSISTING OF 2-3 SENTENCES. THEY HAVE 2 BE SHORT, CONCISE, & **VERY** GENERIC. HAS 2 BE, SO I CAN SOMEWHAT CONTROL MY PBA. BY NOT ATTACHING EMOTIONS.
- I THINK IN PICS (VISUALIZE)--I THINK THAT MAKES MY PBA WORSE!
- I TRY NOT TO CRY OR LAUGH IN CHURCH BECAUSE THEN IT IS UNCONTROLLABLE. SOMETIMES, I FEEL LIKE I WANT TO LAUGH OR CRY BUT THAT IT DOESN'T SIMPLY HAPPEN, IT JUST KEEPS GOING, OR SOMETIMES, I DON'T WANT TO LAUGH OR CRY AT THAT MOMENT BUT THEN I DO. U KNOW HOW U CAN QUIETLY CHUCKLE AT STUFF? I CAN'T. ANY EMOTION I FEEL IS UNCONTROLLED LAUGHTER OR CRYING, SO I CAN LOOK UPSET & BE FINE! YET, I HAVE SEEN FUNNY MOVIES & CAN'T LAUGH. BUT THINGS I DON'T FIND FUNNY-SAY SOME1 HURT, OR FORCING A LOUD, RUDE BURP -I LAUGH--GO FIGURE!
- I HAVE A SUPER HARD TIME W/HOSPITAL SCENES AT MOVIES, & THEN THEY ADD MUSIC! ALTHOUGH MUSIC IS ALSO SOMETIMES A TRIGGER, MOVIES HAVE SOUNDTRACKS. I KEEP TELLING MYSELF HOW STUPID I AM-IT'S JUST A MOVIE! IF I ALMOST CRY, I HOLD IN TEARS, THEN I CRY WHEN THE MOVIE IS OVER. IT MUST BE MY RELEASE, SINCE HOLDING IN THOSE EMOTIONS MAKES ME "EXPLODE" LATER OVER STUPID STUFF.

- IT SEEMS AS THOUGH HUMOR IS A HUGE PART OF GETTING THROUGH ALL THIS STUFF. SO MAYBE PATHOLOGICAL LAUGHING ISN'T SUCH A BAD THING TO HAVE. IT MAKES US LAUGH WHEN WE DON'T HAVE ANYTHING TO LAUGH AT. DON'T YOU FIND IT HARD TO STAY ANGRY ABOUT SOMETHING WHEN YOU GET MAD AND IT MAKES YOU LAUGH?
- PBA IS GOOD & BAD. GOOD BECAUSE SOMETIMES I NEED 2 LAUGH, OR I'D CRY. VERY BAD WHEN U CAN'T TALK 2 EXPLAIN YOURSELF--I AM OFTEN VERY MISUNDERSTOOD. I HATE IT WHEN I'M TOLD, "THAT'S NOT FUNNY." & I'M THINKING, "I **KNOW!**" BUT I'M HYSTERICALLY LAUGHING! I GET SOOO MAD!
- **IT REALLY ADDS TO NOT KNOWING WHO YOU ARE.** YOU REACT IN A WAY THAT IS SO FOREIGN TO YOU. LIKE WHEN I AM PART OF A CONVERSATION WITH A TOPIC OR A JOKE THAT I DON'T THINK IS FUNNY BECAUSE OF THE SUBJECT OR THE CRUDENESS OF THE JOKE, AND I LAUGH ANYWAY, BECAUSE I LAUGH AT EVERYTHING. ADD NO SPEECH 2 THAT, & U HAVE ME! I AM HORRIFIED & CAN'T DEFEND. PEOPLE THINK I REACT-SOMETIMES I DO & SOMETIMES I DON'T, BUT APPEAR IT. THAT'S HARD 2 EXPLAIN! EVEN WHO REALLY KNOW ME, CAN'T TELL. IT'S VERY FRUSTRATING 4 US BOTH.
- **IT'S HUMILIATING**--NOT JUST 2 ME, BUT MY KIDS OFTEN SAY, "OH NO...SHE'S GOING 2 CRY" & MY CRYING IS LIKE NAILS ON A CHALKBOARD 2 SOME PEOPLE. IF I "LET IT OUT", I CAN'T HEAR. OTHERS CAN'T HEAR 2, WHICH DESTROYS WHY THEY R THERE. I CAN'T STOP-SO I'M ALWAYS GAURDED. SOMETIMES I FEEL NOTHING & LAUGH/CRY-& SINCE I CAN'T TALK-DOUBLE WHAMMY-I'M VERY OFTEN MISUNDERSTOOD.
- **SOME LOVE THE LAUGHING SIDE.** I CAN HANDLE IT 2, BUT THE CRYING SIDE IS HORRIBLE, ESP. SINCE I CAN'T TALK. IT CAUSS MISUNDERSTANDINGS A LOT. THE LAUGHING MISUNDERSTANDINGS I USUALLY DON'T CLEAR UP. PEOPLE CAN THINK WHAT THEY WANT!
- SINCE I UNDERSTAND LITTLE POLITICAL TALK, IT HELPS MY PBA WHEN I HEAR IT.
- 4 SOME REASON, I CRY WHEN I MEET PEOPLE...I THINK BECAUSE I HATE 2 BE SEEN AS DISABLED & HATE THE SYMPATHTIC LOOKS (OR GAWKING IF I WASN'T APPROACHED) THAT R SURE 2 FOLLOW.
- I'VE LEARNED MANY TRICKS 2 STOP MY TEARS, WHEN I'M SIGNALLED A WARNING SIGN THAT TEARS R COMING, BUT I HAVE 2 BE VERY CAUTIOUS & NOT ALLOW ME 2 BE EMOTIONAL, RT. B4 I GO SOMEWHERE EMOTIONAL, LIKE, SAY, CHURCH...OTHERWISE, MY EMOTIONS WILL BE OUT OF WHACK, & LAUGHTER/TEARS THAT I NORMALLY COULD CONTROL, I CAN'T CONTROL, AS WELL.
- I HAVE DISCOVERED THAT I LAUGH HARDER AT TIMES BECAUSE I HEAR SOME1 EXPRESS PRECISELY WHAT I'D THOUGHT, BUT WASN'T GOING 2 BOTHER 2 FINGERSPELL IT. (SOMETIMES, THOUGH, IT ISN'T SAID, SO I LAUGH 2 MYSELF, AS I "THINK SOMETHING FUNNY IN MY HEAD.")

