

Randomized controlled trial of individualized treatment summary and survivorship care plans for hematopoietic cell transplantation survivors

Navneet S. Majhail,¹ Elizabeth Murphy,² Purushottam Laud,³ Jaime M. Preussler,^{2,4} Ellen M. Denzen,^{2,4} Beatrice Abetti,⁵ Alexia Adams,⁴ RaeAnne Besser,⁴ Linda J. Burns,^{2,4} Jan Cerny,⁶ Rebecca Drexler,⁴ Theresa Hahn,⁷ Lensa Idossa,² Balkrishna Jahagirdar,⁸ Naynesh Kamani,⁹ Alison Loren,¹⁰ Deborah Mattila,⁴ Joseph McGuirk,¹¹ Heather Moore,² Jana Reynolds,¹² Wael Saber,^{3,13} Lizette Salazar,¹⁴ Barry Schatz,¹⁵ Patrick Stiff,¹⁵ John R. Wingard,¹⁶ Karen L Syrjala¹⁷ and K. Scott Baker¹⁷

¹Blood and Marrow Transplant Program, Cleveland Clinic, OH; ²National Marrow Donor Program/Be The Match, Minneapolis, MN; ³Medical College of Wisconsin, Milwaukee, WI; ⁴Center for International Blood and Marrow Transplant Research, Minneapolis, MN; ⁵Leukemia and Lymphoma Society, White Plains, NY; ⁶UMass Memorial Medical Center, Worcester, MA; ⁷Roswell Park Comprehensive Cancer Center, Buffalo, NY; ⁸Regions Hospital, St Paul, MN; ⁹AABB, Bethesda, MD; ¹⁰University of Pennsylvania, Philadelphia, PA; ¹¹University of Kansas Medical Center, Kansas City, KS; ¹²Baylor University Medical Center, Dallas, TX; ¹³Center for International Blood and Marrow Transplant Research, Milwaukee, WI; ¹⁴Haledon, NJ; ¹⁵Loyola University Medical Center, Chicago, IL; ¹⁶University of Florida, Gainesville, FL and ¹⁷Fred Hutchinson Cancer Research Center, Seattle, WA, USA

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Received: August 6, 2018.

Accepted: November 23, 2018.

Pre-published: December 4, 2018.

Correspondence: NAVNEET S. MAJHAIL majhain@ccf.org

SUPPLEMENTAL MATERIALS

Randomized Trial of Individualized Treatment Summary and Survivorship Care Plan for Hematopoietic Cell Transplantation Survivors

DETAILED METHODS

Patients

Seventeen US transplant centers that report autologous and allogeneic HCT to the CIBMTR and representing diverse location and size participated in the study. Potentially eligible patients from participating centers were identified from the CIBMTR. The CIBMTR is a research collaboration between the National Marrow Donor Program (NMDP)/Be The Match in Minneapolis, Minnesota and the Medical College of Wisconsin in Milwaukee, Wisconsin. By law in the US, transplant centers are required to submit data on all allogeneic HCTs to the CIBMTR. Additionally, approximately 80% of the national autologous HCT activity is captured by the registry. Computerized checks for discrepancies, physicians' review of submitted data and on-site audits of participating centers ensure data quality. Centers submit Transplant Essential Data (TED) on all recipients before transplant, at 100 days and six months after transplant, annually until 6 years, and every other year thereafter, or until death. These data were used to generate the treatment summary including information on patient diagnosis and stage, donor and graft source, and transplantation procedure (e.g., conditioning regimen). HCT specific exposures that determine follow-up and preventive evaluations (age, sex, transplant type, exposure to total body irradiation [TBI], exposure to corticosteroids, and graft-versus-host disease [GVHD]) were abstracted from TED and were used to develop the personalized care plan for each patient.

To maximize generalizability, patient eligibility criteria were intentionally kept broad (≥ 18 years at the time of HCT, recipients of autologous or allogeneic transplantation, with no evidence of relapse, disease progression or secondary cancers, any diagnosis, donor or graft source, and any conditioning regimen). Patients had to be 1-5 years from their transplant, in order to focus on a group of survivors who are frequently no longer under the direct care of transplant centers and are most vulnerable to receive inadequate HCT specific-survivorship and preventive care. Participants could have received more than one HCT. Participants had to be fluent in English so that they could complete study assessments.

