

Writing as a “Righting” Journey

Questionnaire

This is a new writing project. I am the mother of a child with a chronic, autoimmune disease and I have been writing about my journey with my child since 2007. I have published many poems and a small book about this journey. I have also spoken with many other parents in similar situations and have led support groups and writing groups on this subject. Now, I want to expand my writing work to include other’s stories.

I have received a grant from the City of Seattle Arts and Cultural Affairs program to help me in this endeavor. I will be writing and publishing poems in both a small book and to hang in clinics where families are treated. I will also be giving a series of free readings and will invite all families who I have spoken with to attend. This will happen over the next year.

I have a background as a psychotherapist and an artist/poet. I feel very honored to be here with you.

Your answers will remain confidential. You can choose to add your name or not to this form. I will NOT be sharing names with anyone and would greatly appreciate your honest responses.

This brief questionnaire has 4 areas of concern:

- 1) Background Information**
- 2) Emotions/Parenting**
- 3) Self-care**
- 4) Life beyond parenting**

BACKGROUND INFORMATION:

Name (if you want) _____ Date _____

a) your role as caregiver (please circle one)

mother father other caregiver

b) age of child at diagnosis _____

c) age of child now _____

EMOTIONS/PARENTING:

Parents of children with special needs or a chronic illness can experience a range of difficult emotions...e.g. sadness, decreased confidence in themselves as parents, increased stress, strain in their relationships with partners and other family members, etc.

Thinking back over the last **4 weeks**, how much have you experienced one or more of these emotions or events?

See the scale below.

Not at All		Moderately 2-3 times		Very Often more than 5 times
1		5		10

Please write a brief paragraph or a few phrases explaining your answer. If you can name the emotions, that is fine, but you don't have to.

SELF-CARE:

Eating, sleeping and time for oneself, to replenish our inner resources, are all **self-care** needs. In the best of circumstances, parenting is a give and take of time spent caring for and attending to a child's needs and the parent's needs. It is often the case that parents put their children's needs before theirs. When a child becomes ill, it can also be true that parents do this to the exclusion of, or reduced attention to, their own needs.

a) In the past 4 weeks, to what extent have you been **attentive to** your need to **eat well** (however you define this)

Not at All		Moderately 2-3 times		Very Often more than 5 times
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1		5		10

b) In the past 4 weeks, to what extent have you been **attentive to** your need to **sleep well** (however you define this)

Not at All		Moderately 2-3 times		Very Often more than 5 times
1		5		10

c) In the past 4 weeks, to what extent have you been **attentive to** your needs for **rejuvenation time** (however you define that)

Not at All		Moderately 2-3 times		Very Often more than 5 times
1		5		10

Briefly explain anything from the above answers that you would like to.

LIFE BEYOND PARENTING:

Most of us have other activities in our lives that also take time and attention. These include some of the following (and more): work, church, other community activity or participation in a regular event. Some of these activities may be curtailed or suffer as a result of our child's needs.

a) How much of your life “beyond parenting” have you cut short, dropped altogether, **or** ADDED.

None		A few-- more than 2		All of my activities
1		5		10

Briefly explain **What** and **How** these things have changed or not.

Here is another set of questions that I am going to ask you. You may choose not to answer them if you are uncomfortable or for any other reason. I would like to have a discussion around them. I would also like your permission to tape that discussion if possible so I can refer to your thoughts later when I’m writing. If you prefer **NOT** to be taped, that is OK too. Please sign the permission to tape if that is OK. Again, no one but myself will be listening to your words.

Name _____ Date _____

When I do publish a poem and give readings you will remain anonymous unless you want to participate in the discussions. That is entirely up to you.

- 1) What **one** thing has your family done that allows your child to cope with his/her illness? Are there things that you do that help too?
- 2) How do you cope with this illness?
- 3) How do you keep life in balance for your other children? (if this applies)
- 4) How do you deal with family and friends who don’t understand either the illness or what you need to do to care for your child?

- 5) Has your relationship with friends, family, or co-workers changed since your child was diagnosed or became ill?
- 6) What do you do for your child when he/she is in pain?
- 7) Are you always looking at your child for signs of illness vs. just looking them for who they are?
- 8) How do you handle the school system and teachers?