HOW IT AFFECTS MY FAMILY:

- **FOR MANY PATIENTS AND FAMILIES DEALING WITH PSEUDOBLBAR AFFECT, THE DISORDER'S SYMPTOMS CAN BE STRESSFUL AND EMBARRASSING ENOUGH TO CAUSE WITHDRAWAL** FROM SOCIAL SITUATIONS. PSEUDOBLBAR AFFECT IS NOT PHYSICALLY HARMFUL AND SUICIDE IS UNCOMMON, BUT THE ASSOCIATED STRESS CAN IMPACT THE HEALTH OF BOTH PATIENTS AND

CAREGIVERS. ESTABLISHING OPEN, HONEST COMMUNICATIONS AMONG FAMILY MEMBERS AND WITH YOUR MEDICAL PROVIDERS SHOULD PROVE TO BE HELPFUL AND REWARDING.

- **HOW DOES YOUR FAMILY KNOW WHEN A DISPLAYED EMOTION IS REALLY WHAT YOU FEEL OR IF IT IS JUST HAPPENING?** THEY DON'T, UNLESS I SAY SO. IT'S VERY STRESSFUL, & I'M VERY MISLEADING. FOR EXAMPLE, WHEN MY DAUGHTER'S (FIA'S) CHURCH TEACHER BORE HER TESTIMONY AT CHURCH, FIA WAS ON MY LAP WAVING AT HER PRIMARY TEACHER. I LAUGHED BECAUSE SHE WAS SO CUTE & I WAS GLAD FIA LOVED HER TEACHER. I WAS PROUD. BUT FIA CRIED & GOT OFF MY LAP CRYING, CONVINCED MOMMY WAS LAUGHING AT HER. I WAS, BUT NOT HURTFULLY. IN THE END, WE WERE BOTH HURT, BECAUSE I COULDN'T EXPLAIN & MY REACTION WAS MISUNDERSTOOD.

