

"Guilt"

by Mary-Louise Bertram, patron of The Angelman Network

Parent guilt may or may not be something you struggle with. If it is, then this is for you.

Many messages have hit my inbox in the last few months whilst I've been off. The overwhelming feeling in each message is guilt. Guilt that 'I didn't know all this stuff', that 'as a parent I should have done this sooner', guilt that 'I should have pushed for earlier', 'I shouldn't have trusted the SLP', and guilt that 'I'm not doing enough'. Here's my thinking....

A) "I should have known all this stuff"

You shouldn't have. Your child didn't come with a manual. Tell yourself it's absolutely perfectly AOK that you didn't know about PODD or AAC or Proloquo or Aided Language Input. You'd actually be kind of weird (or a therapist or a random googler) if you did know about this stuff before you landed in The Land of Complex Communication Needs.

Repeat after me: We do the best we can with what we know.

B) "I should have done this sooner"

Trust in the timing. For many families the focus is on day to day survival for a while. That's life and it's ok. If you are ready now then we are here for you. If you don't feel ready yet then just stalk us. But remember you may never feel 'ready' and if we wait for the 'perfect time' it may never happen. Sometimes we just have to take the leap of faith and start. But it's also perfectly AOK to tell yourself "life is a bucket of poo right now and I am juggling a bazillion plates in the air and if I add anything new then we are going to have a bazillion smashed plates in a bucket of poo and I can't handle that". Take a deep breath. Think about it again tomorrow.

C) "I shouldn't have trusted the SLP"

You should have. You have landed in this new place and the expert guide, your SLP, was meant to guide you well. You were right to expect to be shown the best way forward and you were right to trust him or her. If the SLP didn't guide you well then that's not your fault. Shake that guilt off. Something must have happened in your mind, in your gut instincts, in your experience to make you think 'there must be a better/other way'. You trusted YOUR gut. You trusted YOURSELF. Woot! No guilt to be had over that. You explored other options. You landed here.

D) 'I have so much to do/catch up on/learn'

It is a steep learning curve but you do not need to know, nor are you expected to know, absolutely everything about AAC and ALgS by the end on this weekend. Baby steps, girlfriend, baby steps.

E) 'I'm too late, I missed the window'

The window never closes fully. Sometimes it gets a bit jammed and we have to recruit a team to try to coax it to open wider but it never closes super mega tightly shut. A bit of elbow grease and a glass of wine helps too. Bottom line is that the day your child was born you got injected with a dose of Grade A Parent Guilt. Know that the communication and literacy journey you and your child are on will have hills, valleys, ebbs, flows, forks in the road, potholes, beauty, laughter, and tears. We're here for you. Please also remember that this AAC, Literacy, and Angelman is still in its infancy. There is so much we are learning. We all have guilt about not doing enough, not being enough. Sometimes we just have to squash that guilt down into our left gumboot and just keep hobbling on. Little and often. Model, model, model. Ask questions, try different things, and reach out when everything and everyone is in a funk. The sun will still rise tomorrow so set little goals like modeling something at bedtime or saying one thing about your day using the AAC at mealtimes.

- Mary-Louise Bertram, March 2015