



NATIONAL MARROW DONOR PROGRAM

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COUNCIL MEETING 2013

You're not Alone! Solutions for Housing and Caregiver Availability Challenges

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Financial Disclosures – None

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Learning Objectives

At the end of this session, you'll be able to:

- Identify the barriers to housing and caregivers among the Network.
- Describe patient and professional experiences with housing and caregiver availability.
- Evaluate strategies/solutions which can be implemented at your center.

Topics

- Background
- Survey results: Barrier & solutions
- Panel discussion
- Roundtable discussion

Background

- System Capacity Initiative
 - Patient needs
 - Future growth
 - Benchmarking
- Study
 - Part I: Focus groups
 - Part II: Survey

Housing Barriers

- Adult (N=31)
 - Cost/affordability of housing
 - Lack of insurance benefits for lodging
 - Lack of housing options available
- Pediatric (N=15)
 - Lack of housing options available
 - Housing options full/long waiting lists
 - Cost/affordability of housing

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Housing Resources Available

- Adult (N=31)
 - Discounted hotel rates (84%)
 - Local hotel/motel (58%)
 - Housing owned in collaboration with another entity (39%)
- Pediatric (N=15)
 - Ronald McDonald House (80%)
 - Discounted hotel rates (73%)
 - Local hotel/motel (33%)

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Adult Housing Solutions

- Local lodging options: Hotels & apartment complexes
 - Contract for special rates with local hotels, lodging options
 - Refer to local apartment complex that provides a free apartment for patients during lengthy stays
- Programs
 - Company's foundation has bought and remodeled a house; purchasing two other houses (6 units)
 - Contract with Assisted Living Organization

Adult Housing Solutions

continued

- Financial Assistance
 - Supplement cost of hotel rooms on campus
 - Small fund that helps with lodging costs
- Other Assistance
 - Family members sleep in room with patient
 - Provide housing list

Pediatric Housing Solutions

- Local housing
 - Working with local hotels to offer discounts
- Timing
 - Assess needs at time of referral
 - Provide housing resources at initial meeting
- Workforce
 - Family resource specialist position was created to help address numerous financial needs,
 - Brainstorming other resources (family, friends)

Pediatric Housing Solutions

- Financial support
 - Foundations
 - National Children's Cancer Society
- Ronald McDonald House
 - New Ronald McDonald House was built with 15 transplant rooms on 2 floors separate from the rest of the house.
 - The Ronald McDonald House will prioritize cancer/BMT patients over other referrals received



Caregiver-Availability Barriers

- Adult (N=31)
 - Patient has limited social ties (e.g., no one to ask, estranged from family)
 - Caregiver would lose income
 - Caregiver cannot commit to the required time period
- Pediatric (N=15)
 - Caregiver would lose income
 - Caregiver has family members to care for
 - Caregiver's employer does not provide time off/leave of absence

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Caregiver Resources Available

- Adult (N=31)
 - Allowed to have multiple caregivers (90%)
 - Hire a caregiver using private funds (71%)
 - Hire caregiver using public/government insurance benefit (23%)
- Pediatric (N=15)
 - Allowed to have multiple caregivers (73%)
 - Hire a caregiver using private funds (27%)
 - Child protective services (14%)

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Adult Caregiver-Availability Solutions

- Multiple caregivers
 - Assist patient with identifying multiple caregivers as needed
 - Utilize online/shared calendars for multiple caregivers
 - mylifeline.org
 - otsahelpinghands.org
 - Discounted parking

Adult Caregiver-Availability Solutions

continued

- Early discussion
 - Orientation
 - Emphasize the importance of committed caregiver
- Funding
 - Create fund to help offset caregiver costs

Adult Caregiver-Availability Solutions

continued

- Social work support and support groups
 - Caregiver support group
 - Availability of social worker
 - Close monitoring of caregiving to provide support and resources before a crisis occurs.

Adult Caregiver-Availability Solutions

continued

- Working with caregivers
 - Educate caregiver on FMLA; provide caregiver letters for employers
 - No requirements for caregiver to stay the whole day with a patient.

Adult Caregiver-Availability Solutions

continued

- Community resources
 - Utilizing church and community groups
 - Relationship with an enhanced assisted living facility that will take auto transplants for a 2 week stay.
- Other
 - Providing med alert buttons when there is no caregiver

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Pediatric Caregiver-Availability Solutions

- Financial support
 - Centers offer financial support
 - NMDP financial assistance program
- Community resources
 - Provide assistance for caregiver by being present with patient and allowing them to leave the facility
- Help families with problem-solving
 - Meet as a care team then with family to talk about caregiver agreement created for the situation

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Protocol Team

- Kent Walters, MBA, CMPE
- William Vaughan, MD
- Margaret Bevans, RN, PhD, AOCN, LCDR
- Carolyn Messner, DSW, MSW, LCSW-R, BCD
- Leslie Parran, MS, RN, AOCN, NE-BC
- Kate Pederson, MSW, LICSW
- Navneet Majhail, MD, MS
- Elizabeth Murphy, RN, EdD
- Ellen Denzen, MS
- Stacy Stickney Ferguson, MSW, LICSW
- Emilie Clancy, BA
- Lih-Wen Mau, PhD

Panel Discussion

- Leah Otterlei, MSW, LICSW
 - Clinical Social Worker
 - Blood and Marrow Transplant Program
 - University of Minnesota Medical Center
- Katie Schoeppner, MSW, LICSW
 - Clinical Social Worker
 - Blood and Marrow Transplant Program
 - University of Minnesota Medical Center
- Allison Breininger, MAEd
 - Caregiver

Roundtable Discussion

- Facilitator:
 - Ellen Denzen, MS
 - Senior Manager, Health Services Research
 - Financial Disclosure- None

Roundtable Discussion

- Please discuss among your table challenges that are unique to your transplant center:
 - Housing challenges
 - Caregiver availability challenges

Roundtable Discussion

- Describe innovative solutions and/or resources that your center has in place to help patients with:
 - Housing challenges
 - Caregiver availability challenges

Roundtable Discussion

- Please suggest program ideas for Be The Match® to consider that could help address:
 - Housing challenges
 - Caregiver availability challenges

Thank you!

- Handouts:
 - TC Resources Flier
 - Your Rights and Benefits
 - Finance and Insurance Matters
 - Preparing to be a Primary BMT Caregiver
- Contact:
 - jpreussl@nmdp.org