

**COUNCIL MEETING***Sharing Our Passion for Life*

# Breaking Bad News The Donor Perspective

## Council Meeting 2016

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## Disclosures

The following faculty and planning committee staff have no financial disclosures:

Name	Institution
Jackie Foster, MPH, RN	NMDP, Be The Match
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Corina Gonzalez, MD	Lombardi Comprehensive Cancer Center/MedStar Georgetown University Hospital

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# Learning objectives

**At the conclusion of this session, attendees will be able to:**

- Describe 2 main types of communication needs (emotional vs. cognitive) a person may have when discussing serious or bad news
- Describe techniques and tools to help communicate serious or bad news in a way that is informative and addresses the person's communication needs
- Apply communication strategies to improve communication around serious or bad news with donors

## Definition of Bad News



- Any information which adversely and seriously affects the individual's view of the future.
- A message that conveys negative or unpleasant information and is likely to disappoint or upset the individual.

## Case 1:

14 year old female with sickle cell disease undergoes a bone marrow transplant in 2014. Her 16 year old brother was her related matched donor. Post-transplant complications included acute GVHD, chronic GVHD, opportunistic infections (treated) and avascular necrosis of both knees and left elbow. It took this patient 2 years to recover from her chronic GVHD and she is now scheduled for knee replacements this coming summer. She restarted school this academic year and so did her brother.



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## Case 2:

13 year old son donates peripheral blood stem cells to his father who has AML (half match). Donation occurs during the academic year and we requested – briefly explaining the rationale – a 7day excuse from school for the donor.

Before collection one of his teachers calls him to the front of the class and shares with his classmates that he will save his father's life. "This boy is a hero"-she said.

Donation proceeds without problem. His father undergoes allogeneic transplant and suffers a disease relapse 6 months after. Donor becomes depressed and refuses to go to school.



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## Case 3:

Videotape

Unrelated donor sharing her feelings about receiving bad news



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## Comments? Observations? Reflections?

- What do these cases have in common?
- What could have been their motivation to donate?
- What sources of information were available to the donors and relatives or friends?
- Could we have prevented these donor outcomes?
- Would these cases change your practice?



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## Unexpected bad outcome – Donors' feelings

- Intense disappointment
- Sadness and depression
- Unable to come to terms with the news
- High burden of responsibility, guilt

*One can never estimate the impact until we have an idea of the person's expectations and understanding of the process*

## Motivations to donate

- **Saving a life:** *moral duty, way of giving back*
- **Family loyalty:** *responsibility to donate, survival of a loved one depended on their donation*
- **Religious conviction:** *a way of repaying god, feeling that they were chosen by god*
- **Building a positive identity:** *gain sense of pride or self confidence, outdo others*
- **Social pressure and obligation:** *donors seen as positive role models, it could be viewed as coercion or pressure to donate*
- **Fear of invasive procedure:** *a way to overcome personal fears*



# Sources of Information for Donors



- The media (TV, Social Media / publications)
- Registry Websites / Donor – Recipient stories
- Word of mouth



- Donor Centers
- Apheresis and Collection Centers
- Transplant Centers



- Informed Consent
- Informed Consent Session

*Progress in transplantation Vol. 24 No2: 129; 2014*



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Josep Carreras  
LEUKAEMIA FOUNDATION

Our fight will endure  
**UNTIL THERE'S A CURE**

**BE THE MATCH** **one match**  
stem cell and marrow network

Be The One to Save a Life

**DKMS**  
WE DELETE BLOOD CANCER

**GIVE SOMEONE A  
SECOND CHANCE AT  
LIFE**

**GIFT  
OF  
LIFE**  
**MARROW  
REGISTRY**

**Register as a Donor**

Take the first step towards a cure.  
Join the bone marrow registry today!

Choose to be a bone marrow donor.  
Choose to save a life.



**BMDP**  
Bone Marrow Donor  
Programme

**save a life**

CENTRE to advance public awareness & recruitment of  
BONE MARROW DONOR  
VOLUNTEERS  
UNIVERSITY OF PATRAS (CBMDP)

**ANTHONY  
NOLAN**

saving the lives  
of people with  
blood cancer



ACT NOW. GIFT A LIFE.

