

## How to Raise an Independent, Successful and Happy Child who just happens to have Galactosemia

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## Acknowledgement and awareness of your journey as a parent dealing with Galactosemia.

- **How has having a child with Galactosemia impacted you?**
  - What have you learned about yourself, your mate, your child on this journey?
  - What have been the surprising benefits?
  - What has been the hardest and most stressful thing for you?
  - What is the one thing that you want to understand or improve the most regarding this issue (e.g., better monitoring of food, patience, self-nurturing, etc)
  - Use the Space below to record your individual answers.
- Partnered exercise: Awareness and acknowledgement of your strengths, accomplishments, growth etc...

## Understanding the Grieving Process and the Potential Impact it Has on You

- Parents all have dreams of how their children's lives are going to be.
- Therefore, when a child receives a chronic medical diagnosis, parents go through a ***grieving process*** as they adjust to the new reality of what their child and themselves, as parents, will be facing.
- And in the case of a medical diagnosis, parents become so busy surviving and coping with doctors, restrictions and the overall unknowns--their grief and stress often gets pushed aside or denied as they try to be everything for their children.
- Can you remember what you felt when you were first told about your child's diagnosis? Record your feelings below.

## Unprocessed grief and stress

- When parents have no chance to deal with their grief and stress it can
  - negatively impact relationships between parents or caregivers
  - cause feelings of depression, anxiety or overwhelm for individual parents
  - impact individual effectiveness and happiness.
- In contrast, when parents are able to discuss how the diagnosis has impacted them, an immediate healing begins.
  - Mental and physical energy increases
  - Parents become more present and effective in their lives.
- Group process: Examine how your feelings of grief or stress might have impacted each of you. Write below what you learned about the way you handled your grief or stress.

## Understanding your personal “cognitive meaning” of having a child with Galactosemia

- In counseling parents through the grieving process my first task is to have them identify their cognitive meaning a/b their child’s dx.
  - ***What did you make it mean when your child was diagnosed with Galactosemia (cancer, diabetes, ADD, learning disorders)?***
- The answers are varied and all are crucial as to how the parent is dealing with this issue.
  - Examples: One young mother— I thought God was punishing me for some reason.
  - Another: my children will face a horrible life of feeling stupid, just like I did.
  - A father: My life feels like it is going to be this constant overwhelm that I just cannot handle.

## The Power of Cognitive Meanings

- What did you as a parent make it mean when your child was diagnosed?
  - Record your answer in the space below
- Group process: See how each of your individual meanings has impacted the way you have dealt with this diagnosis,
  - AND more importantly, how you can change this meaning so you feel more powerful and effective.

## New Beginnings

- Now from your new “cognitive meaning” of having a child with Galactosemia, record below what different actions you might take or how you might feel differently from this point forward:
  - e.g., I can release my guilt
  - It doesn’t have to mean that Jenna will never be independent.
  - I don’t have to give up my career to make sure Hannah is ok.

## Summary

- In raising a happy, independent, and successful child who just happens to have Galactosemia, parents have to acknowledge and understand
  - their own personal feelings about how this dx has impacted them
  - how powerful they have been in their journey, including awareness of their new skills and knowledge
  - the “cognitive meaning” they gave to the diagnosis, and how to change that “cognitive meaning” to something more powerful for the future.

## Part 2: Assessing your Child's Current Strengths/Weakness and Coping Skills

- As you can see from your own experience the personal "cognitive meaning" of Galactosemia has had a powerful impact on how you have dealt with it.
- To understand your child, you will have to explore their cognitive meaning of Galactosemia ,and how that has impacted their self-esteem and their coping strategies.
- All children will have an individual "cognitive meaning"
  - The story of Sarah and "what if your baby is "different?"

## How to identify your child's strengths/ weaknesses and current coping strategies,

- Observe, observe, create more observing opportunities and observe some more.
  - Children's strengths and weaknesses will vary across different situations so make sure you are comprehensive in your observations.
    - I thought Jenna hated sports but when I made her try swimming she just blossomed.
- Discuss with your child what he/she feels strong in, or happy doing,
  - Joe, you seem really happy when you are playing soccer. Is that true? Yes, I get to run fast and my teammates like me. Awesome! What else do you love to do?
- And the opposite, discuss or notice what you child struggles with or doesn't seem to like.
  - Jake, every time we talk about Math or do Math homework, you seem to get upset, is that true? Can you help me understand what is going on?

## Important: When doing the assessment AND communicating in general: **Have no assumptions !!**

- Most important piece of information I can give
- Make sure your questions are open-ended
  - Don't assume you know the answer and I guarantee you will be dumbfounded by what you learn
  - Using the scenario from above for example, Jake may tell you that a kid bullies him in Math class, so he can't concentrate. Otherwise he loves Math.
  - Assumptions will keep you from truly ever hearing your child, spouse, friend, etc...

## Great Examples of Open-ended Communication

- Wow, that sounds awesome, tell me more.
- What was that like for you?
- You look upset, is that true?
  - If you do have an assumption, check it out for validity.
- Can you tell me what happened?
- What are some other ways you could have handled that situation?
  - Before you provide the answer, ask your child for their own answers or ideas
  - This teaches them how to begin to formulate their own logic and wisdom
    - Plus normally, they have really great ideas that they will actually try when facing the same situation.

