

Processing Grief & Taking Care of Yourself

Whether your child's diagnosis arrived last week, last year or several years ago, it's common for parents to experience the stages of grief on a continual basis. This DYRK1A community provides a safe place to share in the hard realities, as well as the joy and blessings each of our children brings. You are not alone on this journey. Parenting an individual with special needs can take a mental and physical toll and remembering to make yourself a priority can be difficult. Let's share ideas on how to best balance and juggle the needs of our children with also caring for ourselves as parents.

PROCESSING GRIEF

- For parents of special needs children, the grief cycle is often experienced on an ongoing cycle.
- Parents experience grief over the loss of their expectations for their child and the loss of their expectation of what their own life or family life would look like. {See "Welcome to Holland" attached.}
- **How has your spouse/family/friends processed grief differently than you?**
 - Ex: When my son was diagnosed, initially I was depressed & my husband was in denial.
 - _____
 - _____
- **What are triggers for you that can restart the grief cycle?**
 - Ex: School evaluations, developmental milestones, peer achievements
 - _____
 - _____
- **What's the best advice you could give to a fellow DYRK1A parent on this road to acceptance?**
 - _____
 - _____

Stages of Grief:

1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance

TAKING CARE OF YOURSELF

- Taking care of yourself as caregiver impacts your entire family for the better. As a parent, you cannot run on an empty battery all the time, you have to recharge yourself.
- Put on your own oxygen mask before assisting someone else!
- Impediments to self-care: time, opportunity, guilt, priorities
- **What are some ways for you to prioritize your self-care PHYSICALLY?**
 - Ex: sleep, diet, exercise, go to your own doctor's appts
 - _____
 - _____
- **What are some ways for you to prioritize your self-care EMOTIONALLY/MENTALLY?**
 - Ex: spend time with friends, support group, journal, talk to a counselor, meditate
 - _____
 - _____
- **What are some ways you could find help and/or community?**
 - Ex: use care.com, ask your therapy places for caregivers, trade nights with trusted friends
 - Ex: find a support group, text a fellow DYRK1A parent, post to the fb page, vent to a friend
 - _____
 - _____

GRATITUDE

- **What are you grateful for?**
 - Ex: this DYRK1A community, child's recent accomplishments, etc.
 - _____
 - _____

WELCOME TO HOLLAND

by

Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

1. Normal Existence

Capable of objective, valid reasoning, unclouded by doubt and undue emotion

2. Receipt of Bad News

Wow, that's bad news.

3. Denial

This can't be true. This is not happening to me. We are not failing. In fact, we know what we're doing. It is you who are wrong.

4. Anger

Get out of here, you so and so!!! Don't tell me anymore! This is nuts! I can't stand news like this!

Aggression

I'm going to slap (or fire) anyone who says anything more about this. I'm going to sue my doctor because he is not doing all he can to help me. You're not even qualified to say what you've said! (And various other forms of ad hominem attacks, such as shooting the messenger.)

5. Depression

Oh no, it is true. But there's nothing I can do. I'm trapped. It's hopeless. Nobody could solve a problem like this.

Confusion, early bargaining, and continued anger and denial

Why did this happen to me? I didn't do anything to cause this. What are we going to do?

6. Bargaining

I might as well agree things are not going to change. A miracle is not going to happen. If I can do that, I can at least get on with the rest of my life. Besides, if I can get out of all this wallowing in misery and avoidance I can think clearly again, manage the problem better, and work more effectively on possible solutions.

7. Acceptance

Well, it could be worse. We'll just have to make the best of this. And hmmm, this is starting to look like a blessing in disguise. I'm glad this happened.

The Cycle of Acceptance

With examples of what happens in the different steps. The cycle applies to individuals or organizations. Most of the examples are for an individual. The cycle begins with receipt of bad news.