TRIGGERS:

- UNFORTUNATELY, PBA CAN BE WORSENERED BY PEOPLE TRYING 2 COMFORT ME WITH A KIND WORD OR ACTION (WHICH IS THE NATURAL RESPONSE, ESP. W/WOMEN). IN FACT, **ANY** EMOTIONAL RESPONSE TO A TV SHOW OR A PERSON OR AN OVERWHEMING PHYSICAL RESPONSE OR EVEN OUR OWN THOUGHTS CAN AND DOES PRECIPATE THE LABILITY ATTACK.
AN EX.: I RECALL MY 1ST DAY AT CHURCH IN TX. I WAS OVERWHELMED BY MEETING PEOPLE, & TRIED NOT 2 CRY (I WASN'T SAD). BUT I DID CRY! GRANTED THE CRYING DOES NOT NEED TO HAVE DEEP SADNESS AS TRIGGER BUT **ANY EMOTION IS THE TRIGGER** TO THE LABILITY ATTACK
- PBA & CRYING/LAUGHING NATURALLY BE IN THE CENTER OF ATTENTION, & THEN U CRY/LAUGH MORE, FROM BEING THE CENTER OF ATTENTION
- **AUDIO & VISUAL STIMULUS:** I HAVE A CARDINAL RULE 2 NOT WATCH SLIDESHOWS/VIDEOS. THE VISUAL STIMULUS IN ADDITION TO HEARING A SONG, IS 2 MUCH 4 MY PBA. MUSIC IS ALREADY A HUGE TRIGGER, & CHANCES R, I CAN'T C ANYWAY, & IF I TRY 2 C, THE MERE FRUSTRATION TRIGGERS MY PBA!
- I'D BE STARED AT LIKE A CIRCUS CLOWN (MID-ELEMENTARY AGED KIDS ARE THE WORST, & I USED 2 TEACH, SO, I'D PROB. CRY, WHICH ONLY BRINGS MORE STARES!)
- I REALIZED THAT I CAN'T EVEN LOOK AT MARK, OR MY PBA IS TRIGGERED, WHEN **I** KNOW THAT **HE** KNOWS IT'S HARD. KNOWING HE IS AWARE OF MY BATTLE, OR ANY SMALL ACT OF KINDNESS, CAN SET ME OFF, BECAUSE I'M TRYING 2 DISTRACT MYSELF, & I'M BROUGHT BACK 2 REALITY. & EVEN THOUGH MK DOESN'T HAVE ALL MY MEMORIES, HE KNOWS OF EXPERIENCES & DESIRES.

ANOTHER EX. OF THIS: I WAS DOING SOMETHING WHERE I ALLOWED MY EMOTIONS 2 BE DANGEROUSLY CLOSE. WHEN MY 1-YR. OLD NEICE WAS KINDLY SET ON MY LAP, IT WAS UNEXPECTED, SO I WAS DISTRACTED FROM DISTRACTING MYSELF, & BROUGHT BACK 2 REALITY. I WAS ALREADY FIGHTING PBA, UN-BEKNOWN 2 ANY1, SO I BURST INTO TEARS...

- LONGER GOODBYES R HARD ON ME. GREETINGS CAN BE AS HARD AS GOODBYES W/PBA.
- BEING IN PUBLIC SPACES AND OVERHEARING OTHER PEOPLE. I DON'T THINK MANY PEOPLE REALIZE HOW MUCH STRANGE, OBNOXIOUS, OR PRIVATE

THINGS THEY OVERHEAR AND IGNORE AUTOMATICALLY. I KNOW I AM ONLY AWARE OF IT NOW THAT I CAN'T PRETEND THAT I DON'T HEAR AND MIND MY OWN BUSINESS.

- MY LACK OF LIFE DESIGNED TO AVOID CIRCUMSTANCES AND SUBJECTS THAT WILL "TRIGGER" THIS ORGANIC, PATHOLOGICAL CONDITION. THIS UNCONTROLLED EMOTIONAL EXPRESSION THAT IS A DIRECT RESULT OF THE STROKE AND IS NOT "JUST IN MY HEAD".

JENNY'S PERSONAL TRIGGERS--TRIGGERS R DIFFERENT 4 EVERY1, BUT KNOWING MINE MAY HELP RELATE 2 ME OR DISCOVER PBA RESPONSES IN SOME1 ELSE.

