Your Personal BMT Survivorship Care Plan: What, Why and How!

Linda J Burns, MD

Medical Director, National Marrow Donor Program (NMDP)/Be The Match
Senior Scientific Director, Health Services Research Program
Center for International Blood and Marrow Transplant Research (CIBMTR)

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I have no conflicts of interest to disclose.
What You’ll Learn Today

• **What** a BMT personalized survivorship care plan is
• **Why** you need one
• **How** to get a plan and use it
  – Role of your transplant center, you and your caregiver
  – Coordinate care between your local healthcare providers, transplant team and other specialists
Recommended that every survivor be provided with a personalized survivorship care plan at the end of treatment that included how to:

- Prevent, watch for, and detect side effects of cancer and its treatment
- Prevent, watch for, and detect new and recurrent cancer
- Coordinate care between specialists and primary care providers to meet survivor health needs
Phase in for 2015.

STANDARD 3.3 Survivorship Care Plan

The cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process is monitored, evaluated, and presented at least annually to the cancer committee and documented in minutes.

DEFINITION AND REQUIREMENTS

The IOM and National Research Council 2005 report, From Cancer Patient to Cancer Survivor: Lost in Transition, recommends that patients with cancer who are completing the first of course treatment be “provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained.” The recommendation suggested that these plans would help cancer survivors make informed decisions about their care and how to best deal with the long-term effects of cancer treatments.

SPECIFICATIONS BY CATEGORY

All programs fulfill the standard as written.

DOCUMENTATION

The program completes the SAR.

During the on-site visit, the surveyor will discuss with the cancer committee the methods implemented to create and disseminate a survivorship care plan.
Commission on Cancer: Survivorship Care Plan Recommendations

• Be prepared by the principal provider(s) who coordinated the treatment for the patient with input from other care providers

• Be given to the patient on completion of treatment

• Contains a record of care received, important disease characteristics, and a follow-up care plan incorporating available and recognized evidence-based standards of care, when available
Requirement Rolled Out Over 5 Years

• Requirement to provide a Survivorship Care Plan rolled out over 5 years for patients with cancer who had completed active therapy
  – Jan. 1, 2016: 25% of patients
  – Jan. 1, 2017: 50% of patients
  – Jan. 1, 2018 and beyond: 75% of patients

Transplant recipients were not specifically addressed
Is Anyone Focusing on the Unique Needs of BMT Survivors?

YES!

Including, among others:
• National Marrow Donor Program (NMDP)/Be The Match
• American Society for Blood and Marrow Transplantation (ASBMT) and Survivorship Special Interest Group
• Federation for the Accreditation of Cellular Therapy (FACT)
Increasing Number of Transplant Survivors in the United States

~240,000 survivors by 2020
~500,000 by 2030

Majhail NS et al, Biol Blood Marrow Transplant 2013; 1498.
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Many Survivors Develop Chronic Health Issues

1022 autologous and allogeneic BMT 2-year survivors

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Recommended Screening and Preventive Practices for Long-term Survivors of BMT


For the Center for International Blood and Marrow Transplant Research (CIBMTR), American Society of Blood and Marrow Transplantation (ASBMT), European Group for Blood and Marrow Transplantation (EBMT), Asia-Pacific Blood and Marrow Transplantation Group (APBMT), Bone Marrow Transplant Society of Australia and New Zealand (BMTSANZ), East Mediterranean Blood and Marrow Transplantation Group (EMBMT) and Sociedade Brasileira de Transplante de Medula Ossea (SBTMO)
Free Guidelines for All Patients

- Recommended general screening/preventive practices for:
  - 6-months post-transplant
  - Annual appointments

- Patient guidelines include:
  - Simple medical descriptions
  - Checklist to take to provider visits
  - Glossary of medical terms

Visit: BeTheMatch.org/careguide
Free Guidelines for All Providers

Recommendations for autologous and allogeneic BMT recipients, including:

• Post-transplant screening and vaccinations
• Graft-versus-host disease (GVHD) screening with photo atlas

Visit: marrow.org/md-guidelines
Doing More Through Research: Developing a BMT Personalized Survivorship Care Plan

