

Stem Cell Transplant Survivorship

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THE UNIVERSITY OF TEXAS
**MDAnderson
Cancer Center**

This slide is the title page for a presentation. It features a blue background with a white vertical bar on the left. The bar contains a photograph of a modern multi-story building, likely a hospital or cancer center, and the MD Anderson Cancer Center logo at the bottom. The main title 'Stem Cell Transplant Survivorship' is in a large, bold, black font. Below the title is the presenter's name and credentials. The MD Anderson Cancer Center logo is at the bottom left.

This session will discuss:

- ▶ **Unique issues related to survivorship for transplant patients beyond GVHD.**
- ▶ **Include both adult and pediatric survivorship issues**
- ▶ **Suggestions for good health behavior and support resources.**

Objectives

- ▶ **Explain unique survivorship issues that transplant patients may experience.**
- ▶ **Describe support materials that will assist transplant patients through the survivorship continuum.**

Goal of Stem Cell Transplantation

- ▶ **Disease cure**
 - Long term remission
- ▶ **Full restoration of health and quality of life**

▶ Tichelli, 2008

Survival is improving and patients are experiencing better quality of life during treatment and in the early recovery period.

- ▶ Expanding pool of stem cell sources
- ▶ More effective, less toxic regimens
- ▶ New supportive care drugs
- ▶ Maintenance therapy

Cause of Death

- ▶ **Disease relapse or progression is the most consistent variable that limits long term survival in the stem cell transplant recipient, both autologous and allogeneic.**

▶ Majhail, 2008

Cancer survivor

- ▶ One who has been diagnosed with cancer from the time of diagnosis through the balance of that person's life
- ▶ The National Coalition of Cancer Survivors (2009) definition includes
 - ▶ the patient family,
 - ▶ caregivers and
 - ▶ friends

Stem Cell Transplant Survivor

- ▶ When providing survivorship care the definition may be:
- ▶ One who has lived through stem cell transplant
 - From the end of active treatment and acute recovery
 - through the evidence of disease relapse, progression or death.

Stem Cell Transplant Survivorship

- ▶ Encompasses all aspects of the survivors life experience
 - Physical
 - Functional
 - Developmental
 - Cognitive
 - Psycho-emotional
 - Social
 - Spiritual

The Goals of Survivorship Care

- ▶ provide education for empowerment,
- ▶ promote wellness,
- ▶ identify problems early,
- ▶ intervene quickly, and
- ▶ provide communication and direction to community health care providers

Long term effect

- ▶ Disease or treatment related adverse effect which is active during treatment and continues beyond the end of treatment for months to years.

Late effect

- ▶ Disease or treatment related influence on the patients health/life experience months to years after the completion of treatment.

Labels in transition

- ▶ Long term follow up clinic/program
- ▶ Late effects clinic/program
- ▶ Survivorship clinic/program

- ▶ All of these programs generally have the same goal.

Risk Factors for Development of Long-Term or Late effects

- ▶ Age at diagnosis/treatment
- ▶ Comorbid conditions
- ▶ Past treatment(s)
 - Consider previous cancers
- ▶ Graft versus host disease

Age at diagnosis and treatment

- important in children and adolescents because of developing organs in the growth phase vulnerable to damaging effects of treatments
 - developing brains, skeletons and sex organs

- important to remember developmental stage for both the pediatric and adult survivor
 - Schwartz, 2007

Comorbid conditions

- Diabetes
- Cardiovascular disease
- Pulmonary disease
- Depression

Treatment history

- Surgery
- Chemotherapy
 - Intrathecal chemotherapy
- Radiation
 - cranial radiation PRIOR to transplant conditioning
 - chest
- Dose, duration and site of treatment

- Take into account past cancers and the impact of those treatments

Development of GvHD

- ▶ Drugs used to treat graft versus host disease and the myriad of adverse effects
 - Infectious complications
 - Microvascular damage
 - Renal function changes
 - Steroid myopathy

- ▶ Site/extent of GvHD

- ▶ Autologous versus allogeneic

Survivorship Care

- ▶ Surveillance
- ▶ Risk reduction and early detection
- ▶ Monitoring for late effects
- ▶ Quality of Life