HERE'S MY CRY TRIGGERS:

1. I EMBARRASS MYSELF A LOT, BUT IT DOESN'T SHOW FROM BENEATH THE FAKE EMOTION.
2. HEARING MY NAME
3. MUSIC, ESP. IF I FEEL THE SPIRIT, LIKE WITH HYMNS AT CHURCH (& SOME CHURCH MUSICIS WRITTEN W/THE INTENT 2 MAKE PEOPLE CRY), OR WHENEVER FAM. SINGS. IT CAN BE A HUGE MISTAKE 2 TRULY LISTEN 2 THE LYRICS. &, AS A MUSICIAN, NO OFFENSE 2 THOSE WHO PERFORM, BUT WHEN I HEARD THEM, I CAN FIGHT MY PBA W/THOUGHTS LIKE, "THAT WAS PITCHY!"
4. SOME1 IS NICE 2 ME
5. HEARING SOME1 ELSE CRY (USUALLY THEY ARE PEOPLE I KNOW & HAVE AN EMOTIONAL CONNECTION WITH THEM SOMEHOW)
6. HEARING CERTAIN PEOPLE SPEAK (USUALLY THEY ARE PEOPLE I KNOW & HAVE AN EMOTIONAL CONNECTION WITH THEM SOMEHOW)
7. 1STS (LIKE THE 1ST TIME I WORE SUNGLASSES)
8. MEETING PEOPLE
9. IF I'M PACKED-UP W/EMOTION, I HAVE A "DELAYED CRY" I'M HOLDING IN (U'D BE SURPRISED BY THE WILLPOWER IN TELLING YOURSELF NOT 2 CRY/LAUGH, BUT IT BUILDS UNTIL A SMALL, STUPID THING--EVEN JUST A TRANSFER FROM YOUR WHEELCHAIR-- SETS U OFF.
10. I MAY CRY SIMPLY BECAUSE I SENSE I MADE SOME1 UPSET
11. FRUSTRATION
12. FEELING PROUD OF SOMETHING MY KIDS DO, I USUALLY CRY
13. MEMORIES/THOUGHTS THAT I THINK R PAINFUL (LIKE BEING IN A HOSPITAL MAY REMIND ME OF MY EXPIERENCE
14. IF CRYING IS MY TRUE FEELING, IT MAKES ME CRY HARDER.
15. PEOPLE TALKING 2 ME, WHO HAVEN'T SEEN ME, WILL MAKE ME CRY. FAMILY WILL BRING THE TEARS I CAN'T HOLD IN. I HATE BIG GOOD-BYES & HELLOS.
16. I KNOW SOME1 CAN TALK/EXPLAIN MY CONDITION BEFOREHAND IN SOME SOCIAL SITUATIONS, BUT IF PEOPLE R TALKED 2, I'M WELL AWARE & STILL HUMILIATED THAT I MAY HAVE A PBA EPISODE & THAT IT WAS DISCUSSED! I HATE IT, & IT ISN'T ANY EASIER WHEN PEOPLE KNOW (I CAN BE CONTROLLING IT, THEN BURST INTO TEARS BY LOOKING INTO SOME1'S "UNDERSTANDING" EYES).

17. HEARING MY WEDDING SONG OR ANY MEMORY OF MY WEDDING, I WILL LOUDLY CRY.
18. TAKING PICS. CAN MAKE ME CRY ANYTIME, ESP. IF A SPECIAL EXCEPTION IS MADE 4 ME (WHICH IS THE NATURE OF THE BEAST, BEING IN A WHEELCHAIR).
19. PRAYERS AT CHURCH, OR ANYTIME I FEEL THE SPIRIT. I HAVE 2 COMPLETELY BLOCK THE SPIRIT 2 NOT LOUDLY CRY OR BE TOLD 2 BE REVERANT. HENCE, I NEVER FEEL INCLINED 2 PRAY OR BEAR TESTIMONY.
20. EVEN IF I KNOW THEY'D UNDERSTAND MY TEARS, I CAN FEEL BAD BECUZ I'M SO FREAKIN' LOUD W/MY HOWLING. NOT EVEN I CAN HEAR. IT'S SOOO EMBARRASSING. & ONCE I START, I CAN'T STOP.

