Hope, Trust, and Access to Transplant Information

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Debbie Berg Post Transplant

Transplant Reunion: We are in the business of hope
In A Land Called Overwhelm

Number of Transplants is Increasing

- Over a 1 million patients have been touched by bone marrow transplant.
- SCCA performs over 400 Transplants each year.
Straightforward Mission

- Simple
- Direct
- Clear
- By steps, provide anticipatory guidance.
- Provide details when appropriate.
- Provide what is taught while pointing out the common emotional struggles that impact understanding.

Debbie Berg Sharing her Experience

- 4 years post Auto transplant
- Poem tells so much
- My experience can inform the way you guide future patients
Outline

- Information accessible for staff, patients, and caregivers will be reviewed throughout the presentation.
- Review steps involved in transplant process.
- Review role of caregiver and time commitments.
- Address commonly asked questions and issues.
- Review support, resources, and information available as patients make transitions to pre-transplant and post-transplant care.
- Hear from someone that has been there.

Why have a Transplant?

- Because you have to …..
In the business of hope and no regrets

“Hope is faith holding out its hand in the dark.”
-George Iles

National Marrow Donor information

- NMDP - Why have a transplant? Because you have to... [http://bethematch.org](http://bethematch.org)
- Survivorship data and number of transplants are available by center on the site.
- How many transplants have been done by disease, and center can be found at this site – very overwhelming information.
Distribution of Allogeneic

Example of the Data
Purpose of Consultative Visit

- Meet with the doctor and other team members
- Tour the building
- Pretransplant book sent ahead of time

Types of Transplants

- Allogeneic/Mixed Chirmerism
- Autologous
## Source of Cells

- Related
- Haplo
- Unrelated
- Cord
- Syngeneic
- Self

## Overview of Types

Transplant Decision

- Disease
- Response to chemo
- Able to reach remission
- Health of body systems
- Age
- Donor options

Auto Diseases

- Multiple Myeloma
- NHL
- HD
Allo Diseases

- AML
- MDS
- ALL
- Aplastic Anemia
- CLL

Non Malignant Diseases

- Inherited metabolic disorders such as Hurler, SCIDS
- Autoimmune diseases - such as Systemic Sclerodema
Diseases

- Extensive list of all diseases and subtypes of diagnoses are provided.

Decision Has Been Made
Transplant Steps—See Handout

- Planning ahead
- Preparation
- Conditioning
- Transplant
- Waiting for Engraftment
- Recovery
- Long term Recovery

Use the information from the center you are sending the patient

- Too much information overwhelms patients and inconsistent information confuses people.
- For example, we ask that the National Bone Marrow information not send pretransplant, because it adds to the confusion.
- A member of the Patient Ed Advisory committee for Be a Match (NMDP).
Trust

• “Trust is the easiest thing in the world to lose, and the hardest thing in the world to get back.”
  - R. Williams
• Consistent information is foundation of trust

Intake

Transplant Team

• Clinical Coordinator MD who speaks directly with callers, reviews cases, and determines next steps
• Transplant Coordinators provide education for patients and donors and assist with protocol assignments.
• Patient Care Coordinators schedule patients and coordinate the procurement of external medical records, diagnostic films, and pathology slides.

The Clinical Coordinator can be reached by phone at (206) 288-7222 or email at hutchdoc@seattlecca.org.
Unrelated Donor Program

Unrelated Donor Search

• Patients in need of an allogeneic bone marrow or stem-cell transplant who do not have a suitable donor match in their family work with the Unrelated Donor Program to find a match.

• The search specialists work with registries worldwide to find bone marrow, stem-cell, or cord blood donors.

Donor Information

• HLA handout
• Stem cell guides – one contained in the Pre-transplant book
Information Packet (Intake)

• Letters
• Preparing for Transplant book and donor information in same book
• Video links and classes within the Preparing for Transplant
• Clinic Brochure

Clinic Brochure

• Phone Directory of Services
• Directions & Parking Information
• Housing Information
  – SCCA House
  – Pete Gross House
  – Ronald McDonald House
• Billing Information & FAQs
• Advance Directives
• [Website Link]
Orientation Videos in Facebook

- Orientation video available in English and Spanish
- [https://videocenter.seattlecca.org/videos/channel/10/recent/page1/](https://videocenter.seattlecca.org/videos/channel/10/recent/page1/)
- Video has images of each floor of the Clinic
- Older transplant video

Planning Ahead: Issues

- Housing
- Financial issues
- Kids-Hutch school is available for siblings
- Immunizations for family members
- Advance directives
- Fertility
- Caregiver
Planning Ahead

- Understand the basics
- Panic & Frustration
- Logistics
- Need for caregiver
- Financial considerations
- Fertility
- Kids and other family members

“Preparing For Transplant” Book

- Practical answers
- Types of transplant
- Caregiver expectations
- Steps of the transplant
- Directions
- Support services
- Glossary of terms
“Preparing for Transplant” tour

www.seattlecca.org/patienteducation

Housing

- Patients MUST stay within 30 minutes of the SCCA Clinic during Transplant
- Patients can stay in other housing
  - Other apartments
  - Hotels
  - Single house rentals
- RV parks can decrease cost

www.seattlecca.org/client/forms/SCCA-Housing-Information.pdf
Financial

• Out-of-pocket costs
• Housing costs
• List of resources provided to focus in travel and financial funds.