Only centers without an existing mechanism for routinely providing SCPs to their patients were invited to participate in our study. Information on prevalent practices for caring for autologous and allogeneic HCT long-term survivors, including templates for discharge summaries and any routine communications with patients and their local providers, was requested from centers and was reviewed by study investigators to confirm their eligibility to participate and enroll patients. Participating centers also committed to not providing patients a SCP during routine post-transplant care and outside the context of this study during the enrollment and follow up period.

SCP Template

We have previously reported on the development of an individualized SCP instrument generated using CIBMTR registry data and specifically targeted for use by HCT survivors.¹ Briefly, a draft paper-based template for the SCP was generated by the investigators and consisted of three elements: an introductory page with information on appropriate use of the SCP, a treatment summary with diagnosis and transplant information electronically abstracted from CIBMTR data, and a care plan that listed recommended preventive evaluations based on published guidelines and patient specific exposures (age, sex, transplant type, exposure to TBI or steroids, or occurrence of GVHD). To obtain qualitative feedback on content and formatting of the SCP,

phone focus groups were conducted with HCT survivors/caregivers (3 focus groups, N=22 participants), HCT physicians and advanced practice providers (2 focus groups, N=14 participants), hematology-oncology and primary care physicians and advanced practice providers (3 focus groups, N=24 participants), and HCT nurses and social workers (4 focus groups, N=17 participants). Qualitative analyses identified patient-centered elements that informed the generation of the final SCP templates used as the intervention in the RCT.¹ A sample SCP template is available as part of Supplemental Materials.

Study Procedures

The RCT used a multi-center design with patient-level randomization to treatment (Figure 1). The RCT was reviewed and approved by Institutional Review Boards (IRBs) at the NMDP and each participating site and was registered on clinicaltrials.gov (NCT02200133). To minimize bias in patient enrollment, a random order list of potentially eligible 1-5 year survivors for each center was generated using the CIBMTR database and released in blocks of 10-20 patients. Center coordinators then reviewed medical records to confirm patient survival, disease status, and accuracy of SCP related research data that had been submitted by the center to the CIBMTR. Centers contacted patients by phone and presented the study, and then mailed an information packet to patients who agreed to consider participation; some center IRBs required a mailed letter/post-card with an opt in/opt out option, followed by mailing of the information packet to patients who opted in or with follow-up phone calls if no response to the mailing was received. On receiving the signed informed consent form from patients, transplant centers informed the CIBMTR, who then proceeded with the rest of the study procedures.

The CIBMTR Survey Research Group (SRG) conducted a baseline assessment by phone within 30 days of receiving a completed participant enrollment form and contact information from the transplant center. CIBMTR data were then used to generate personalized SCPs for all consenting patients. Patients were randomized 1:1 to either the SCP arm or standard care with delayed SCP (control) arm. Since centers may preferentially follow long-term allogeneic HCT survivors, patient enrollment was weighted such that at least one-third of the cohort consisted of autologous HCT recipients. Patients randomized to the SCP arm were express mailed an information letter and their printed SCP from the CIBMTR, while patients on the control arm received only an information letter. All patients received a phone call from the CIBMTR SRG between 7-28 days of mailing study materials to conduct a health literacy assessment using the Newest Vital Sign.² During this phone contact, patients on the SCP arm were also given the opportunity to ask and address any questions about the content or use of their SCP. No further contact was made with patients till their 6-month outcomes phone survey conducted by the CIBMTR SRG. After completing their end-of-study assessments, printed SCPs were provided to patients in the control arm. Study accrual began in April 2015 and the last patient was enrolled in June 2016. Patients were not offered any compensation for participating on the study.