MY LAUGH TRIGGERS:

1. BODILY FUNCTIONS. A FART ON THE TV CAN HAVE ME GOING FOR HOURS!
2. SOMETHING THAT U MAY CHUCKLE ABOUT CAN HAVE ME DOUBLED OVER LAUGHING HYSTERICALLY.
3. NOISES WHEN IT SHOULD BE QUIET
4. WHATEVER EMBARESSES ME OR MAKES ME FEEL UNCOMFORTABLE—LIKE SPEAKING OF PRIVATE PARTS OR IF I A EMBARESSED BY CRYING LOUD
5. IF I'M PACKED-UP W/EMOTION, I HAVE A "DELAYED LAUGH" I'M HOLDING IN
6. I'D RATHER LAUGH THAN CRY, SO I CAN LAUGH IF I'M TRYING 2 STOP PBA TEARS
7. I **HATE** THIS: WHEN I HAVE WANTED 2 CRY, IF I HEAR LAUGHTER, I HAVE LAUGHED IN RESPONSE, GIVING A FALSE IMPRESSION. C-ING OR HEARING CERTAIN PEOPLE LAUGH (USUALLY THEY ARE PEOPLE I KNOW & HAVE AN EMOTIONAL CONNECTION WITH THEM SOMEHOW), DESPITE MY TRUE FEELING, MAKES ME IGNORE MY OWN FEELINGS, & RESPOND 2 THEM. SINCE I REACT 2 OTHERS, I MAY LAUGH (EVEN IF I'M MAD OR WANT 2 CRY) BECAUSE I HEAR A LAUGH. IF THEY R SMILING, U LAUGH (EVEN IF IT IS A BAD JOKE OR BEING TEASED). IT'S A BLESSING & A CURSE,
8. IF SOMETHING CAUSES ME 2 REMEMBER A MEMORY/THOUGHT (THAT I THINK IS FUNNY), CAN MAKE ME LAUGH HARDER THAN I WOULD NORMALLY LAUGH
9. WHAT IS HARD IS IF I LAUGH WHEN SOME1 GETS HURT. 4 EX. WHEN MY HUSBAND, MARK, GETS HURT, I LAUGH. THEN I FEEL BAD, & MY LAUGH BECOMES A CRY (FROM LAUGHING WHEN I SHOULD CRY)! I HAVE NO CLUE WHY I DO IT, & CAN'T CONTROL IT. I DON'T THINK IT'S FUNNY! IT'S VERY FRUSTRATING 4 HIM & ME.
10. "KIDS SAY/DO THE DARNDEST THINGS!"
11. KIDS SOMETIMES TRY TO BE FUNNY, & ARE DELIGHTED IF I LAGH!
12. SINCE I SPELL EACH WORD W/ASL, I MAY LAUGH FOR 5 MINUTES B4 I SHARE WHAT I'M LAUGHING ABOUT...& MY FRIENDS JUST SMILE, & KNOW SOMETHING FUNNY IS COMING!
13. IF THEY THINK AS I DO: THEY SAY WHAT I THINK A LOT, SO THEY KNOW WHAT I THINK IS FUNNY, WHICH CAN CAUSE ME 2 LAUGH MORE!
14. I COULD BE PART OF A CONVERSATION WHERE THINGS ARE SAID THAT I DON'T THINK ARE FUNNY. I'LL LAUGH AT THINGS THAT OFFEND ME, OR AT THINGS THAT PASS FOR HUMOR BUT THAT I FIND STUPID OR RUDE.
15. THERE ARE PEOPLE WHO ALWAYS TRY TO MAKE OTHER PEOPLE LAUGH. THESE PEOPLE MAKE ME LAUGH REAL LAUGHTER. THERE IS ALWAYS REAL LAUGHTER. I LIKE REAL LAUGHTER. YET IN THE MOMENT, MAYBE I'LL

LAUGH LONGER OR LOUDER THAN I FEEL IS WARRANTED. THESE PEOPLE WHO MAKE ME LAUGH REAL LAUGHTER WILL EVOKE LAUGHTER AT THE MERE SIGHT OF THEM.