**DATRI**

Blood Stem Cell  
Donors Registry



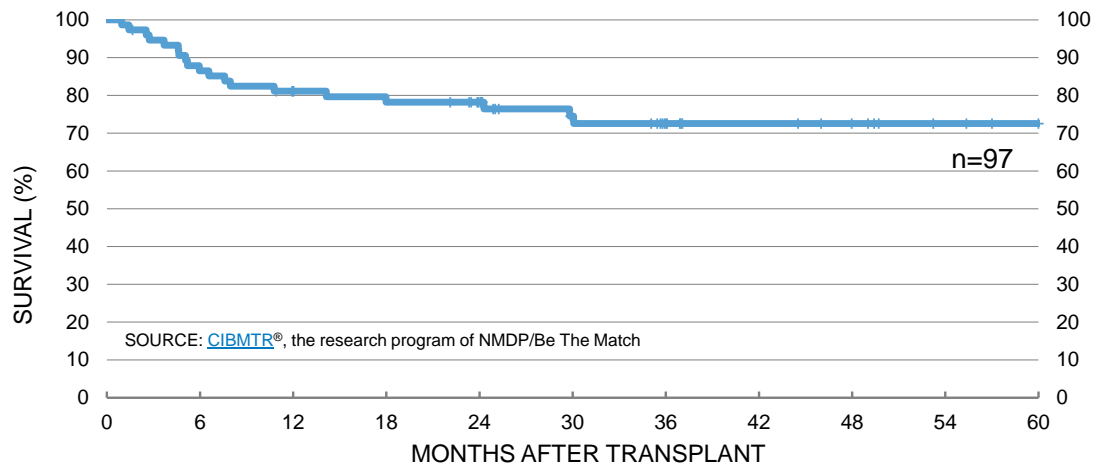
Salvar uma Vida: tornar-se um  
doador voluntário de medula óssea



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## Sickle Cell Disease Overall Survival

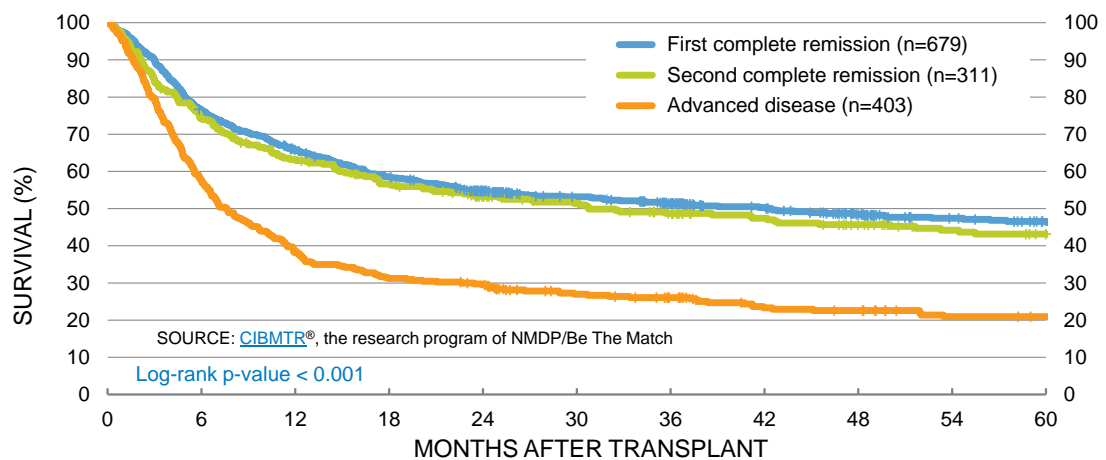
Transplantation with Bone Marrow, PBSC and Cord Blood for Pediatric Patients  
Unrelated Transplants Facilitated by NMDP/Be The Match (2004-2013)



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## Acute Myelogenous Leukemia Overall Survival