• Phone focus groups provided feedback on *how the plan should look and what it should contain*
  - BMT recipients/caregivers
  - Hematology/Oncology and primary care physicians/nurse practitioners/physician assistants (NPs/PAs)
  - BMT physicians/NPs/PAs
  - BMT nurses/social workers

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Blood and Marrow Transplant Survivor Treatment Summary
For: Jane Doe
Date: March 31, 2014

Your Medical Information

Date of birth: 01/01/01
Sex: FEMALE
Diagnosis: ACUTE MYELOID LEUKEMIA
Date of Diagnosis: 01/01/01
Important past medical history at time of transplant:
- DIABETES
- OBESITY

Your Transplant Information

Transplant center name: CLEVELAND CLINIC
Address: 9500 Euclid Ave, CA60, Cleveland, OH 44195
Phone number: 216-445-5600
Date of transplant: 01/01/01
Age at transplant: 60 YEARS
Transplant type: ALLOGENEIC UNRELATED
Cell source type: BONE MARROW
Prior transplant: NO
Date of prior transplant: NOT APPLICABLE

Your Blood and Marrow Transplant Survivorship Care Plan
For: Jane Doe
Treatment Factors: Allogeneic transplant, Female, Graft-versus-host disease, Steroid exposure, Total body irradiation

Recommendations For Your Annual Preventive Care

**IMMUNE SYSTEM**

- Even 2 years or more after transplant, you are at risk to get infections. This is because it takes time for your immune system to recover from transplant. You might also take medications that lower your body’s ability to fight disease.

  - Vaccines to prevent infection
    - Because you have a history of GVHD, you might need to take antibiotics
      - To prevent infections like pneumonia and meningitis, for as long as you are on immunosuppressant drugs
      - Before dental work
    - If you are on immunosuppressant drugs, you should have a blood test for Cytomegalovirus (CMV) screening.

**EYES**

- Wear sunglasses every time you go outside.
- Vision screening by your eye doctor 1 time every year to check how well you can see
  - Because you have a history of GVHD, you may need to have eye exams more often.

**QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES**

- What things can I do to lower the risk of getting an infection? Ask your doctor about things like water, food, safe sex, travel, and avoiding second hand smoke.
- Are my vaccines up-to-date?
- Do I need to see an eye specialist?
- How often should I have eye tests?
Study Concept

Patient clinical data routinely submitted by transplant centers to CIBMTR

Follow-up recommendations

- Age
- Sex
- Transplant type
- Conditioning
- Radiation
- GVHD
- Steroids

Personalized Survivorship Care Plan

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Randomized Study of Adult BMT Survivors

• 1-5 years after most recent post-autologous or allogeneic transplant
• All primary diagnoses
• Disease in remission
• All types of transplant and graft sources
• Could have more than 1 transplant
• Randomly assigned (like flipping a coin) to receive or not receive a personalized care plan from their transplant center

Supported by a PCORI award #CD-12-11-4062
How The Study Was Done

- 17 transplant centers
- Patients identified from research database
  - Patient contact, consent
  - Baseline assessments
    - Randomized
    - Control Arm
      - 6 mos: final assessments
        - 199 patients
    - Plan Arm
      - 6 mos: final assessments
        - 231 patients
“How Useful Was the Care Plan In Helping You To…

**Better understand:**

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**Communicate:**

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Helped Survivors Focus on Overall Health

“The care plan was useful because it **gave me a list of questions to ask medical providers** in one document. Before seeing this treatment summary and care plan, I did not know that I was at a higher risk for certain cancers and health problems.”

“It got me to go for my mammogram, blood work and I just scheduled a colonoscopy. **It made me look at the bigger picture of my health.**”

“It’s made me aware of what I’ve been through and what is important for my well-being…The **care plan and summary have given me a lot of confidence**…”
“It enabled me, and gave me the knowledge, to let local health providers know what they need to know - to challenge them if they didn't think I needed certain follow-up.”

“It gave me an opportunity to dialogue with my primary physician and other providers - like my orthopedist - and to be able to talk in some detail about my cancer. It is a very useful tool - specifically as a springboard for conversation. It has been very helpful for my wife as well.”
“The care plan has been helpful to me and my husband both- to read and understand what's going on- to know that certain things are not unusual- to 'not get bent out of shape'. My husband uses it a lot.”

