



## THE SIBLINK | April 2016

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We are pleased to announce that the *Sibling Scribblings* articles are now available on the [Bruce K. Smith Sibling Network](#) website page.

Thank you again to Patty, David and Grace for sharing their sibling stories. If you would like submit a *Sibling Scribblings* article, please email Beth K. Shapiro at [BShapiro@jfg.org](mailto:BShapiro@jfg.org).

### RECAP

#### *How to Have a Future Planning Conversation with Parents*

Thank you to the siblings who attended our JFGH Bruce K. Smith Sibling Network Educational Program on February 24, 2016 with Liz Mahar, Program Manager, Individual & Family Support at The Arc.

The goal of the program was to stress the importance of future planning for a sibling and to learn how to start the critical conversation with parents. Liz also discussed that some parents may have been told that their child's future was very uncertain and/or they may not have a productive life, so the child's future wasn't considered.

Today, these same parents have to change their mindset to include a future for their child that is better than expected. This includes planning for a time when they, as parents, may not be able to care for their children. As one JFGH sibling shared, "My mother had a medical event which gave me the window to talk to her about the future."

Because this conversation is difficult, Liz and the group shared some suggestions to get the conversation started:

- Tell your parents that you have been attending JFGH sibling meetings and they suggested and encouraged having a conversation about the future care of your brother or sister.
- If your parents already have a plan (whether in their thoughts or documented), encourage them to share it with you so you can fulfill their expectations.
- Start the conversation in general terms and then move into the specifics. For instance, ask what conversations have occurred with other family members and then focus the conversation more on your role as a sibling.



- Having shorter conversations over time may be more effective than one long one.
- Take a break from the conversation and go back later. This is a heavy topic and can be emotionally draining for everyone.
- Bring up new conversations as a follow-up to the previous ones.
- In some cases, parents may be more open to listening to a spouse or a close family friend in discussing your brother or sister's future.

As a reminder, Beth K. Shapiro, LCSW-C, JFGH Director of Social Work is available to meet in person or by phone, with or without parents, to help facilitate a conversation. Please see additional resources provided throughout this newsletter.

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## COMING UP

Join us at our next Bruce K. Smith Sibling Network program!

### **Annual JFGH Sibling Outing: Brunch & Boatride**

Sunday, May 1, 2016  
10:00am  
Nick's Riverside Grill  
Washington, D.C.

RSVP by Monday, April 25 to Shaunna Pickett at [SPickett@jfgh.org](mailto:SPickett@jfgh.org).

Click [here](#) for directions.

**This annual event is generously hosted and underwritten by resident sibling Nick Cibel.**

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## SIBLING SCRIBBLINGS

### ***An Honest Inventory: Guilt, Gratitude, Resentment & Acceptance***

**By: Grace Leonard, sister of JFGH resident Alison**

My sister, Alison, lives at the Goldsten home. She has been a resident there since the mid-1980s. She is now 52. Our father died about a year and a half ago, our mother preceded him in 2000. When our father's health declined precipitously in mid-2014, I abruptly became the conservator of both his and Alison's legal, medical, and practical affairs. It has been a bumpy road.

I would like to describe some of the issues I have struggled with, both over the long term and since the death of our father 18 months ago. I suspect that many of us face these and other challenges and sometimes are at a loss as to how to address them in a way that does justice to our siblings while allowing us to live our own lives, as well. My goal is to provide an honest assessment of how being a JFGH sibling, a sibling of an adult with very complicated and profound special needs, impacts me. And since I've committed to an honest assessment, I intend to address both the happy consequences of having a JFGH sibling, and the less attractive (and probably less discussed) consequences.



*Alison in front. Family photo August 1973.*

So, here goes. I'll confess that I juggle an overabundance of emotions when I think of my sister, my relationship with her and other family members, and my responsibilities for her. Most of these emotions can be herded into the categories of guilt, gratitude, resentment, and acceptance. I fully realize that my identifying and addressing some of these categories might make readers uncomfortable, and might not cast me in the most flattering light. But I think I would do a disservice to other siblings if I did not provide an honest inventory.

Sometimes I feel guilt, or at least a vague uneasiness, about many aspects of my relationship with Alison, and about my involvement, however minimal it is, in her care. How do I know I am making good decisions for Alison? Given how difficult our visits are for me and my husband, and how dearly she loves them, how often should I visit her and how often should I allow her to visit me? How involved should I (and can I) really be in her life? Although I am not at all involved in her daily routine, I think it's important that I have a fundamental understanding of what her daily life looks like.



*Alison with Grace's dog, Nala*

As she gets older, I am also finding it necessary to work closely with JFGH staff to adjust her care as her abilities change. I worry that I'm not handling things the way my parents intended. I worry that something I have done or neglected to do will exacerbate Alison's mental illness. I worry that I did not do enough to help my parents with Alison while they were alive, especially during their declining years. I fear that I am not patient or compassionate enough with Alison, that because I knew her when she was a very happy, charming, outgoing child and young woman, I expect her to behave as she did then, and that is more than is within her power to do. I feel guilty that I don't enjoy being with her as much as I used to.