Assessments

Supplemental Table 1 describes our study instruments, including their psychometric properties. The Confidence in Survivorship Information (CSI) was the primary endpoint. The CSI is a 13-item questionnaire that uses a 3-point Likert scale of “not at all” to “very confident”.³ The instrument has two subscales, one that tests confidence in knowledge of past cancer diagnostic and treatment details (3 items, Cronbach’s $\alpha=0.77$) and second that evaluates confidence in

knowledge about prevention and treatment of long-term and late-effects of disease and treatment, prevention of disease recurrence, access to resources, and familial risk of cancer (10 items, Cronbach's $\alpha=0.95$). Internal consistency reliability for the CSI in our HCT sample at baseline was $\alpha=0.87$. Secondary endpoints focused on Cancer and Treatment Distress (CTXD), a 23 item instrument validated in HCT recipients that assesses distress and worry specific to HCT and associated complications,^{4,5} as well as measures of Knowledge of Transplant Exposures (developed by study investigators), Health Care Utilization,⁶ and HRQOL using the SF-12.⁷ The phone-administered assessments required 30-45 minutes to complete. Patients on the intervention arm also received an investigator developed 12-item assessment that obtained qualitative feedback on patient utilization of the SCP at the 6-month assessment.

Statistical Analysis

Sample size and power calculations were performed using a standard error formula that allowed for possible variability in treatment effect across centers and considered dropouts from baseline to 6 months. Our targeted enrollment goal was 495 patients, which yielded adequate power to detect standardized effect sizes of ≥ 0.3 , which are considered to be clinically meaningful, and anticipated a 10% drop-off from baseline to 6-months. An intention-to-treat approach was followed for analysis.

Baseline characteristics between the two groups were compared using Chi-square tests for categorical variables and t-tests for continuous variables. A mixed model with center-level random effects and a fixed treatment effect was used to test whether a change in baseline and 6-month existed between the treatment and control groups for the primary and secondary endpoints. The model, in addition to accounting for center-to-center variation (center effect), allowed for patient responses to be correlated within centers. The 6-month assessment was used as a response variable and the baseline assessment was used as an explanatory variable in the regression models. If a treatment effect existed, we further evaluated whether the effect was modified by demographic variables (including age, sex, transplant type, acute and/or chronic GVHD, diagnosis, and health literacy), or any interactions between variables. Given the short time period projected for accrual and the low risk of adverse events, no interim analyses were planned. Analyses were performed using SAS software (Version 9.4). All P-values reported are two-sided and $P<0.05$ was considered significant.

Data Sharing Statement

The study was funded by Patient Centered Outcomes Research Institute (PCORI), and their data sharing policy applies (www.pcori.org).

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Supplemental Table 1: Study assessments and patient reported outcome measures

Instrument	Description	Items	Time point	Estimated Time to complete
Confidence in Survivorship Information (CSI) ¹	Assesses confidence in knowledge of past cancer diagnostic/treatment details and confidence in knowledge about prevention/treatment of late complications, prevention of future disease, access to resources and familial risk of cancer. This 13-item patient self-reported tool assesses confidence in knowledge of past cancer diagnostic and treatment details (3 items; Cronbach's alpha = 0.77) and confidence in knowledge about prevention and treatment of long term and late-effects of disease and treatment, prevention of future disease, access to resources, and familial risk of cancer (10 items; Cronbach's alpha = 0.95). The scale uses a 3-point scale ranging from "not at all" to "very confident" in each knowledge item. Sample items include "I am confident in the stage of cancer I have/had" and "I am confident in strategies for treating long term physical effects of cancer". Higher score indicates greater confidence in knowledge of treatment details and preventive recommendations.	13	Baseline 6 mos	2 mts
Cancer and Treatment Distress (CTXD) ²⁻⁵	Assesses distress or worry specific to HCT and associated complications using items such as "costs of healthcare", "possibility of relapse" and "being a burden to other people"; subscales include uncertainty, family strain, medical system demands, health burden, finances and impact on function. Response options can range from 0 ("none") to 3 ("severe"), and the scores represent the mean response across the scale/subscale item. In an analysis of 701 HCT recipients, Syrjala et al reported strong internal consistency reliability at pre-transplant, and at day 100 and day 180 post-transplant (Cronbach α 0.94, 0.95 and 0.95, respectively). The mean scores (standard deviation) at the three time points were 1.12 (0.60), 0.93 (0.60), and 0.85 (0.59), respectively. Subscale reliability was high across time ($\alpha > 0.70$), and there was strong correlation of pre-transplantation CTXD with post-transplant CTXD. A higher score indicates higher level of distress among HCT recipients. Testing supports its value as a predictor of health outcomes and it has been in several randomized clinical trials.	27	Baseline 6 mos	3 mts
Knowledge of transplant exposures	Investigator developed measure to assess knowledge of HCT exposures (conditioning type, TBI use, transplant type, donor type, GVHD). Higher score indicates greater knowledge of transplant exposures.	5	Baseline 6 mos	2 mts
Health Behaviors	Standardized measures to assess health behaviors: Godin Leisure Time Exercise Q as a measure of minutes/week in moderate/vigorous activity (<150 as cutoff); ⁶ Tobacco use (any as cutoff); ^{7,8} Alcohol use (≥ 1 drinks/day for women, ≥ 2 drinks/day for men as cutoff); ^{7,8} Sunscreen use (daily use of >SPF 30 sunscreen as cutoff); ^{7,8} Diet (>2 fast food meals/week and <5 fruits and vegetables/day as cutoff); ^{7,8} Body Mass Index (>30 as cutoff) ^{7,8} Health behaviors are	31	Baseline 6 mos	8 mts