Survivorship Care

- ▶ **Surveillance:**
 - Disease
 - Graft versus Host Disease
 - Immune Status

Survivorship Care

- ▶ **Risk Reduction and Early Detection**
 - Wellness promotion
 - Weight control, Nutrition, Exercise
 - Sun protection
 - Meticulous self exams: oral and skin
 - Aggressive management of comorbid conditions,
 - ie DM, HTN, Dyslipidemia, B/P control
 - Re-vaccination
 - Risk factor and age related screening
 - Cancer
 - Blood pressure
 - Lipid

• Domino 2009

Survivorship Care

- ▶ **Monitoring for late effects**

Hematologic

- Hematologic
 - Secondary malignancy:
 - myelodysplasia, Acute myeloid leukemia
 - B cell lymphoproliferative disorder (PTLD)
 - Iron overload

• Demarosi, 2005; Majhail, 2008; Ortega, 2005
• Argyropoulou, 2007; Rizzo, 2006

Other secondary malignancies

- ▶ Solid tumors
 - Squamous cell carcinoma of oral tissues, head, neck and vulva
 - Thyroid cancers
 - Melanoma and non melanoma skin cancers
 - Breast cancer
 - CNS tumors

◦ Demarosi, 2005; Majhail, 2008; Ortega, 2005; Rizzo, 2006

Neurologic

- Neurologic
 - cognitive
 - memory, concentration/focus, word finding
 - neuropathy
 - pain
 - hearing

Immunologic

- ▶ Late Infection

▶ Robin, 2007; Socie, 1999

Endocrine

- ▶ Endocrine
 - Growth and development (pediatric)
 - Skeletal linear growth and body composition (growth hormone related)
 - Organ
 - Gonadal failure/Early Ovarian failure/premature menopause
 - Infertility
 - Thyroid disease: hypothyroidism
 - Diabetes
 - Bone mineral changes
 - Osteopenia, osteoporosis, avascular necrosis
 - pathologic fracture

• Vance, 1999; Socie, 2008

Ophthalmologic

- Dry Eyes
 - Sicca Syndrome
- Cataract
- Retinopathy

◦ Ogawa, 2002; Leite, 2006
◦ Socie, 2003

Oral/Dental

- ▶ Oral/Dental
 - ▶ Sicca syndrome
 - ▶ Infectious: viral, fungal, bacterial
 - ▶ Dental caries
 - ▶ Tooth development in pediatric survivors
 - ▶ Agenesis: lack of development of permanent teeth
 - ▶ Microdontia: reduced size of permanent teeth
 - ▶ Taste alterations

▶ Epstein, 2002; Curtis, 1994; Holttta, 2005

Cardiovascular

- ▶ Stroke
- ▶ Coronary Artery Disease
- ▶ Peripheral Artery Disease
- Hypertension
- Dyslipidemia
- Metabolic syndrome
- Cardiomyopathy

Tichelli, 2007; Tichelli, 2008; Couriel, 2005; Biederman, 2002

Pulmonary

- Pulmonary
 - Obstructive
 - Restrictive
 - Diffusion disorders

• Socie, 2003; Bunin, 2007

Gastrointestinal

- ▶ hepatitis,
- ▶ cholestasis,
- ▶ gastroparesis,
- ▶ failure to thrive,
- ▶ weight gain

Renal

- ▶ Renal
 - chronic kidney disease

• Hingorani, 2006; Kersting, 2007; Rizzo, 2006

Genitourinary

- ▶ hemorrhagic cystitis,
- ▶ urinary urgency
- ▶ erectile dysfunction

Muscular/joint

- ▶ atrophy
- ▶ pain
- ▶ joint contractures

▶ Syrjala, 2010

Integumentary

- ▶ Integumentary
 - ▶ Skin changes and lesions
 - Hair thinning and poor regrowth
 - Hair pattern distribution changes
 - Nail growth pattern changes

Survivorship Care

- ▶ **Quality of Life**
 - Psychosocial screening
 - Work/School
 - Financial
 - Social integration
 - Sexuality

• Schulmeister, 2005. Worel, 2002. Mosher, 2008. Tierney, 2004

- ▶ Fatigue
- ▶ Sleep disorders
- ▶ Body image disturbance
- ▶ Sexuality/sexual function impairments
 - Poor libido
 - Vaginal dryness, Loss of pleasure, pain,
 - Erectile dysfunction
- ▶ Anxiety disorders, depression
- ▶ Post traumatic stress disorder
- ▶ Post traumatic growth
 - ▶ Socie, 2003. Chatterjee, 2000, Syrjala, 2009.