Bone Marrow Transplantation for Adult Patients by Disease Status at Transplant  
Unrelated Transplants Facilitated by NMDP/Be The Match (2004-2013)



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## Some Conclusions

- Good results make the news
- Donor / Recipient stories are highly inspirational
- Catchy single liners used in advertisement imply cure, are highly effective, used widely and I do not think that needs to change
- Donors may have different motivations to proceed with donations
- Transplant outcomes are available but very technical.
  - *Transplant is not a guarantee of cure*
  - *If the transplant doctor is requesting it is because transplant will increase the chances for your recipient of surviving his disease in a significant way*
  - *Even if it works only for a period of time, extending life is precious*

## Why give bad news?

- Donors want to know about the recipient
- Donors want to know the truth
- We are ethically bound to provide the the information we promised





## **SPIKES: A system to optimize delivery or receipt of bad news (modified for donors)**

- **S**et up the interaction
- **P**erception: assess donor's understanding
- **I**nvitation: obtain permission to give Information
- **K**nowledge: provide at tailored level
- **E**mpathy: acknowledge emotions
- **S**trategy/Summarize

*Baile WF et al., Oncologist 2000; 5: 302-11*



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## **Set up the interaction**

- Physical setting is important  
Manage time and interruptions
- Call home, not work. Know best time to call from previous contacts
- Ask if donor has significant others present that may offer support on site
- Use a translator if needed



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## Perception:

- Know your donor's motivations to donate
- Easiest way perform an assessment at first contact
- Check your notes

## Information

- Provide the information about the recipient's outcome
- Specify if recipient engrafted if you know it –good parameter to say that your stem cells worked well
- Provide a positive statement, if possible – make their donation meaningful in some way
  - *You gave the recipient hope*
  - *You gave the recipient time*
  - *You gave the recipient the possibility to do... or be with....*
  - *Add a religious statement, if you know is important for them*
  - *You gave the recipient's family the inner peace of providing any treatment modality available*

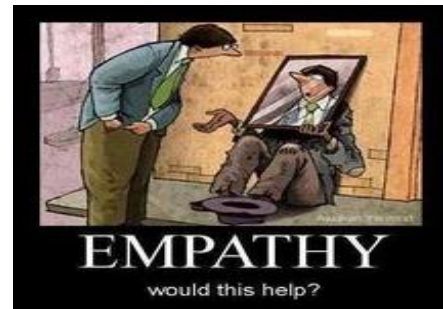
# Knowledge Conveyance



- **Convey** information in lay language, in manageable amounts; use pauses to allow processing
- **Assess** understanding along the way
- **Acknowledge** that is OK to feel sad and disappointed. But that you know that he/she did her best.
- **Guide:** you may feel sad for a while
- **Reassure:** clarify that nothing that they did made this happen.

# Empathy

- **Acknowledge whatever emotion is expressed**
  - I see that you're upset.
  - Would you like to share what you're feeling and thinking right now?
  - You must be very angry that the disease is back even though you did everything asked of you.
  - I feel sad with you.
  - I wish the news were better.
- **Exploratory questions:**
  - Could you tell me more?
  - You said you are worried. Could you describe your concern?
  - What is it that you fear?
- **Validate responses**
  - I can imagine why you must feel that way.
  - Many donors expressed the same, too.
  - It seems to me that you have a solid understanding of this.



## Strategy/Summary

- Donors may need time to understand and heal
- Encourage them to talk to friends and family about his/her feelings
- Be available to them if they need to discuss further information in the future
- Set up a follow-up call



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## Conclusions

- Giving bad news is an important and unavoidable part of life but there are ways to optimize its delivery.
- It is our responsibility to care for donors both physically and mentally.
- Know your donor. You will understand the impact of delivering bad news to then better.
- Always recognize the donor for their selfless gift. Make their donation meaningful, if possible.
- Pay attention to the setting.
- Deliver information in a way that the donor can digest.
- Be cognizant of cultural and language considerations.
- Follow-up.



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# Acknowledgments



- NMDP Council organizers for the opportunity to speak today
- Many many donors and patients who have taught us and inspired us all with their courage and strength