	scored as a sum from 0-7, with one point for each behavior: non-smoking, alcohol less than one glass a day for women or two glasses a day for men, moderate to vigorous physical activity ≥ 150 minutes a week, regular use of sunscreen of SPF ≥ 30 , food intake of 5 servings of fruit and vegetables a day, body mass index ≤ 25 , sleep averaging ≥ 7 hours a night. Item content is matched to NHANES or BRFSS for normative comparisons. Higher scores indicate positive health care behaviors.			
Health Care Utilization ⁹	Widely pretested measure of SCP recommended screening and preventive evaluations; scores range from 0-15 with 2 gender specific items each. Scores are transformed to the proportion preventive care recommendations met as indicated on the SCP. Higher scores indicate greater and appropriate health care utilization for preventive care.	26	Baseline 6 mos	4 mts
SF-12 ^{10,11}	Validated health quality of life 12-item sub-set of the MOS SF-36 which accurately reproduces the two summary component scores: Physical Component Summary Score (PCS) and Mental Health Component Summary Score (MCS). In the general population, the test-retest reliability has been reported to be 0.89 and 0.76 for the two scores, respectively. Studies have shown that the relative validity of SF-12 is comparable to the more comprehensive SF-36 quality of life instrument. The mean PCS scores for chronic health conditions are in the range of 40-45, while that for MCS range from 50-55; in comparison, the mean general population PCS and MCS scores are ~ 50 and ~ 50 , respectively. Higher scores correspond to better health-related quality of life.	12	Baseline 6 mos	3 mts
Generalized Self-Efficacy scale ^{12,13}	Assesses optimistic self-beliefs used to cope with a variety of demands in life known as self-efficacy, i.e., the belief that one's actions are responsible for successful outcomes. The scaled score for each question ranges from 1 to 4. Higher scores indicate stronger patient's belief in self-efficacy.	10	Baseline 6 mos	2 mts
Newest Vital Sign ¹⁴	Measures health literacy level using 1 scenario of an ice cream container nutrition label; 1 score (6 items) includes assessment of two main constructs, numeracy and reading comprehension. Higher score indicates greater health literacy.	6	1-4 wks	2 mts
Survivorship Care Plan Utilization Assessment	Treatment-group participants will be asked whether they if they have any questions about the SCP and how they plan to use it. At the 6 month follow-up assessment, treatment-group participants will be asked how they did use their SCP and what they liked or did not like about it.	5	1-4 wks 6 mos	3 mts

HCT – hematopoietic cell transplantation; TBI – total body irradiation; GVHD – graft-versus-host disease; SCP – treatment summary and survivorship care plan; mos – months; mts – minutes

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Supplemental Table 2. Baseline characteristics of patients who completed the baseline assessments, and then either completed the study or dropped out/were excluded from the analysis