An interesting concept

- ▶ Post traumatic growth
- ▶ The concept of thriving after stem cell transplant
 - Bishop, M.M. and Wingard, J.R. (2004). *Thriving after hematopoietic stem cell transplant: a focus on positive changes in quality of life*. Expert Reviews in Pharmacoeconomics Outcome Research, 4(1), 111-123.
 - Lee, S.J. et al. 2003. *Optimistic expectations and survival after hematopoietic stem cell transplantation*. Biology of Blood and Marrow Transplantation, 39, 595-603.

The importance of survivorship assessment

- ▶ Review systems
 - Zero in on the negative **and** the positive responses
- ▶ Look at some “snapshots” of **life and living**
 - Tell me about your usual day...
 - Tell me some of the things you have been doing for fun...
 - How are those kids/pets/grandkids?
 - What activities do you do with the...

Immersion Tips

- ▶ Remember that every moment you are spending with the survivor is an “assessment”
- ▶ Discuss the **positive** first
- ▶ Help the survivor get some perspective from an outside observer (you), reading materials
- ▶ Ask what their priority “issues” when looking at review of systems.
 - Teach, discuss, suggest, counsel, provide written materials, websites etc.
 - Help with goal setting

Maintain a healthy weight



Participate in daily physical activity



Weight bearing and resistance exercise



Consistently use sun protection

- ▶ Get yearly skin exams

Wearing sunglasses



Limit alcohol intake



Do not smoke



Re-immunize
Receive influenza vaccine yearly



Socialize



Manage health problems



Participate in health screening



Know your resources

- ▶ www.bmtinfont.org
- ▶ www.marow.org
- ▶ www.nbmtlink.org
- ▶ www.supersibs.org
- ▶ www.cancercare.org
- ▶ www.stupidcancer.com
- ▶ <http://www.planetcancer.org/>
- ▶ www.fertilehope.org
- ▶ www.oncofertility.northwestern.edu/
- ▶ www.resolve.org/
- ▶ www.lls.org

- ▶ www.cancer.org
- ▶ <http://www.cancer.gov/>
- ▶ <http://www.vitaloptions.org/>
- ▶ <http://www.youngsurvival.org/>

- ▶ Books
 - Woman Cancer Sex Anne Katz
 - Man Cancer Sex

Internet Explorer browser window showing the National Bone Marrow Transplant Link website. The URL is http://www.nbmmlink.org. The page features the nbmmlink logo and a navigation menu with links for Home, Site Map, Contact Us, and Terms of Use. The main heading is "A second chance at life is our first priority". Below this, there is a "Welcome!" section stating the mission of the National Bone Marrow Transplant Link to help patients, caregivers, and families cope with the social and emotional challenges of bone marrow/stem cell transplant. A "What We Offer" section lists services such as in-depth information, practical support, and links to online resources. A "Stay Informed!" section encourages signing up for newsletters and staying informed about events. A "nbmmlink Online Library" section offers specific advice on bone marrow/stem cell transplant.

Internet Explorer browser window showing the National Bone Marrow Transplant Link website. The URL is http://www.nbmmlink.org. The page features contact information for the National Bone Marrow Transplant Link, including a phone number (1-800-LINK-BMT) and an address in Southfield, MI. A "Feel free to download any of our original publications" section lists various resources. A "What's new at the National Bone Marrow Transplant Link?" section highlights new publications, including "Voices of Hope & Healing for Bone Marrow/Stem Cell Transplant" and "Survivorship Guide for Bone Marrow/Stem Cell Transplant, Coping with Late Effects". A "New Available!" section lists topics such as Emotional Well-Being, Sexuality and Intimacy, and Returning to Work.

Internet Explorer browser window showing the CancerCare website. The URL is http://www.cancercare.org. The page features the CancerCare logo and a navigation menu with links for Our Services, Help By Diagnosis or Topic, Stories of Help and Hope, and Ask CancerCare. The "Our Services" section lists various support services, including financial assistance, counseling, and survivorship. The "Help By Diagnosis or Topic" section lists various cancer types and topics, such as Breast, Lung, and Financial Assistance. A "Calendar at a Glance" section lists upcoming events, including the 30th Annual San Antonio Breast Cancer Symposium. A "From Our Blog" section features a post about financial help for women coping with metastatic breast cancer.