16. IN THE MIDDLE OF EVERYDAY ACTIVITY, A RANDOM THOUGHT OF SOMETHING THAT HAPPENED LAST WEEK WILL MAKE ME START TO GIGGLE. IF THIS GIGGLE IS ACKNOWLEDGED BY SOMEONE ELSE, AS IN "WHAT'S SO FUNNY?", I WILL LAUGH EVEN MORE. THEN I HAVE TO EXPLAIN MY LAUGHTER.
17. EVERYDAY THINGS THAT HOLD NO EMOTIONAL DRAMA WILL BRING LAUGHTER OR TEARS. DOING SOMETHING OF DIFFICULTY OR EXERTION WILL BRING NERVOUS LAUGHTER. OR NOT. NOT BEING ABLE TO PREDICT YOURSELF IS CONFUSING.

WAYS I HANDLE IT:

- STATE OF MIND...IT'S HARD 2 BE DEPRESSED & LAUGH!
- RUN THROUGH THE SITUATION, & GET THE TEARS OUT! IT HELPS IMMENSELY IF A PBA REACTION IS ANTICIPATED B4-HAND & TREATED ACCORDINALLY 2 PREP ME. 4 EX.: WATCHING THE DRESS REHEARSAL OF A SHOW/PERFORMANCE WHERE I SUSPECT I MAY BE EMOTIONAL OR WATCHING A SLIDESHOW B4HAND, SO I CAN ANTICIPATE THE MUSIC, & MY REACTION. IT HELPS ME 2 DEVELOP A "NUMBNESS" OF MY INITIAL REACTION. THIS OFTEN HELPS PREPARE MY MINDSET, AS WELL, SO IT IS EASIER 2 COPE...OTHERWISE, I'M AWARE OF THE FUTURE BATTLE & AM LIKE A COW GOING 2 IT'S SLAUGHTER!
- RELAXING & SLOWING DOWN MY RESPIRATORY PATTERN AND STOMACH MUSCLES: I C MY BELLY BREATHING FAST BEFORE I CRY SOMETIMES, SO I SLOW DOWN MY BREATHING, AS I LEARNED IN MUSIC THERAPY (BREATH FOR EVERY MEASURE-2 BEATS, THEN 4).
- I LOOK AWAY, DOWN, OR CLOSE MY EYES , IF I CAN'T LEAVE THE ROOM. IT HELPS 2 CHANGE THE ROOM/SITUATION. POOR MARK GOES BONKERS, BECAUSE I CAN DROOL, BUT IT'S THE LESSER OF 2 EVILS!
- FOCUS ON SOMETHING ELSE...4 EX., DISTRACTION BY LOOKING AT THE SPEED CONTROL ON MY WHEELCHAIR (WEIRD)
- I HAVE A SONG I SING 2 MYSELF THAT SEEMS 2 MAGICALLY CALM ME DOWN!
- I DISTANCE MYSELF SO IT IS LESS PERSONAL.
- I USE DISTRACTION (CHANGING THE TOPIC, THE SCENERY, CHANGE MY THOUGHTS, EVEN SOMETIMES JUST CLOSING MY EYES)!
- I TEND 2 DEAL W/MY CRYING EPISODES BY LAUGHTER. BUT ONCE I START LAUGHING, IT IS HARD 2 STOP, & I MAY CRY FROM THE EMBARRASSMENT OF LAUGHING! HOWEVER, LAUGHING IS WAY MORE ACCEPTED, & CAN CURB THE CRYING, SO IT IS A RISK I'M WILLING 2 TAKE.
- COME EARLY SO I DON'T MAKE A "GRAND ENTRANCE"
- DON'T LOOK AT VIDEOS/SLIDESHOWS (MUSIC IS A **HUGE** TRIGGER)
- DO NOT THINK OF STUFF SENT/SAID 2 ME.
- LET MY MIND WANDER, IF I FEEL AN EPISODE COMING
- HOW DETERMINED I AM **NOT** 2 CRY CAN MAKE ME TRY HARDER.