Characteristic	Completed study (N=399)	Drop out/ excluded (N=59)	P-value
Age at HCT, years; Median (range)	58.8 (19.4-81.1)	54.5 (20.2-77.2)	0.6760
Time from HCT to enrollment (months); Median (range)	42.6 (15.7-66.3)	45.3 (17.3-63.8)	0.6760
Age group at baseline survey, years; N (%)			
18-29	12 (3.0)	4 (6.8)	0.1755
30-39	19 (4.8)	5 (8.5)	
40-49	41 (10.3)	5 (8.5)	
50-59	99 (24.8)	14 (23.7)	
60-69	159 (39.9)	16 (27.1)	
≥70	69 (17.3)	15 (25.4)	
Sex; N (%)			
Male	212 (53.1)	36 (61.0)	0.2667
Female	187 (46.9)	23 (39.0)	
Ethnicity; N (%)			
Hispanic/Latino	13 (3.3)	2 (3.4)	0.4346
Non-Hispanic/Latino	375 (94.0)	57 (96.6)	
Declined	11 (2.8)	-	
Race; N (%)			
White	380 (95.2)	50 (84.8)	0.0062
African-American	12 (3.0)	8 (13.6)	
Asian	4 (1.0)	1 (1.7)	
Pacific Islander	1 (0.3)	-	
Declined	2 (0.5)	-	
Diagnosis; N (%)			
Acute myeloid leukemia	90 (22.6)	8 (13.6)	0.0801
Acute lymphoblastic leukemia	15 (3.8)	3 (5.1)	
Myelodysplastic/myeloproliferative disorders	40 (10.0)	2 (4.8)	
Chronic myeloid leukemia	5 (1.3)	-	
Hodgkin lymphoma	16 (4.0)	7 (11.9)	
Non-Hodgkin lymphoma	84 (21.1)	12 (20.3)	
Plasma cell disorder/multiple myeloma	134 (33.6)	24 (40.7)	
Other	15 (3.8)	3 (5.1)	
Time from diagnosis to HCT, months; Median (range)			
Year of transplant; N (%)			
2010	28 (7.0)	5 (8.5)	0.5831
2011	112 (28.1)	16 (27.1)	
2012	86 (21.6)	15 (25.4)	
2013	125 (31.3)	20 (33.9)	
2014	48 (12.0)	3 (5.1)	

Transplant type; N (%)			
Allogeneic	191 (47.9)	20 (33.9)	0.0503
Autologous	208 (52.1)	39 (66.1)	
Donor type; N (%)			
Allogeneic, related	77 (19.3)	6 (10.2)	0.0975
Allogeneic, unrelated/umbilical cord blood	114 (28.6)	14 (23.7)	
Autologous	208 (52.1)	39 (66.1)	
Graft type; N (%)			
Bone marrow	29 (7.3)	2 (3.4)	0.4685
Peripheral blood	356 (89.2)	54 (91.5)	
Umbilical cord blood	14 (3.5)	3 (5.1)	
Number of transplants; N (%)			
1	347 (87.0)	50 (84.8)	0.6809
≥2	52 (13.0)	9 (15.3)	
Conditioning regimen intensity; N (%)			
Myeloablative (including autologous regimens)	296 (74.2)	48 (81.4)	0.4533
Non-myeloablative/Reduced-intensity	101 (25.3)	11 (18.6)	
Missing	2 (0.5)	-	
TBI as part of conditioning regimen; N (%)			
Yes	87 (21.8)	8 (13.6)	0.1449
No	312 (78.2)	51 (86.4)	
History of acute GVHD; N (%)*			
Yes	123 (64.4)	14 (70.0)	0.8062
No	68 (35.6)	6 (30.0)	
History of chronic GVHD; N (%)*			
Yes	119 (62.3)	14 (70.0)	0.6288
No	72 (37.7)	6 (30.0)	
Health Literacy; N (%)†			
Adequate literacy	309 (80.1)	17 (56.7)	0.0112
Possibility of limited literacy	54 (14.0)	9 (30.0)	
High likelihood of limited literacy	23 (6.0)	4 (13.3)	

SCP – survivorship care plan; HCT – hematopoietic cell transplantation; TBI – total body irradiation; GVHD – graft-versus-host disease

* Allogeneic HCT only

† Assessed by Newest Vital Sign instrument; N=386 for those retained and N=30 for those who dropped out/were excluded from the analysis

Supplemental Appendix: Sample template for treatment summary and survivorship care plan used in the study.