## Hands-on and Creative observations

- Do activities or role-plays with your child so that you can assess what their strengths/ weaknesses and coping strategies are.
  - Susan, I noticed when we were playing this game that you struggled with the counting part. Is that true and what was going on for you?
  - Paul, I noticed that your friend took your ball today and you got upset and left the game. What are some other things you could have tried when that happened? How do you think the other kids felt when you left?

## Utilize 3<sup>rd</sup> parties

- Talk with the teacher, karate instructor, babysitter, other caregivers about what they have identified as your child's strengths, weaknesses.
- Often a 3<sup>rd</sup> party can provide significant insight into areas you may not have noticed:
  - (e.g., Karate instructor: "I've noticed that Tim has great focus when he is one on one with me, and he is quite skilled in listening").
  - Gabi's preschool teacher
  - Use the space below to make a list of people who could give you good feedback.

## Helping Your Child Understand his/her Strengths and Weaknesses

- Once you have a pretty good awareness of your child strengths and weaknesses, help him or her become aware of them as well.
  - This way your child can capitalize on his strengths while being aware of what he needs to work on as well.
- Let her know when she seems to have ease in doing certain things
  - Jenna, you are like a little fish in that water. You are such a great swimmer. I'm so proud of you!
- Point out more subtle things that he might not be aware of:
  - Chelsea, I noticed that when Paul and Johnny were fighting, you didn't get involved but just went to get the teacher. That was good thinking.
  - Zach, your karate instructor told me that you are one of the best listeners in his class. That is a really great skill to have son.
- Explore with your child again using **open-ended questions** about what he identifies as his strengths and weaknesses.
  - Zoe, you said that Holly is a very good violin player, what do you think you are good at doing? What do you love to do? What is generally hard for you? You will be amazed at their spot-on awareness.

## Strategies for working on weaknesses and self-esteem

- Don't be afraid to push your child to some extent. Often children recognize when they are strong or weak in things and therefore tend to avoid the areas of discomfort or weak skill level
  - (e.g., ice-skating) with Ethan and Sarah
- We now know that the brain is consistently rewiring itself, so areas that have been damaged or impacted by the Galactosemia can be repaired.
  - Pushing your child to try different sports or different activities even if they feel initially awkward can actually help repair areas in their brain.
- But shop around. Try many different ones in which your child might succeed. You don't want to push so hard that your child feels overwhelmed and helpless.

## Create a Practice Community

Create a support group for your child of understanding and patient friends if you can and have them meet on a regular basis.

- Use this group to help your child work on his/her social skills.
- Try different social scenarios—
  - having only one friend over who is calm and understanding,
  - having a small group of friends engage in an activity in which your child feels strong and at ease—
    - playing a particular game or jumping on the trampoline.

## Utilizing the Practice Community

- Learn to effectively eavesdrop and begin to notice what your child does that works socially, and what he/she does that pushes friends away.
- Use that information to create fun role-plays or activities for him to practice those specific skills.
  - Josh, I've noticed that when your friends come over you have a very hard time sharing your toys. Let's practice being a good friend by sharing. Can I borrow that?
  - Susan, when your friend was talking about her vacation, you might ask her specific questions about what she did on her vacation and that will show you are interested and listening. Let's practice.
  - Melissa, I've noticed that you often interrupt or don't stop to listen when your friend is talking with you. Let's practice a conversation where I can show you when you do this and maybe some other ways you could handle it. We can talk while we color.

## Create Academic Support

- Enlist your school, or other caregivers in what you are working on so that they can continue reinforcing your child's strengths while building the weaker areas.
- If you can get a specific learning evaluation to understand your child's strengths and weaknesses academically, so that teachers can teach to them in ways that are powerful and effective.

## Effective Practicing for Learning New Social or Behavior Skills

- Never assume your child understands what you are wanting him/her to get.
- You must be specific, detailed, and repetitive
- Practicing the skill over and over and across several situations is needed before they will truly master it.

### Part III: What if my child cannot communicate with me?

- Depending on how your child's brain has been impacted by the Galactosemia, he or she may have significant problems with non-verbal and verbal communication.
  - 11 year old Susan struggles to read non-verbal social cues. You have noticed that when she is with a group of her peers she becomes easily overwhelmed and retreats. When you try to discuss what you see, she tells you that having friends is no big deal and to leave her alone.
  - Your attempts to talk to her or understand her do not work and she may continue using retreat and silence as her way of coping with an overwhelming and very confusing world.

### Strategies for improving your child's communication.

- Using the same methods listed above, Observe, observe, and observe again how your child communicates
- Be as still as you can and listen at all levels.
- You will eventually begin to get glimmers of the way your child DOES communicate effectively.
- As you do this, engage in activities that don't require verbal communication and then point out what you notice.
  - e.g., Hannah, I noticed that when we were playing Guess Who, you seemed to really like that guy with the hat. Is that true? What did you like about him?
- Your child will be so appreciative of your noticing of her communication that she will crave more.
- You will become masterful at noticing the way your child communicates and each time you are able to communicate with her in her own language, you will become her bridge to learning more about this powerful skill in this world.