

Families helping Families

Tips for the caregiver
before, during and after

a

Bone

Marrow

Transplant

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Pre Transplant Efforts

- Learn as much as possible about Fanconi anemia (FA)
 - FARF
 - Publications: handbooks, newsletters, etc.
 - Family Meeting at Camp Sunshine & Adult Meeting
 - Facebook Family Support Group – private group by invitation and managed by FARF
 - FAmily online journeys (blogs, caringbridge, private facebook pages, etc.)
 - Be careful what you find on the Internet, check source and date of posting
- Seek treatment at a recognized transplant center:
 - Referrals from primary care doctor
 - Insurance approval
 - local hematologist interacting with specialized FA hematologist
- Adopt healthy habits
- Raise \$\$\$\$ for FARF to fund research for better treatments, maybe a cure
- Appreciate every day – live life

Insurance

- Request a case manager from your insurance carrier.
- You are your loved one's advocate. And, YOU are the most knowledgeable about your child/loved one. Seek the best possible expert care, even if it means requesting an out of network provider.
- No does not necessarily mean Never. Inquire about the appeal process.
- Be willing to make hard decisions to maintain insurance.

Doctor/Patient Relationship

- Establish a relationship with transplant hospital & hematologist early on
 - Routine screenings and appointments develop into a trusting patient - doctor relationship

Medical History Information Sheet

1 page (2 sided) document containing the following:

- Patient's name, date of birth, address
- Medical History
 - Congenital anomalies
 - Surgeries
 - Medications
 - Hematology status & transfusion history
- Points of Contact (include name, address, phone, fax, ID #)
 - Parent/Insurance Guarantor
 - Primary Care Manager – Pediatrician
 - Transplant Hematologist
 - Local Hematologist
 - Specialty care (Urology, Endocrine, Cardio, etc.)
 - Insurance carrier and assigned Case Manager

*****Make Multiple Copies and Carry it at all Times*****

TRANSPLANT

The only known cure for
bone marrow failure
is a
Bone Marrow Transplant.

Be Honest with Your Child

- Educate your child about FA (age appropriate level)
- 3-6 months out started discussing the transplant process with age appropriate material in small intimate loving sessions
 - Sources:
 - Pediatric hematologist “My Bone Marrow Transplant”
 - Be The Match “Me and My Marrow”
- Talk about it all - the good, bad and the ugly
- Be Positive! * This is a Life Saving Experience*

Transplant Facility

- Tour facility with patient (child) ahead of time
- Patient privileges
- Parent (caregiver) privileges
- Restrictions
 - Discuss special meds or foods with dietician & doctor
- Visitor policy
- Patient room – personalize it
 - Bed sheets from home
 - Holiday decorations
 - Books, music, video games
 - Family photos/ posters
 - Soft pajamas and hats

Family Readiness

Divide responsibilities with partner/others

- Fielding insurance issues (a transplant case manager should be assigned when approval authorized for BMT)
- Medication/Medical appointments
- School – both for patient and siblings
- Household
 - Bill paying
 - Care of siblings
 - Extra help needed to grocery shop, cook meals, laundry, clean house, transport siblings to after school activities, etc?

Education

- School provided a tutor at home while in isolation, before and after transplant
- Hospital Education Coordinator
 - Establish video link with patient's classroom
 - Hospital tutor can use same curriculum
 - Provide written request to home school district for education accommodations after transplant (Summer tutoring, IEP, 504, etc.)

Communication

- Within immediate family
- Extended family & friends (caringbridge site, facebook, text, skype)
- School
 - Patient's teacher
 - Alert sibling's teachers to situation at home
- Wireless Internet / Computer access / WiFi at hospital

FAMILY SUGGESTIONS

- Create a Daily Activity Chart for patient while in hospital
- Wrapped prizes/rewards for difficult activities (mouth care)
- Tap hospital personnel resources:
 - Social workers to aide family during transplant
 - Child Life Specialists to engage patient, siblings

FAMILY SUGGESTIONS (con't)

- Bring something soothing for caregiver while patient is sleeping during daytime: book, Bible, knitting, iPod with favorite soothing music, laptop, electronic games
- Travel lint brush (sticky wand kind) – roll over patient's head to remove loose hairs from chemo
- Try to do something physical for yourself (climb stairs to and from cafeteria, walk around to discover something new, etc)

Post Transplant - Extended Stay

- Discharged from inpatient care but need to stay locally
 - Find out before transplant what expenses your insurance will cover for patient and adult companion for both inpatient and outpatient
 - Your social worker can assist with local lodging (Ronald McDonald house, etc.) and any other items you might need during stay
- Complications and readmission to the hospital can happen, even with a sibling donor.

Transplant forever
changes everyone
in your
family.