Kids and Family Milestones

• Hutch School - great resource
• Family intact positive, yet a stress
Immunizations

- Household members need to be up to date to protect the patient.
- List is provided

Advanced Directives

- Recommend a medical power of attorney
- Best to have these intense conversations before the Transplant
Fertility – First Things First

• **What are my fertility options?**
  Undergoing treatment with radiation and chemotherapy puts both males and females at risk of becoming infertile. Difficulty in conceiving a child as a result of these therapies may be temporary or permanent. Several factors, including your gender, age, type of chemotherapy drugs used, location of radiation, total dose of chemotherapy and/or radiation, and length of time since treatment all influence the ability to have a child after cancer treatment. It is difficult to predict the outcome for any individual. Your oncologist can discuss the fertility risk of your particular treatment with you.

• **Women need more time than men.**
  • Insurance coverage for fertility interventions varies. Work with your reproductive clinic to determine what may or may not be covered and what the costs will be. Ask them about financial assistance programs such as Sharing Hope.

Caregiver and Location

• **Caregiver requirement**
  – Live within 30 minutes of Clinic
  – Only very acutely ill patients in hospital
  – Triage RN available 7 days/week
  – RN telephone triage available 24/7
  – Minimum Clinic visit schedule is 1x/week
The Caregiver’s Role

• Expectations are outlined in the “Preparing For Transplant” book
• What is the most stressful at the beginning and in the long run?

Caregiver Expectations

• Responsibilities - Clinic visits, medications, central line care, food, home infusions, calling for symptoms, communication, schedules, cleaning, advocacy
• Consistent, Intermittent, Minimal
• What is the most stressful at the beginning and in the long run?
How long do patients need caregivers?

- Typical Autologous - month plus
- Typical Allogeneic - 4 months and beyond

Caregiver Companion Guide

- Includes helping children to cope
Bookmarks - Make it Simple

Online Transplant Resources

- “Preparing for Transplant” book—includes donor information and videos
- Clinic Brochure
- Allogeneic manual
- Autologous manual
- Caregiver Companion Guide
- Central Line information
- Facebook and Video library
Facebook Page – Can help

- [www.facebook.com/scca\n  patientfamilyeducation](http://www.facebook.com/scca\n  patientfamilyeducation)

- No log-in needed
  - Symptom management
  - Upcoming classes
  - Coping with treatment
  - Support/Encouragement
  - Food recalls
  - Clinic Updates

Video Library

- Over 80 videos available
  - Memory and Concentration
  - Oral Chemotherapy at Home
  - How to Talk to Your Doctor
  - Relaxation Videos
  - Caregiver Informational Luncheon

- Live Streaming available for
  Classes/Lunch & Lecture Series
Video Library-Transplant Specific Classes

- Managing Care at Home
- Food Safety
- Central Line Classes-series
- Long Term Follow Up
- GVHD
- Donor Selection Class
- Caregiver Informational Luncheons

Infection Control Education

- Flu shots for caregivers and not patients
- Hand washing and finger nails/acrylic nails
- High risk activities and fungal risk
- No supplements
- No gardening
- Use of masks
- Cleaning suggestions
High- Risk Activities

- No new pets—After tx
- Plants—none in the home
- Marijuana
- Dirt
- Weeding
- Construction
- Plumbing problem with mold
- Sleeping with pets

Infection Control Education

Long term infection control suggestions and frequently asked questions in the last chapter of the manual.
Donors

- Video about donor search online in video library
- Stem Cell Guides – one for donor, one for patient
- Most donors arrive on same date as the patient
- Workup, education, informed consent ~ 3 days
- Donor can leave and return when mobilization for cell collection starts – usually patient has started conditioning.
- Schedules are planned in parallel so donor will be collected at the end of patient’s conditioning.

Transplant Steps

- Planning ahead
- Preparation
- Conditioning
- Transplant
- Waiting for Engraftment
- Recovery

\[ \text{Transition} \]
Preparation

- Written Resources
- Meetings
- Classes
- Exams and tests
- Central line
What happens when patients arrive?

