

Helping Couples with Medically Fragile Children: Tips for MRE Practitioners

“Ten fingers and ten toes!” is a common joyful exclamation when a child is born. This count seems to provide some reassurance of a child’s good health. However, this is not always the full story. Medically fragile children include those who have serious chronic medical conditions that are not always present at birth and may or may not be life threatening. These conditions vary widely, but include developmental disabilities like cerebral palsy or autism spectrum disorders and health conditions such as diabetes or a traumatic brain injury.

The diagnosis of a medical condition can increase parental worry, often causing tremendous strain on the couple’s relationship. Marriage/relationship education (MRE) practitioners can help couples navigate their child’s medical needs while nurturing their relationship. A good couple relationship can have positive benefits for the child’s experience and his or her medical condition. This Tip Sheet provides practitioners with strategies to support couples in this journey and make services more accessible and relevant for couples with a medically fragile child.

Communication

MRE delivers skills to help couples communicate more effectively, resulting in greater relationship satisfaction. Couples with a medically fragile child can apply these same skills in communication with their child’s providers, with each other, and with their child(ren).



With medical providers. Encourage couples to form a partnership in their communication with the medical providers caring for their child. It is important that both parents participate and become collaborators in their child’s care. Working together as a team to ask questions and to manage expectations creates a bonding experience. This process also keeps the couple equally informed about the status of their child’s health and decisions regarding care. Couples do not have to sacrifice their relationship for the sake of their child; they need to reinvent their relationship to include the care and needs of a medically fragile child.

With each other. Promote that the shared experience of collaborating with medical providers will also improve a couple’s communication with each other. Through this process, the couple spends time together, makes decisions together, and negotiates household (and illness) responsibilities together. Sharing the care giving burden in an equitable way can help couples avoid role strain, thereby decreasing disagreements and

frustration. This allows couples to have space in their life for fun and romance.

Encourage couples to share not only their positive experiences, but also their fears and frustrations. This helps normalize the situation for each other and promote a safe place of support. Teach couples how to be responsive to their partner using active listening. Parents of a medically fragile child can be at risk of developing mood disorders including depression. Symptoms of depression in one parent can impact the couple relationship and the parents' ability to care for their child(ren). By communicating with each other, couples can get the support they need and have a stronger relationship.

With their child(ren). Developing a supportive couple relationship forms a stronger foundation to parent their children. Medically fragile children rely on their parents and caregivers for their basic and emotional needs. Children can be greatly affected by having a medically fragile sibling. Discipline, education, and social activities for *all* children are important but can sometimes be consumed by the needs of one child. Work with couples to role play ways to positively communicate with their children and practice answering questions about the medical condition. For example, a child may ask, "Why does Karen get to stay at home with you while I have to go to school?"

Teach parents three simple rules for parenting their medically fragile child: 1) be reassuring, 2) be appropriately honest, and 3) know that it is okay to show emotion. Ask parents to role model and teach their children how to adapt to the medical condition and its symptoms. Tell parents that it is fine to be appropriately honest (consider the child's age, experience, and ability to navigate the different levels of the truth). It is also okay for parents to

show emotion and to share why they are happy or sad, "Mommy is feeling happy today because Jose got a good behavior report from his teachers."

Support

From each other. The child's illness becomes a shared experience for the couple—one in which they can be partners and support each other. This can cause greater cohesion in the relationship. It can also provide a new baseline, "Once we survived Cameron's cancer diagnosis, we knew we could survive anything!" Teach couples to use their communication skills to get the support they need from each other. Couples can negotiate household roles and prepare for changes to their daily routines, for example, doctor appointments, physical therapy, home care and medication.

From family, friends, and community. Couples will need to also look outside their relationship for additional support. Often, couples internalize what is going on and forget they have family, friends, and community to support them through tough times. Share with couples the benefits of accessing support and resources from their family and friends. Teach couples to be specific with what they need, "Can you please pick up Jayla from soccer while I take Deon to the physical therapist?" Encourage couples who have a strong faith community to use this resource for support. This community can also help a couple cope with loss—the loss of having a healthy child or, in the case of a terminal medical condition, the death of their child. Support couples in your classes in connecting with each other and sharing their common experiences.

From Practitioners. Not only have you taught couples in your classes vital relationship skills, you have become an additional source of support to them. By offering your relationship education

in locations where couples with medically fragile children are, you recognize and respect the demands placed on these couples. Contact hospitals, support groups for specific illnesses, and places like the Ronald McDonald House to ask if they will include your marketing materials. Also inquire if there are opportunities to speak or offer your class at their location.

Fun

This may seem like a tall order, given what the couple is facing, but having fun is so important! Encourage couples to engage in recreational activities on their own, with each other, and with the whole family. Be creative in what fun looks like. Remind couples to set boundaries around time for their relationship and romance. Help the couple develop a list of options that meets their definition of fun, their budget, and their calendar.

Using the information in this Tip Sheet, you will be able to tailor your MRE program to meet the needs of couples with medically fragile children. Focus on skills that deal with the daily needs of these families and encourage them to remember that a healthy couple relationship is one of the best supports for their child(ren).

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Additional Resources

Dream House for Medically Fragile Kids

<http://www.dreamhouseforkids.org/>

Fragile Kids Foundation

<http://www.fragilekids.org/>

Ronald McDonald House Charities

<http://www.rmhc.org>

The Medically Fragile Child

<http://medicallyfragilechild.com/>

Welcome to Holland

<http://www.our-kids.org/Archives/Holland.html>