Internet Explorer browser window showing the Post-Treatment Survivorship section of the CancerCare website. The URL is http://www.cancercare.org/page/post-treatment-survivorship. The page features a heading "Post-Treatment Survivorship" and a sub-heading "Browse all resources about Post-Treatment Survivorship." Below this, there are several sections: "Support Groups" (Connect with others in our free support groups), "Online Groups" (Post-Treatment Survivorship Support Group), "Telephone Groups" (Post-Treatment Survivorship Support Group), "Face-to-Face Groups" (Post-Treatment Survivorship for Young Adults Support Group), and "Connect! Education Workshops" (Listen in by telephone or online as leading experts in oncology provide up-to-date information about cancer-related issues). A "Browse By" sidebar on the right lists categories like "By Topic", "By Diagnosis", and "Counseling".

Internet Explorer browser window showing the SuperSibs! website. The URL is http://supersibs.org. The page features the SuperSibs! logo and a navigation menu with links for Home, Sib Spot, Get Help, Who We Are, and What We Do. The main heading is "Serving Siblings of Children with Cancer". Below this, there is a "Latest From SuperSibs!" section with links for "January Sib Spot Activities" and "Sibling Profiles!". A "Sib Spot" section features a profile for "Eric K." and a "Get Help" section with a link for "January Sib Spot Activities".

Internet Explorer browser window showing the i21 website. The URL is http://www.i21.com. The page features the i21 logo and a navigation menu with links for Home, About Us, and Contact Us. The main heading is "I'm too young for this cancer foundation" and a sub-heading "the voice of young adults". Below this, there is a "Young adults can and do get cancer. Here is where they get busy living." section featuring a quote from Ethan Zeln, Hodgkin's Lymphoma. A "I'M TOO YOUNG FOR THIS!" section states that young adults, a largely unknown group in the war on cancer, account for 72,000 new diagnoses each year. A "Contact Us" sidebar on the left lists various contact options. A "Live Broadcast" sidebar on the right lists various live broadcasts.

http://www.stupidcancer.com

HOW CAN WE HELP YOU?

I'M ALL ALONE I NEED MONEY I NEED A LAWYER I CAN'T WORK I NEED A BREAK

ASK A YOUNG ADULT WHO HAS A PARENT WHO IS SICK ASK A YOUNG ADULT WHO HAS A PARTNER WHO IS SICK ASK A YOUNG ADULT WHO HAS A PEDIATRIC CHILD WHO IS SICK ASK A YOUNG ADULT WHO HAS A YOUNG ADULT CHILD WHO IS SICK

YOUNG ADULT ORGANIZATIONS GENERAL CANCER SUPPORT CAMPS, RETREATS & EXCURSIONS
 FORUMS & CHAT ROOMS SOCIAL NETWORKS YOUNG ADULT BLOSSOMERS
 COPING LITERATURE BOOKS, MAGAZINES & FILMS YOUNG ADULT ADVOCACY TOOLS

SOCIAL & COMMUNITY EVENTS CALENDAR

Don't see anything? Click here. (22) hosts numerous social activities and young professionals events around the country each year. If you'd like to meet your peers, gain inspiration, and your business and be a part of your generation's cancer movement, check back and look for happenings in your neck of the woods.

Monday, January 30
 7:00pm SC NYC/Mets | Karaoke
 Tuesday, January 31
 6:00pm SC Denver | Stupid Cancer Happy Hour
 Monday, February 6

http://www.blogtalkradio.com/stupidcancershow

blogtalkradio On Air Featured Popular Stations

the stupidcancer SHOW the voice of young adult cancer

The Stupid Cancer Show is a multi-award winning international talk radio webcast that tackles hard hitting issues from politics, health care, civil rights and the environment to social media, entertainment, cancer research and education.

http://www.blogtalkradio.com/stupidcancer
 http://www.facebook.com/stupidcancer

Upcoming Broadcasts

http://www.paincancer.com

CANCER: There are easier ways to live

Welcome to PainCancer, a community of young adults with cancer. You're here because you've been told you have to choose whether to give up a lifestyle or have a serious illness or live with it. It's a choice that's tough, scary, and hard. In our place you'll find the support you need to live with your cancer. You'll find the support you need to live with your cancer. You'll find the support you need to live with your cancer.

