Towards Tomorrow

FOR PARENTS COPING WITH THE LOSS OF THEIR CHILD



WINTER 2018

Welcome to our first edition of the Towards Tomorrow newsletter!

For the past 25 years, the Towards Tomorrow program has given bereaved parents opportunities to meet, talk, and share about how to live life after the death of your child. Our meetings offered a safe place to discuss your children and the changes your family is going through. We know that every family lives with the loss of their child differently and support can come in many forms. We also know that families may not always live close to each other and that support isn't always easy to find. We hope that this newsletter will bring you closer to others who are walking a similar path. This newsletter will give you information, educational resources, and stories from parents and family members like you, pediatrics staff, and other bereavement experts. Most of all, this newsletter is for you, so we welcome your



feedback and ideas about what to include and feature. We are here for you!

Parent Reflection

Joan, Parent-to-Parent Volunteer

Our son Neil was diagnosed with Ewing's sarcoma at age 13. He was in camp, and woke up with a lump on his neck. The doctors didn't get it right at first. The lump grew and a few weeks later after the first of too many scans, blood tests, biopsies, tears, and pain, we were sure it was cancer. Neil was our firstborn, handsome, athletic, and fun loving.

Four months short of his 15th birthday, he was dead. Through it all, Neil was brave beyond words and I have always tried to follow his example. It is not easy to be brave when your child is very ill and as a parent you must let others take care of him. It is not easy to be brave when your child dies and your family needs you and all you want to do is lie in bed and never

get up. It is not easy to be brave when your younger child starts to act out and act up and you just want to be left alone. I can truthfully say to newly bereaved parents that there is life after your child's death. But first there is grief.

The grief is profound and allencompassing. It must be respected and dealt with. You will have to make a conscious decision to live and not be defined by your loss. This is not easy. There are people who can help you navigate the horror that you are experiencing. As a parent-to-parent volunteer, I am one of them. When you are afraid that you are drowning in sorrow, I will be a phone call away. It does get better. I am living proof.

HOLIDAYS, BIRTHDAYS, AND OTHER MILESTONE EVENTS

Jessica Anenberg, Child Life Therapist

It's OK to celebrate differently.

Holidays, birthdays, and other milestone events like graduations can seem extremely daunting after your child's death. It may "feel wrong" to celebrate and continue family traditions without your child present. but it's OK to celebrate. Ask yourself, "What do I want my experience to be this holiday?" It could be alone time or family time. It could be a time for reflection, distraction, or a combination. Talk to your family about ways you can remember and honor your son or daughter. This may mean keeping a family tradition or starting a new one. Some ideas for honoring your child at a holiday are:

- Share memories through pictures or stories
- Set a place setting at the holiday table
- Serve your son or daughter's favorite food
- Write or make a birthday card

Or you may choose to focus only on the present or celebrate on an entirely different day. Whatever you choose, remember that grief is not linear or predictable. With trial and error, you will find what works best for you and your family.

The Parent-to-Parent Volunteer program connects bereaved parents with other bereaved parents who uniquely understand their loss. Parent volunteers provide bereavement support to families wherever they reside. The program is available to bereaved parents whose children received treatment at MSK. If you are interested in learning more about the program, please contact Towards Tomorrow at 212-639-6850.



Grief Counseling for Parents and Family Support Projects at MSK

Department of Psychiatry and Behavioral Sciences

Grief Counseling Project for Parents

MSK is offering a research trial that gives grief counseling to parents who have lost a child (39 years old or younger) to cancer at least six months ago. Below are details of the trial and therapy:

- Therapy is done through videoconferencing so that parents do not need to return to the hospital for support.
- Parents must live in New York or New Jersey for legal reasons.
- Parents need a computer and Internet access for videoconferencing.
- Parents will receive 16 weekly, one-hour counseling sessions with a therapist.
- Parents will participate in either a therapy that focuses on grief support and expressing their feelings or a therapy that focuses on grief and a sense of meaning, purpose, and identity.
- There is no charge for receiving the services provided through this study.
- Participation involves the completion of questionnaires.

For more information, please contact the research team at aimstudy@mskcc.org or 646-888-0134.

SUGGESTED BOOKS AND ARTICLES

A Bereaved Parent's Wish List

compiled by Diane Collins, The Compassionate Friends, Bay Chapter Area, Houston

The Empty Place: A Child's Guide **Through Grief**

by Roberta Temes, PhD

Healing a Parent's Grieving Heart: 100 Practical Ideas after Your Child Dies

by Alan D. Wolfelt, PhD

If you would like to receive a free copy of any of the books or articles listed above, please contact the Towards Tomorrow program.

Towards Tomorrow: Resources for You and Your Family

No matter where you are in the world, there will always be help available to you and your family. MSK offers a range of resources for grieving families and friends. You can learn more about these resources at www.mskcc.org/cancer-care/counseling-support/supportgrieving-family-friends.

TOWARDS TOMORROW PROGRAM

The Department of Pediatrics' Towards Tomorrow program offers support and resources to bereaved families, including:

In-Person Meetings

Our in-person parent bereavement support group is led by a social worker and a nurse. We invite all parents who have lost a child to cancer at MSK to join.

Parent-to-Parent Volunteer Program

A program that can connect you with other MSK bereaved parents across the country who have also experienced the loss of a child to cancer.

For more information about these programs or to sign up, call Towards Tomorrow at 212-639-6850 or email towardstomorrow@mskcc.org.

MSK COUNSELING CENTER

646-888-0200

Some bereaved families find counseling helpful. Our psychiatrists and psychologists lead a bereavement clinic that provides counseling and support to individuals, couples, and families who are grieving, as well as medications to help if you feel depressed.

CHAPLAINCY SERVICES

212-639-5982

Our chaplains are available to listen, help support family members, pray, contact community clergy or faith groups, or simply to be a comforting companion and a spiritual presence. Anyone can request spiritual support, regardless of formal religious affiliation.

ADDITIONAL RESOURCES

Bereaved Parents of the USA

www.bereavedparentsusa.org National nonprofit organization that provides support to bereaved parents and their families.

The Compassionate Friends

630-990-0010

www.compassionatefriends.org National nonprofit organization that works to support parents, siblings, grandparents, and other family members grieving the loss of a child. Offers an online support community and educational workshops.

Alive Alone

www.alivealone.org National network of parents who have lost an only child or all of their children. Provides newsletters, education, and resources to promote healing.

GriefNet

www.griefnet.org Provides online support groups for different types of loss, including the loss of a child.

Each Year Is Not the Same

Margery Davis, LCSW, Towards Tomorrow Support Group Leader

Through the years, our in-person parent support group has been small, medium, and large. Some parents have come alone and some with a partner or a family member to support them. There are parents who have only just begun living with the incredible pain of their child's death and there are those who have lived with their loss for a year or more. A common and understandable question from newly bereaved parents is "Will this pain ever get better?" A silence usually follows, and another group member explains "The pain just becomes different; each year is not the same."

Parents interested in participating in an in-person or online support group with other MSK bereaved parents may contact Towards Tomorrow at 212-639-6850.