

Family Council

“Family: A Hub to Cheer You Up” Family Education Videos – Tough as a Mother

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Quick-fire Q&As

- Question : Optimistic person?
Margaret : (Yes)
- Question : Enjoy family time?
Margaret : (Yes)
- Question : Workaholic?
Margaret : (No)
- Question : A competent mother?
Margaret : I know that there’s always room for improvement
I wouldn’t think that I’ve done a perfect job
- Question : Would your daughters get any scolding for doing something wrong?
Margaret : Yes
- Question : Play favourites towards the elder girl?
Margaret : It depends
- Question : Taking care of your daughters feels tiring sometimes?
Margaret : Yes
- Question : Does your daughter’s illness make you grumble?
Margaret : No
Never

Facing a rare disease with family

- Margaret : I really didn’t have much time to think at that moment
When the doctor said that Isabella had Wolf-Hirschhorn Syndrome
I hurried to ask
“Has checking been done for her heart, kidneys and brain?”
As for whether I feel sad
crying during downtime
such sudden surges of emotions
I may feel several times a day
but would be fine really soon
It was roughly two years later that
I allowed myself the chance to feel the feelings
to feel what had happened
I felt myself psychologically fine all along
I felt I was fine
But my body gave off signals of contradicting conditions

For example, I became less patient than before
So I discussed it with my husband, and also friends
“I feel different”
I felt a bit in a dissonant state
yet psychologically, I believed I am okay
But for all that, my husband encouraged me to
start teaching yoga again
He actually cued me in
when I should start taking care of myself if there’s time
If I were asked whether I feel sad
burnout and dissonant
yes, for sure
Luckily, I’ve my husband to share my feelings

Learning from Mom

Margaret : I think all people see their own mother
as the best mother
I believe all mothers would teach their child
how to be an optimistic
committed and hardworking person
But my mom has done so in a unique way
She doesn’t lecture too much
I’ve always observed my mom’s example of how to approach life
When she was diagnosed with cancer
I was really sad
I did ask, “Why does my mom have to experience cancer?”
Mom thought that
as she told me frankly
“That doesn’t matter. It was confirmed anyway”
“There’s no point in crying over it too much”
“You may cry. Mom is upset too”
“That’s okay. Just go for the treatment”
“Do whatever can be done”
“Let’s not stay at where we are”
I realised that Mom was right
Whenever something has happened to a person
and nothing can be changed
don’t spend too much time on that point
asking why
Nor give too much time to
efforts that don’t require making

Instead, we should think over what to do during recovery
I think there're many different perspectives to look at every single matter
For example, my mom taught me that nothing is ever right or wrong
Her way of going about things is focusing not on their absolutes
She approaches them from a different angle
Seeing with new eyes
will make oneself more joyful
This approach really works for me
What my mom taught me was
take for example, to go over whether I should ask "why"
while Isabella had already been diagnosed with this illness
Let's say, a mother's reaction would normally be
wondering if I have done something wrong
or something causing the girl special needs
This is a normal reaction
Any mother in the world, including myself, would think likewise
But I would jump out of this mindset sooner
I wouldn't linger over the period for too long
and let it take a toll on my next move

Parenting tips

Margaret : I didn't deliberately make it at my younger daughter's early age
to tell her about the special needs of Isabella (elder daughter)
"Isabella is your sister"
That's it
I think that's end of story
My younger daughter's classmate once asked her
"Why didn't your sister chat with me?"
So, I started giving my younger daughter the facts
Whenever she asks me, I will answer her
How I teach her is (to tell her)
"See how I carry on with your elder sister"
Let her watch how we take care of the elder one
We never lecture her on what to do
"Watch mom and dad"
"What are we doing?"
I think we've to let things take their own course
Some families may also face similar situations
Don't ever pressure yourselves
to tell your other normal kids
to be overly softhearted for this child (with special needs)

Just teach them by example, that's good enough

Impacts of the pandemic on life

Margaret : I think the pandemic also has its impacts (on life)
For instance, we have to get used to using Zoom (video conferencing software)
Isabella uses Zoom too
She likes using Zoom
because with the iPad
she can see many classmates
and listen to music as well
She feels happy about it
Luckily, her school is very supportive
An example is making available the gear Isabella uses at school
like the standing frame
for lending to us
We could borrow them home
for therapeutic use with Isabella
That can't be called stressful
It's a gratifying experience
For Isabella, attending classes on Zoom during the pandemic
is a new learning experience
Of course we haven't gone out too often
but stayed home as much as possible
giving Isabella stimulations for capability building with different things
That's nothing extraordinary
We brace together for this period as a family

Encouraging others in the same boat

Margaret : Sometimes in the face of hardship
it's very difficult to break away from it
I shared my experience with other parents some time ago
We had our own stories
How I went about things
should never be taken as the right way
My way was as good as it was mine
I was just sharing what ways had been possible
to make me live more positively and happily
That was why I told them
"to gladden your own heart more whenever possible"
I feel that a few minutes spared "for yourself"

are already something done “for yourself”
By that, I don’t mean going on a one-day spa trip
and not being home for the whole day
Not like that
I just want you to spare 5 minutes for yourself
to do what you like
You also need to know how to let go
Take for example, if you are a mom, be a mom
Don’t take on the role of a therapist at the same time
or the role of a teacher
Don’t be in any role not required on your part
Allow others the chance to help you whenever possible
I think that’s important too