APPENDIX D: SURVIVORSHIP CARE PLAN AND STUDY FOLDER TEMPLATES

Blood and Marrow Transplant Survivor Treatment Summary

For: [First name_ Last name]

Date Your Treatment Summary was Created: [Month DD, YYYY]

The information presented on this Treatment Summary comes from transplant-related data provided to the CIBMTR by your transplant center. There may be additional medical history that is relevant to you and important to share with your doctors and other medical care providers.

Your Medical Information
Date of birth: (text date)
Sex:
Diagnosis:
Date of Diagnosis: (date)
Your Transplant Information
Transplant center name:
Address: (hospital)
Phone number: (BMT program number)
Date of transplant: (date)
Age at transplant: (yrs)
Transplant type: (autologous/allogeneic unrelated/allogeneic related)
Cell source type: (bone marrow, peripheral stem cell, cord blood unit(s))
Prior transplant: (yes/no)
Date of most recent previous transplant: (date or not applicable)
Type of most recent previous transplant: (autologous / allogeneic / syngeneic(twin) or not applicable)

Patient CIBMTR research ID (**CRID**):

Your Transplant Treatment
Chemotherapy drugs received as part of the preparative regimen: (list or not applicable)
Steroid drugs received as part of the preparative regimen (for example, prednisone): (list or not applicable)
Total Body Irradiation (TBI): (list dose and dose unit (cGy, Gy)/Yes/No)
Graft versus Host Disease (GVHD)
Drugs to prevent GVHD: (yes/no/not applicable)
GVHD prevention drugs: (list or not applicable)
Acute GVHD: (yes/no/ not applicable)
Chronic GVHD: (yes/no/ not applicable)
Date of chronic GVHD diagnosis: (text date or not applicable)

Your Blood and Marrow Transplant Survivorship Care Plan

Your survivorship care plan is based on research¹ and was developed by doctors and researchers from around the world. This information is not intended as medical advice and does not replace your transplant doctor's recommendations. **Your doctor may recommend or order other tests or evaluations on a different schedule based on your specific situation. Follow his or her recommendations carefully.**

In the table below, you'll find information on the tests and evaluations that physicians commonly recommend for transplant recipients after transplant. Items in **bold** are found in the Glossary.

The information below will help you:

Patient CIBMTR research ID (**CRID**):

- Understand what to expect at your checkup appointments, and
- Discuss your questions or concerns with your doctor.

There are questions you can ask your doctor to help you prepare for these tests and exams. Also, these questions will help you understand what the test results mean for you.

Some questions to ask your doctors

- Which tests and evaluations do I need to have more often? How often?
- How should I prepare for my exam? How long will the tests take?
- How long does it take to learn my test results?
- Are my test results within an acceptable range for my age and situation?
- How do I know when to call the clinic about symptoms I'm having?

Your care plan is organized by parts of the body (for example, eyes, mouth, and heart). Each section includes more questions to ask your doctor that are specific to a body part. There is space for you to take notes in each section and at the end of the care plan.

You should share this care plan with your doctors. Also, if you need to go to urgent care or the emergency room, it is helpful to take the care plan with you.

¹ Majhail NS, Rizzo JD, Lee SJ, et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation; Center for International Blood and Marrow Transplant Research (CIBMTR), American Society for 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). Co-published in Biol Blood Marrow Transplant. 2012; 18(3): 348-371; Bone Marrow Transplant (2012) 47, 337–341; and Hematol Oncol Stem Cel Ther 2012;5(1):1-30.

Summary of Recommendations for Your Preventive Care

IMMUNE SYSTEM

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

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

MOUTH

- Because you have a history of **GVHD** and/or have received total body irradiation, you need to have mouth, teeth, tongue, and throat exam at least 2 times every year. Talk to your doctor and dentist about when you should have these check-ups.
- Dental exam and tooth cleaning by a dentist at least 1 time every year. Ask your doctor if you should take antibiotics before dental exams.