- GREETINGS/GOODBYES: I JUST AVOID THEM OR, IF I DO THEM, I DISTANCE MYSELF 2 AVOID CRYING. USUALLY I DISTRACT MY THOUGHTS OR CLOSE MY EYES. I ALSO LOOK DOWN OR AVERT MY EYES.
- REST WELL. MY PBA IS WORSE IF I'M TIRED, BECUZ IT CAN BE PHYSICALLY EXHAUSTING FIGHTING MY PBA .EACH STRUGGLE TAKES ENERGY. WHEN I HAVE LESS ENERGY, I HAVE LESS CONTROL. LESS CONTROL LEADS TO MORE FAKE EMOTIONS, MORE TRYING TO REGAIN CONTROL, AND A GREATER EXPENDITURE OF ENERGY. A VICIOUS CIRCLE.
- MINDLESS ACTIVITIES TO HEAR THINGS, YET I'M DISTRACTED ON ACCOMPLISHING ANOTHER TASK
- DISTANCE MYSELF FROM THE SPIRIT ...HOWEVER, IF I CAN USE THE INTERNET: I AM ALONE, SO I LET MYSELF FEEL THE SPIRIT, NOT WORRYING I'D CRY 2 LOUD. I FELT MYSELF COME CLOSE 2 TEARS, BUT WHEN I DID, I COULD DISTRACT MYSELF & STILL HEAR IT!
- IF I FEEL ANXIETY ABOUT A SITUATION, SOMETIMES I "LET IT OUT" & GET IT OUT OF MY SYSTEM BEFORE-HAND, OR WHEN I'M ALONE
- I PREFER 2 NOT BE IN PUBLIC, "ON DISPLAY."
- IF SOMEONE I HAVE AN EMOTIONAL CONNECTION TO IS GOING 2 BE SPEAKING OR SINGING PUBLICLY, I "PREP" BY LOOKING DOWN.
- IF I NEED 2 SAY ANYTHING SPIRITUAL OR EMOTIONAL, IGARY EMOION,& F AN I "HIDE BEHIND MY KEYBOARD," & TYPE IT THERE., SO I GET OUT THE "RAW EMOTION " THEN, I CAN USE SIGN LANGUAGE 2 "SAY" IT, BUT I PREFER 2 E-MAIL OR PRINT IT OUT.
- DON'T ALLOW MY EMOTIONS 2 BE DANGEROUSLY CLOSE, ORTHE SLIGHTEST THING CAN SET ME OFF.
- A QUICK ESCAPE. DON'T SIT ALONE IN A ROOM W/CLOSED DOORS--I'D RATHER BE ISOLATED, WHERE I CAN CRY & NOT FEEL LIKE I'M "IN JAIL" & CAN'T LEAVE
- I TRY REALLY HARD TO CRY QUIETLY. I AM AFRAID THAT PEOPLE ARE GOING TO FEEL UNCOMFORTABLE AROUND ME. IN ORDER 2 FIGHT, SOMETIMES I DON'T LET THINGS EMOTIONALLY TOUCH ME!

WAYS I HANDLE SPIRITUAL THINGS:

- AT CHURCH, I DISTANCE MYSELF: I HEAR STUFF, BUT IT'S DISTANT. I SEE A LITTLE, & HEAR STUFF IN A DISTANCE. I DON'T TAKE THINGS PERSONALLY. I AM NOT ABLE 2 LET MY EMOTIONS BE TOUCHED. JUST THE FACT I'M THERE, STUFF SEEPS IN--SO I GO. BUT WHEN U CAN'T PRACTICE YOUR FAITH, IT WEAKENS. I CAN'T PRAY OR SHARE MY TESTIMONY OR EVEN COMMENT IN A LESSON, OR I CRY 2 HARD. RT. NOW IT SEEMS I CONFORM 2 SOCIAL GRACES & APPEAR "REVERANT"
- IN CHURCH (U'LL UNDERSTAND IF U R LDS), MARK HAS OFFERED 2 TRANSLATE MY ASL IF I WANT 2 BEAR MY TESTIMONY, BUT PEOPLE WHO DO IT, DO IT BECAUSE THE SPIRIT SAYS 2 DO IT & GUIDES WHAT 2 SAY. I HAVE 2 PUT UP A WALL, BECAUSE OF PBA, SO I DON'T GET THAT DESIRE OR GUIDANCE. USUALLY, IF I ALLOW THE SPIRIT 2 BE THERE, I CRY & HOWL LIKE NO1 IMAGINES (I CALL IT MY "PBA-FEST"), SO OTHERS MAY NOT HEAR, & THE PRIDE I

HAVE IS DAMAGED THROUGH EMBARRASSMENT (I RARELY ALLOW IT BECAUSE I HATE 2 BE SUCH A SPECTACLE)!

- I MAY NOT RECOGNIZE THAT I WAS SPIRITUALLY TOUCHED BY SOMETHING UNTIL PBA MAKES ME REACT. BUT THEN I NEED 2 FIGURE OUT IF MY REACTION WAS REAL OR NOT!

