

**Collaborative Coping, Stress
Management and Self Care: Living
with MPS and Related Diseases**

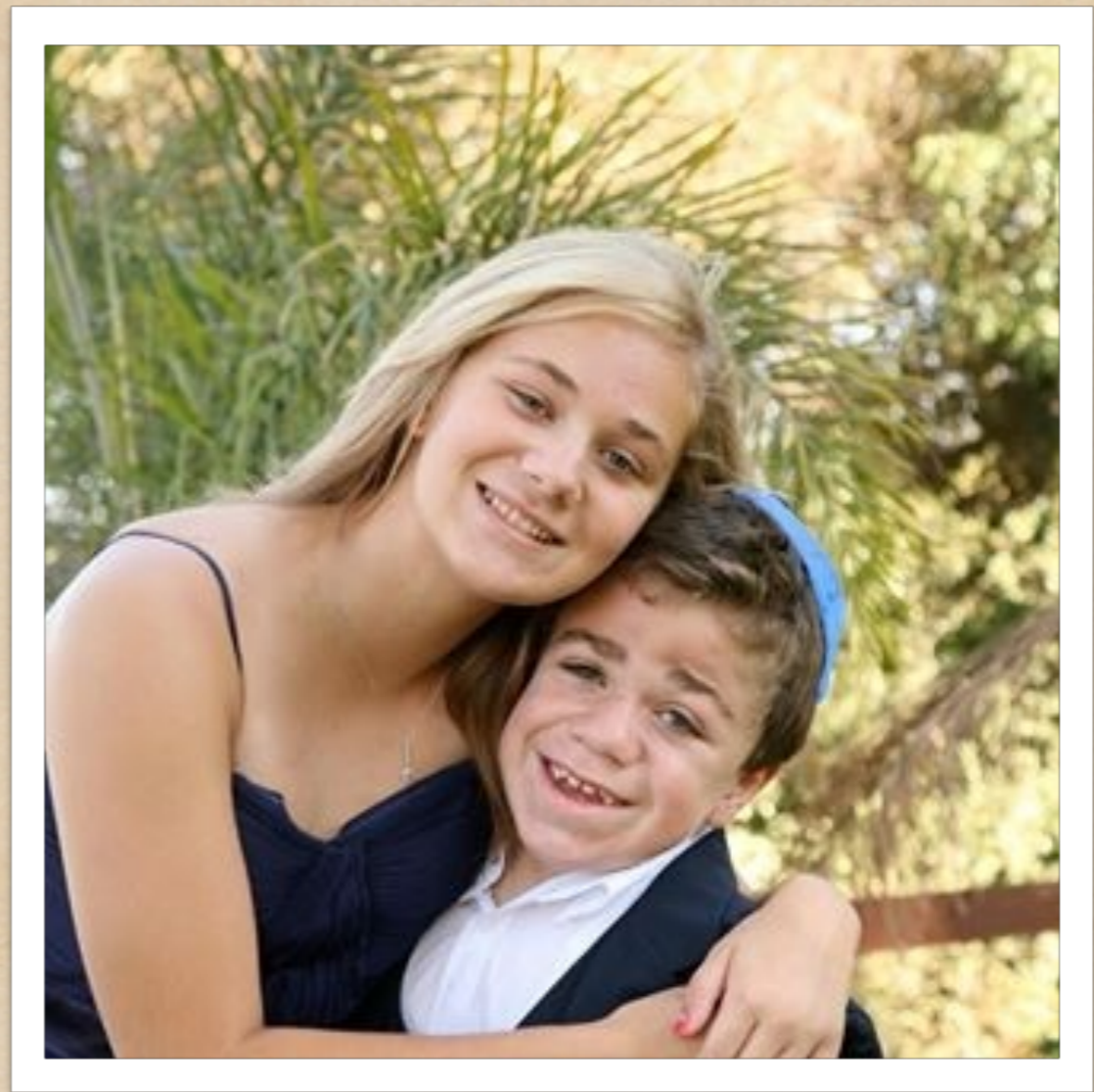
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MPS II Parent

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A little background...

- Was married 16 years
- Daughter Nicole 14 years old
- Son Jack 10 years old
- “WE” were diagnosed in 2004
- “WE” began treatment in 2006



Jack & Nicole, December 2012

We must let go of the life we
have planned, so as to accept
the one that is waiting for us.