“I was blindsided by the emotional aspect of getting cancer- ravaged by going through some of these things... knowing that the researchers were aware of the emotional components is very important and validating.”

“The plan gave me permission to ask for help. That was one of my biggest things - not wanting to ask to help...”
We recommend that every transplant center provide a personalized BMT survivorship care plan to all BMT survivors
Plan Should Include Entire Journey As a BMT Survivor

Pre-BMT health concerns

Primary therapy

BMT therapy

GVHD

Post- BMT Infections, medications

Long-Term Follow-up

Pre-BMT

BMT

Post-BMT

Genetic factors

Age and gender

Lifestyle factors

Pre-BMT Treatment Summary

Provided by care provider for primary disease to you and transplant center for incorporation into survivorship plan

• Contact information of treating institutions and providers
• Health issues
• Diagnosis of primary disease and date
• Treatment, if any, including:
  – Surgery: Procedure with body location, date(s) of treatment
  – Chemotherapy: Names of drugs, total doses, date(s) of treatment
  – Immunotherapy: Names of drugs, total doses, date(s) of treatment
  – Radiation: Body area treated, total dose, date(s) of treatment
  – Transfusions: Red blood cells, platelets
• Side effects, management and recovery course
BMT Treatment Summary
Provided by transplant center to you and your other care providers

- Your contact information
- Contact information of treating institution and providers
- Conditioning/preparative regimen
  - Chemotherapy: Names of drugs, total doses, dates
  - Immunotherapy: Names of drugs, total doses, dates
  - Radiation: Body area(s) treated, total doses, dates
- Type of transplant and date
- Stem cell source and donor gender
- Graft-versus-host disease (GVHD) prevention
BMT Treatment Summary
Provided by transplant center to you and your other care providers

- Engraftment: When, any concerns, growth factor use
- Graft-versus-host disease: Type, parts of body, treatment
- Infections: Which ones, how diagnosed and treated
- Any other health issues and how treated
- Medications: Which ones, why being used, side effects, how long to take
- Ongoing side-effects and likely course of recovery
- Symptoms to watch for plus what to do, who to call, who to see
Long Term Follow-Up Care Plan
Provided by transplant center to you and your other care providers

• Schedule of follow-up clinical care:
  – Who will schedule the visit
  – Who will provide the follow-up care and at what facility
  – How often are visits needed
  – What exams/tests are needed, why they’re needed, and at which visit they’re to be done
  – Who will order the exams/tests
  – Who will communicate results of ongoing care, to whom, and how often
How To Use Your Plan

• Refer to it often for your long term health needs
• Use it to know when to schedule appointments and with which provider
• Take it to all your visits with all care providers and use it to ask questions, take notes
• Take it to your visits for tests/exams and record what was done, results
Share Your Plan With Caregivers

• Caregivers are important members of your support team.
• Caregivers can help you coordinate visits and tests, remind you of questions to ask your care providers, and may even notice symptoms that you haven’t.
• Parent caregivers can use the plan to keep track of their child’s health care needs, which will change as their child grows up and becomes an adult.
What If You Never Had A Care Plan Or It’s Old?

• Ask your transplant care team to prepare one and review it with you
• Ask about anything that you don’t understand
• If your transplant was several years ago, your care plan may need updating because:
  – we know more than they did in the past about how to best care for BMT survivors
  – your care needs may change and your plan should reflect current needs
Is It Really That Important?

• **YES!**
  – So you and your care providers know what your specific long-term needs are based on the specific details of all therapy, including BMT, that you’ve received
  – So you can be followed appropriately
  – So your care can be coordinated among all care providers

• Prevention and early treatment reduces risk for chronic health issues after BMT
Take Home Points

• A personalized survivorship care plan is critical to maintaining good health after BMT

• Your transplant team provides your plan to you
  – Keep your plan updated
  – Take it with you to appointments
  – Use it to keep track of what needs to be done, by whom and when, and to have conversations with all providers about your health care needs
  – Share it with your caregiver
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