PainCancer provides a critical network of peer support and advice for young adults with cancer.

American Cancer Society Information and Resources for Cancer: Breast, Colon, Prostate, Lung

THE OFFICIAL SPONSOR OF BIRTHDAYS

HOME LEARN ABOUT CANCER STAY HEALTHY FIND SUPPORT & TREATMENT EXPLORE RESEARCH GET INVOLVED

WAYS TO STAY HEALTHY ALSO IN THIS SECTION

Stay Away from Tobacco Eat Healthy and Get Active Be Safe in the Sun Other Ways to Protect Yourself Find Cancer Early

Progress to Help You Stay Well The American Cancer Society has programs to help people of all ages stay healthy and reduce their cancer risk.

Tools and Calculators Our interactive tools, quizzes, and videos will help you learn more ways to lower your risk for cancer or find it early.

Information for Health Care Professionals ACS provides resources for health care professionals.

HOW CAN WE HELP YOU? Enter search terms or location. Search

YOU CAN CALL US ANY TIME AT 1-800-227-2345.

http://www.cancer.org/Treatment/TreatmentandSideEffects/PhysicalSideEffects/SexualSideEffectsForMen/sexuality

Sexuality for the Man with Cancer

The most reliable cancer treatment information

Treatments and Side Effects Physical Side Effects Sexual Side Effects in Men Sexuality for the Man with Cancer

Sexuality for the Man With Cancer

In this guide, we offer you and your partner some information about cancer, sex, and sexuality. We cannot answer every question, but we try to give you enough information to help you and your partner have open, honest talks about your sex life. We also share some ideas about talking with your doctor and your cancer care team. Click on the topics below to get started.

Cancer, sex, and sexuality
 How the male body works sexually
 Keeping your sex life going despite cancer treatment
 Erections and pelvic surgery to treat cancer
 Erections and pelvic radiation therapy
 Erections and chemotherapy
 Erections, desire, and hormone therapy
 Erections and the psychological effects of cancer treatment
 Ejaculation and cancer treatment

http://www.cancer.org/Treatment/TreatmentandSideEffects/PhysicalSideEffects/SexualSideEffectsForWomen/sexuality

Sexuality for the Woman with Cancer

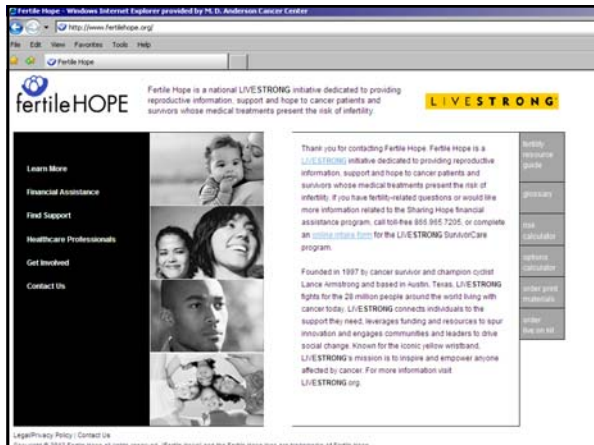
The most reliable cancer treatment information

Treatments and Side Effects Physical Side Effects Sexual Side Effects in Women Sexuality for the Woman with Cancer

Sexuality for the Woman With Cancer

In this guide, we offer you and your partner some information about cancer, sex, and sexuality. We cannot answer every question, but we try to give you enough information to help you and your partner have open, honest talks about your sex life. We also share some ideas about talking with your doctor and your cancer care team. Click on the topics below to get started.

Cancer, sex, and sexuality
 How the female body works sexually
 Keeping your sex life going despite cancer treatment
 Sex and pelvic surgery to treat cancer
 Radical hysterectomy
 Abdominoperineal excision
 Surgery for cancer of the vulva (vulvectomy)
 Total pelvic exenteration



Conclusions

- ▶ Assess each survivor considering all aspects of their life
- ▶ Encourage aggressive management of comorbid conditions
- ▶ Make a plan and include age/risk related screening
- ▶ Use every opportunity to teach, teach, teach
 - Use those teachable moments!
- ▶ Survivorship care is done across a life continuum, it does not end at day xxx...