*~ ~ Joseph
Campbell ~*

What is Coping

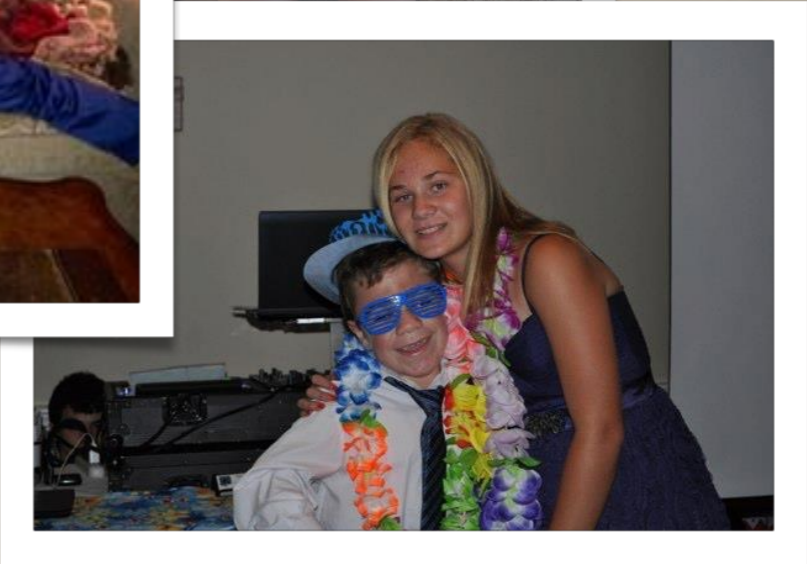
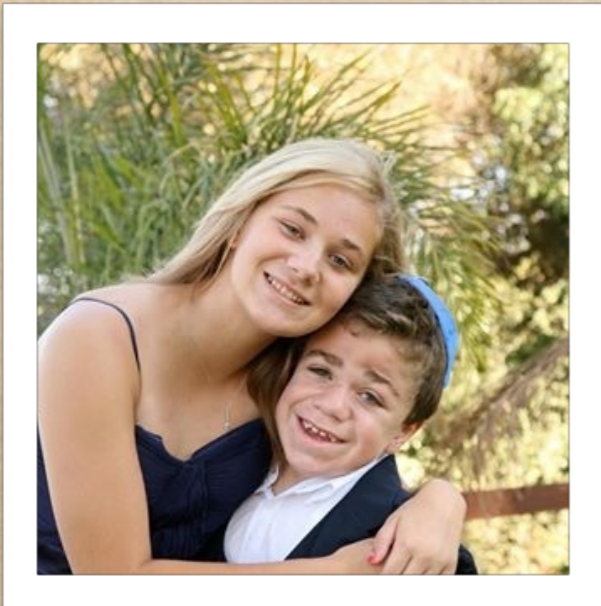
The things people do
to avoid being harmed
by life strains

(Pearlin & Schooler, 1978)



MRI & CT prior to spine fusion, April 2011

A critical component of effective coping is balance.



Coping: What does it really look like?

- ◆ an action
- ◆ requires effort
- ◆ observable
- ◆ not simply a thought or feeling
(important BUT

not the point of change)

- ◆ If you are coping you are "doing something"

Using a "Whatever It Takes" Approach

- ◆ Evaluate or reflect on how you cope
- ◆ Is this a successful strategy?
- ◆ Would most others agree?
- ◆ How is that going to help or hurt you now?
- ◆ Adjust to achieve your desired result
- ◆ Remember you don't live in a vacuum

From Distress to Coping

- ◆ Progress NOT Perfection
- ◆ Every coping event builds on the one before it
- ◆ Our coping improves with each event
- ◆ Research supports acknowledging and actively dealing with stressful events lead to higher levels of perceived growth
- ◆ What does that mean really????
- ◆ Talking with others (SUPPORTIVE OTHERS)
- ◆ Journaling about it
- ◆ Not dwelling on the moments when preferred coping was elusive
 - ◆ but do not IGNORE these moments either
 - ◆ Learning from mistakes. These are opportunities for growth.
 - ◆ This can also be an opportunity for GENUINE and LASTING connection

WHAT THERAPY IS **NOT**

- ◆ friendship
- ◆ mutually supportive
- ◆ abusive
- ◆ abandoning
- ◆ easy

WHAT THERAPY IS

- ◆ supportive to *you*
- ◆ collaborative
- ◆ safe
- ◆ consistent
- ◆ hard

When you have come to the edge of ALL the
light you have,
and you must take a step into the darkness of
the unknown,

Believe that one of two things will happen to
you,

Either there will be something solid for you to
stand on, or,

You will be taught how to fly.