1st day:
- Registration
- Blood Draw
- H & P with advanced practice provider
- Followed by 1 hour meeting with Team RN
  - Given Patient Resource Manual
  - Schedule for rest of week reviewed
  - Names of Team Members and their contact numbers
  - Emergency phone numbers
  - Consents to review for meeting with attending MD next day

What is the pre transplant workup like?

2nd Day
- Conference with Attending MD and Team RN
- BMA

3rd Day
- Social work assessment
- “Orient/Teach” with Team RN

Over next 5-6 workdays
- Pharmacist Assessment
- Nutrition Assessment
- Pulmonary Function Tests
- Oral Medicine
- GYN
- Radiology appropriate to their disease
- LP

Phase ends with “Data Review” Conference with Attending MD and Team RN where consent for Transplant is signed
Conditioning

- Inpatient or outpatient
- Length of stay varies
- Dramatic period

Recovery and Post Transplant

- Minimum of 2 Clinic visits a week, more often if neutropenic
- Back and forth to the Clinic
- Highs and lows
- Intense and fatiguing
- Emotionally draining for patient and caregiver
How long do patients stay in Allogeneic Transplant Program?

Total about 4 months:
- Workup/informed, intensive education, consent for Transplant ~ 2 weeks
- Line insertion Day before chemo/ total body irradiation starts
- Start conditioning ~ 6 days
- Transplant
- Transfer back to referring MD ~ 100 days post transplant

How long do patients stay in Autologous Transplant Program?

- Total about 2-3 months
  - Workup/informed consent for Mobilization and Collection
  - Mobilization
  - Collection/cells frozen

- Usually wait a minimum of 1 month before:
  - Additional workup/informed consent for Transplant
  - Line insertion
  - Start conditioning
  - Transplant
  - Transfer back to referring MD ~ 30 days post transplant
Issues Post Transplant

- Infections and long term immunosuppression—nothing magical about 100 days post transplant
- Readmission after going home—commonly fever
- Long term infection control guidelines in last chapter.
- Secondary Cancer increases after 5 years
- Bone Health
- Fear of Recurrence
- Skin health

Allo Issues

- GVHD and steroids
- Steroid-induced diabetes
- Cataracts—If TBI, 20% develop cataracts within 5 years
- Skin and mouth changes
Vaccinations

• Recommendations are outlined in the manual for one year after transplant.
• If patient is around some one who had the Varicella vaccine, patient should take acyclovir

Helping with Separation Anxiety

• Long-term follow up class and department
• Survivorship
• Frequently Asked Questions for infection control
• Chapter in manual
• Home Packet
• Outside resources and online support groups
LTFU Clinical Program

- Telemedicine – 5 days/week
  - 2-3 RNs/day available on phone for patients and providers
  - Rounds with medical providers 3x/week
- Consult Clinic Visits 20/week
  - Recommended annually for allo transplant patients – 1 week
  - Some patients seen more often for consult (every 4 months)
- Transplant Transitional Clinic
  - Similar to other acute care teams - Total patient care
  - ~ 20 patients

Long Term Follow Up Information


- The Long Term Follow Up class is online.
Recommendations

- Patient Recommendations
- Physician Recommendations – 100 pages long

LTFU Support Group

Long Term Support for Patients and Caregivers after Transplantation

Please join us for conversation and camaraderie with other patients and caregivers. Come to listen and share as much as you want.

Location: 6th floor, Room 3
Time: Thursdays, 11:30 am - 12:30 pm

Unable to join us? Feel free to contact us on the conference line: (644) 715-5300. At the prompt, enter 882679#.

Questions? Call Anne Chafee at LTFU: (206) 667-4415
Separation Anxiety

• Happy to be done, but the routine gives the person a sense of purpose and calm
• Prevent Falling off a bridge

Resources After Transplant

• Online resources
• See handout
Online Access

- www.seattlecca.org
- Educational materials
  - www.seattlecca.org/patienteducation

Emotional Memory

“I’ve learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.” - Maya Angelou
Chronic Issues and Emotional Sequelae

- Profound emotional responses impacting patients and caregivers, including PTSD
- Depression patients caregivers
- Profound physical changes
- Fatigue
- Memory changes
- GVHD

Concerns about Relapse - Debbie

- The elephant in the room let us keep this real
Questionnaires Online

- Positive and Negative comments, speaking to quality of life issues.

LTFU Contact Information

- Phone = (206) 667-4415

Handoffs between Institutions

- Confirm date of 1st appointment
- Medication list/any tapers
- Main clinical issues
  - Vascular Access? Home Infusions?
  - Graft Versus Host Disease for Allos
  - ID
    - Isolation?
    - CMV screening plan
  - Transfusion dependent?
    - Frequency of RBCs, Platelets, last transfusions
- Psychosocial Issues?

Contact Information

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Questions and Discussion