HOW PEOPLE CAN HELP:

- IF U FEEL LIKE A JERK, U ARE PROBABLY DEALING CORRECTLY W/PBA!
- IF I'M FIGHTING AN EPISODE, DON'T TALK 2 ME-I WOULD BREAK CONCENTRATION & CRY
- EVEN THOUGH U MEAN WELL, UNLESS U HAVE PBA, DON'T TRY 2 ACT LIKE U UNDERSTAND MY PBA & EXPRESSING EMPATHY, BECUZ U CRY A LOT. IT ACTUALLY CAN BELITTLE MY BIGGEST, DAILY BATTLE. NO 1 ELSE GETS CHOKED UP WHEN THEY DO NORMAL THINGS OR 4 NO REASON!
- IGNORE. UNFORTUNATELY, PEOPLE'S INNATE TENDENCY 2 CONSOLE, CAN MAKE IT WORSE!. IT'S JUST IN THEIR NATURE TO TRY AND CONSOLE WHEN SOMEONE IS CRYING. IF I SEEM TO BE UPSET, TRY TO ASK YOU ONE TIME IF I'M OKAY - IF I SAY YES, THEN I TRY TO IGNORE ME, BUT WATCH MY HAND CAREFULLY IN CASE I SIGN! :) THEN WHEN IT SEEMS LIKE I'M BACK IN CONTROL, DOUBLE CHECK IF I NEED SOMETHING - BUT VERY UNEMOTIONALLY SO IT DOESN'T SET ME OFF AGAIN.
- EDUCATE OTHERS. GIVE IS A MINIMAL EXPLANATION –LIKE, “THEY NOT RETARDED, & THEY CAN'T CONTROL WHEN THEY LAUGH/CRY.” IT HELPS.
- GETTING ME OUT OF A ROOM, OR KEEPING ME OUT OF A ROOM, WILL HELP
- IF U R NOT SURE, ASK. ASKING IF THE EMOTION EXPRESSED REFLECTS MY TRUE FEELINGS --SOMETIMES THE EMOTION DISPLAYED SEEMS INAPPROPRIATE. IT MAY BE UNRELATED TO WHAT IS HAPPENING AROUND YOU.
- AFTER THE INDIVIDUAL IS COMFORTABLE AGAIN, YOU CAN RETURN TO THE TOPIC AT HAND.
- PBA/CHURCH: BEING TOLD 2 BE “REVERANT,” WHEN THEY R ALREADY AWARE THEY R NOT, SO TELLING THEM MAY COMPOUND THE PROBLEM. BEST 2 NOT SAY ANYTHING. IN FACT, THE LDS PRIMARY SINGS ABOUT REVERANCE BEING “MORE THAN JUST QUIETLY SITTING...IT'S LOVE.”
- WHEN U LEAVE, BE "MATTER OF FACT" & NO BIG DEAL. LONGER GOODBYES R HARD

THERE IS LIFE W/PBA, IF THE RT. PRECAUTIONS R MADE. **IT IS POSSIBLE 2 CONQUER BY DEALING W/PBA, NOT 2 BECOME SECLUDED.**

TAKING THE DRUG NEUDEXTA:

(PREVIOUSLY, PBA WAS TREATED WITH ANTI-DEPRESSANTS, WHICH DID NOTHING FOR ME)

- I HAVE A MORE CAREFREE, RELAXED MOOD
- I AM MORE POSITIVE, LESS DEPRESSED, & LESS ANXIOUS
- MY BRAIN SEEMS “UNSCRAMBLED,” & LESS “CLOUDY”

- I STILL HAVE LAUGHING & CRYING EPISODES, BUT THEY ARE SHORTER & MUCH LESS FREQUENT!
- I HAVE ACTUALLY CONTROLLED A FEW EPISODES, & FELT THEM STARTING, BUT WAS ABLE TO STOP THEM!
- I CAN ACTUALLY FEEL ANYTHING SPIRITUAL OR EMOTIONAL NOW!
- I HAVE BEEN ABLE TO FEEL THE SPIRIT MORE.
- I HAVE SEEN AN INCREASE IN MY SPEECH ABILITIES
- I CAN MOVE QUICKER & SEEM STRONGER