

## Summary – Overwhelmed No More – Tips for Enjoying the Holidays! Joan Celebi

1. *Take care of yourself.* Whether you are a parent, caregiver or person with mitochondrial disease, the holidays can be exhausting especially with the pressure to do everything. The natural reaction to all this activity is to put yourself on the back burner - and to try to take care of everything and everyone. This is not the way to go! A great analogy is the oxygen mask lesson given to passengers every time you get on an airplane. Parents are told to put their oxygen masks on FIRST when they are traveling with children. Our first reaction is to help the kids and to get the masks on them BUT, you are no use or help to others unless you have your mask on first. The same goes for caring for yourself during the holidays: you will not be helpful to others unless you can care for yourself first. With that in mind, think of all the things you do for others and try to balance that with things you need to do for yourself to stay healthy: sleep, eat, hydration, deep breaths. If you do not attend to these basics, the other strategies won't work either. An especially good technique is to take 30 seconds first thing in the morning to take three (3) really deep breaths - to center yourself for the day. Then throughout the day, when stressed or overwhelmed, do the same thing - take 30 seconds and in that time take 3 deep breaths. This is just like recharging your phone batteries. You would never ignore the flashing signal on your phone that tells you the batteries are low, so don't ignore your body's signals, otherwise you will have a rebound crash later that day or in a few days. No matter how difficult it is, you need to care for yourself first; "toughing it out" does not work.
2. *Sort out what matters most and what does not matter so much.* Weed out those things that you do not want to do or that you do not especially like to do or that you feel you do not really need to do. This means you need to observe and analyze yourself and activities so that you can rid yourself of those things that you do not need to do. You do not have to do everything every year! Do you really need to make all those different kinds of cookies? Must you put up every single decoration? Give yourself permission to choose what you want to do. If you are asked to make brownies for a party or to help out at a fund raiser, it is "ok" to say, "no," if you really cannot add these things to your already too busy life. Practice saying "no" ahead of time so that when you are asked, you will be able to answer honestly.
3. *Prepare an elevator speech.* This means that you have a practiced statement that you can give to anyone anywhere who asks you to do something that you just can't do because you need to set limits on your activities/time/energy. In the business world this is the 30 second speech that you give when caught in an elevator and someone asks you, "What do you do?" It is practiced and allows you to be ready and not feel awkward or stressed. Briefly you say that this is what I am dealing with, these are my limitations and these activities (or whatever) will not fit in right now. Make and practice a list of "talking points" so that if someone needs/wants further explanations, you will have a short list of specific things to say. This will help you deal with the stress that these moments can often cause. It is frustrating to have to explain over and over again why you (or your child) cannot do something or go somewhere or have to leave early.....

Then when others say, "but you look so good," you won't be so frustrated having to explain why you have to leave early or not eat or whatever it is you truly cannot do. The 30 second speech already practiced and memorized will save you the emotional burden of having to come up with something every time you are faced with a situation. It is exhausting to have to explain everything (child's behavior, fatigue, diet restrictions) especially when these issues are irreversible. Save yourself this kind of stress by having memorized your speech. Will it sound too automatic or rehearsed? Perhaps but that is all right; you will customize your response anyway and can always add a thing or two as the occasion arises. The important thing is to have the speech ready!

4. *Focus on the things that do matter.* Visualize your holiday season. Think about your favorite memories. Make a list of the best things and then circle those that are the most important to you - the holiday would not be the same without those things. Then do only those things. Spend your time and energy on those 2 or 3 things that mean the most to you. Make time and space in your life for these important things. They do not have to be the big things or time-consuming things - they can be small and simple traditions. For example, in Joan Celebi's family every year they pick one night during the season to light the small candles on an angel ring. When the candles are lit, they cause the angels to spin and bells to ring. This one magical moment is very meaningful and they make sure it is a part of every holiday season.

5. *Setting standards.* Often, we hold ourselves to very high standards - almost perfection - for how the holidays should "look." We need to let go of some of these standards that no one could really meet (except in some magazine layout). We do not need to have the "perfect house, perfect decorations, perfect tree, etc". Step back and ask what kind of standards do you really want. Use the techniques already discussed here to come up with a different mindset. An important phrase to use in order to adjust our expectations is this: "I give myself permission to..." All too often we let others set expectations for us; we need to set them for ourselves.

### **Other helpful hints**

Dealing with family members or friends who don't always understand can be very difficult. Families who are spending the holidays in a hospital may have to deal with phone calls from well-meaning friends/family who may call to ask how you are doing, but quickly launch into tails of their own troubles. You need to learn to change the subject quickly and take charge of the conversation. Mention something positive (we are lucky/thankful etc) or say that you just cannot talk right then, "Thank you for calling, but..." It is important to surround yourself with only those people who are supportive and helpful; the others are only a drain on your energy. Let go of your expectations for family members who just cannot be supportive. Especially for those with mitochondrial disease because of the ups and downs of the symptoms, you may have to "reschedule" the holiday. Plan to spend time with those you want to spend time with.

Focus on being with people who are supportive. It is all right to decline invitations to social events where you know it will be difficult. You can plan a one-on-one get together at another time at your convenience. For the holidays you may actually want to make

appointments ahead of time to spend time with those folks you want to see, those that matter the most to you.

Do not get overwhelmed with your "to do list." It is time to get help. This is a good thing to do for the whole year, but you can use the holidays as a way to start. Some examples are to have your groceries delivered by one of the many services now offered. It is worth the \$10 delivery fee to save all that energy! Try different services until you find one that you like. Often the delivery people will even put some things on high shelves or hard to reach places for you. Another service available may be an errand service; there are several in the Boston area and probably this is true in other urban/suburban areas. They can do things like go to the post office or cleaners for you. Also, use young people in the neighborhood as helpers to walk the dog or wrap gifts. They are happy for the extra money and you get a break! The important thing is to be resourceful here.

Traveling can be an issue, especially sitting in a car for a very long time. This immobility can trigger deep muscle pain. So, you need to plan into your time schedule frequent stops for exercise. You may also need to consider not making trips every year but alternate the site of the holiday celebration. Some families decide to find a place half way and they all meet in a central location. Others may decide that home is still best, but use the pot luck approach so no one person is doing all the cooking and preparing. Hydration is important when any travel is involved, so plan ahead. Also, staying overnight may also be a good idea when you can do this.

The challenge of the holidays is to pace yourself. Everyone feels that if they do not do certain things during a particular holiday, they may never do them. But again, plan ahead to do only those things that are important to you. Make a list and share it with family members. The original list may be too long, but together you can work out a list that everyone agrees is important.

Ongoing therapies sometimes take a back seat during the holidays but this is not a good idea. It is really important to continue with therapies (PT, etc) even if the professional folks are off - family members need to be sure to continue the treatments. One idea is to go to a hotel in your area that has a heated swimming pool - go during or right after the holidays when the rates are a bit lower - and everyone can enjoy the therapeutic effects.

### **Summary**

- Let go of what others think
- Know what works for your family
- Take little time outs, anything, just to take a breather, throughout the day
- Savor the small moments, they are the most worthwhile
- Laugh
- Remember that one special cookie may be all you need to make the holidays special!