I feel gratitude, and when I don't, I try to. I am grateful to our parents that they had the foresight to find an excellent group home solution for Alison. I'm grateful that after Alison moved to the Goldsten home, our parents had a number of happy years living alone together before our mother got sick. I'm grateful to know that Alison is safe and as happy as she is capable of being. I am grateful that I was able to marry, raise my children, and care for my family without the physical, financial, emotional,

and mental burden of having to care for Alison in my home. I am grateful for very happy childhood memories of our parents, Alison, our brother, and me. I am grateful that for many years Alison was able to find stimulation and self-worth in a job or day program. I am grateful that our brother is always willing to give his opinion (if I ask), but leaves all decisions, large and small, regarding Alison to me. As difficult as some of those decisions are, I do not perceive any expectations on his part or any feelings of disapproval from him. I am grateful that over the past year or so I have finally felt more support and understanding from my husband when it comes to caring for Alison.

Sometimes I feel resentment. There are so many decisions to make: medical care and insurance, legal and financial decisions; dealing with Social Security; planning for me to visit her and her to visit me (major undertakings involving travel by air, hotels, management of a truly astounding number of medications, attempts to fill at least part of the day with some interesting activities, and, let's face it, I'm pushing 60 and just don't have the stamina or enthusiasm I used to); making sure I am familiar with her daily routine and that she has adequate, appropriate activities and stimulation; making sure she has adequate, appropriate clothing; making sure she has a small allowance for outings with other residents. Some of these things are extremely frustrating and challenging (have you visited your local Social Security office lately?), and some of them are not difficult at all, but all of them take time, energy, and attention that I could devote to other things. There are days when I cheerfully tackle a long to-do list, all related to my sister, and days when I am too sullenly resentful to even consider looking at the list. And there are days when I am simply at a loss, like the day shortly after I buried our father when I came across some JFGH documentation and realized that at some point I would most likely have to make some decisions about burial arrangements for Alison.



*Grace & Alison*

I resent not having the kind of sister other people have - the kind of sister that I can giggle and share secrets with, the kind of sister some of my friends have, vacation with, raised their children with, receive real emotional support and encouragement from. I resent that my brother cannot be more involved with Alison (at the same time I am grateful that he leaves all decision-making to me! It's irrational, I know, but it's what I feel!). I resent how much time and energy I pour into Alison, and it's never enough. I resent that I sometimes feel that I'm navigating all of this alone, entirely on my own. None of my friends have siblings with special needs, and although my closest friends try to be supportive, it's really impossible for them to grasp how difficult it is to handle some of these issues, or even just to spend several days with Alison. I resent that my relationship with Alison is really a one-way street. Because she has so many mental and physical health issues, all of which are compounded by her cognitive deficits, I have to be on my guard during every interaction I have with her to make sure that I am encouraging appropriate choices and not triggering an episode.

And sometimes I am able accept all of this and be at peace. I treasure those moments.

#### **Note from Grace Leonard**

As I started writing, my thoughts galloped in a number of directions. This was much harder than I expected and somewhat therapeutic. I wrote this hoping that it will stimulate open, honest discussion among us. I was intrigued and secretly a little thrilled to learn that Beth Shapiro at JFGH is initiating outreach to JFGH siblings. The sibling network is in its incipient stages--that means that siblings of current JFGH residents have the opportunity right now to put some real thought into what we might want from this network and how we can shape it, for ourselves now and for the future.

***If you have a sibling story you'd like to share, please email [BShapiro@ifgh.org](mailto:BShapiro@ifgh.org)***



## SIB RESOURCES

### Tips for Siblings:

#### Getting the Future Planning Conversation Started

Click [here](#) for tips on how to get the conversation for future planning started. Share this with other family members who should be part of the conversation.



#### Disability Scoop: *New Website to Serve as ABLÉ Account Clearinghouse*

"As states prepare to offer accounts that will allow people with disabilities to save without losing government benefits, a new website is launching to help families navigate the offering." [Continue reading...](#)



## IN THE FAMILY

### Peggy Gilman<sup>z</sup><sup>1</sup>

On behalf of the Bruce K. Smith Sibling Network, we extend our heartfelt sympathies to Ken Gilman, passionate supporter of the Sibling Network and JFGH board member, on the loss of his beloved sister, Peggy Gilman<sup>z</sup><sup>1</sup>. Peggy will be remembered for the love, laughter and joy she shared with family and a life that produced insight and inspiration for those whose lives Peggy touched.

**May the memory of Peggy Gilman<sup>z</sup><sup>1</sup> always be for a blessing.**

## FROM THE DESK OF...

### Beth K. Shapiro, LCSW-C, JFGH Director of Social Work

On April 16, 2016, it was **National Healthcare Decisions Day** (NHDD). NHDD has a comprehensive website providing Advance Care Planning Resources you may find useful. Please click [here](#) to learn more and to access free planning toolkits.

Earlier this year, JFGH siblings updated their health care directives as required by the JFGH Continuous Support and Decision Making Policy. They or a family member provided JFGH documentation stating who to contact in the event they are unable to make a medical decision.

Have *you* done that for yourself? Just in case...this is the [Advance Directive Form](#) that can be used for Maryland, Virginia or DC.

If you live in another state, please click [here](#).

As always, I am available to help facilitate future planning conversations. Please feel free to email me at [BShapiro@jfg.org](mailto:BShapiro@jfg.org) if you would like to set up a mutually convenient time.

Best wishes,  
Beth



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