LUNGS

- Lung exam at least 1 time every year
- Because you have a history of **GVHD**, you might need to have lung exams and pulmonary function tests more often. Talk to your doctor about when you should have these check-ups.
- Don't smoke or use tobacco. Stay away from places where people usually smoke.

HEART AND BLOOD VESSELS

- Blood pressure checked every time you visit the clinic
- Blood tests to check your cholesterol level at least 1 time every year. This includes triglycerides, **LDL**, and **HDL**

LIVER

- Liver function blood tests** (to see if your liver is working well) at least 1 time every year

- If you had red blood cell transfusions, have a blood ferritin test to check the level of iron in your blood.

KIDNEYS AND BLADDER

- Blood pressure checked every time you visit the clinic
- Kidney test at least 1 time every year which includes testing: protein levels in your urine and nitrogen levels in your blood (BUN) and creatinine test
- Because you have a history of GVHD, you might need to have your kidneys checked more often.

MUSCLES AND JOINTS

- If you have **myopathy** (weak muscles), muscle pain, or joint pain, schedule an appointment with your doctor right away. Your doctor will check your muscles to find out if you need treatment.
- Because you have a history of GVHD and have taken steroids (such as prednisone), you may need clinical tests of muscle strength and range of motion in your joints

BONES

- Bone density scan** (test) every year.

SKIN

- Do a self-exam of your skin every month to check for any changes (for example, rash, unusual growth, or patch).
- Use sunscreen with SPF 15 or higher every time you go outside. Reapply at least every 2 hours, or more often if you're sweating or in and out of the water.
- Avoid direct sunlight. Wear a broad-brimmed hat or use a large umbrella to protect your skin.

NERVOUS SYSTEM

- Clinical exam by your doctor at least 1 time every year to check for changes or problems

ENDOCRINE ORGANS (THYROID, GROWTH AND SEX HORMONES)

- Blood test to check how well your **thyroid** is working
- Blood tests to assess your sex hormone levels
- Fasting glucose (sugar) test to check for Diabetes

GENITALS AND SEXUAL HEALTH

- Discuss with your physician if you are experiencing sexual side effects such as vaginal dryness, pain with sex, or difficulty having an erection.
- Gynecology exam at least 1 time every year

FERTILITY AND FAMILY PLANNING

- If you want to have children in the future, ask your doctor to refer you to a **fertility** doctor.

EMOTIONAL HEALTH

- Going through transplant is a very emotional experience. Your feelings and needs will change a lot, maybe even every day. It's important that you talk openly and regularly with your doctor, family and friends.

DIET AND NUTRITION

- Eat a healthy diet
- Keep yourself well hydrated
- Avoid foods with lots of processed (fake) sugar or saturated (bad) fat like candy or soda

GENERAL HEALTH

- Use alcohol in moderation (less than 2 drinks a day)
- Stay physically active (2.5 hours each week of moderate exercise)
- Don't smoke, stay away from second hand smoke, don't use chewing tobacco

NEW CANCER SCREENING

Talk to your doctor about:

- Breast cancer screening (**mammography** every 1 to 2 years starting at age 25)
- Cervical cancer screening
- Colorectal cancer screening (starting at age 50 or earlier if you have a family history of colorectal cancer)
- Skin cancer screening

Your Blood and Marrow Transplant Survivorship Care Plan

For: [First name_Last name]

RECOMMENDATIONS FOR YOUR ROUTINE SCREENING AND PREVENTIVE CARE	
IMMUNE SYSTEM	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES
<p>Even 5 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.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Vaccines to prevent infection <input type="checkbox"/> Because you have a history of GVHD, you might need to take antibiotics: <ul style="list-style-type: none"> • To prevent infections like pneumonia and meningitis, for as long as you are on immunosuppressant drugs • Before dental work <input type="checkbox"/> If you are on immunosuppressant drugs, you may need a blood test for Cytomegalovirus (CMV) screening. 	<ul style="list-style-type: none"> • 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?
EYES	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES
<ul style="list-style-type: none"> <input type="checkbox"/> Wear sunglasses every time you go outside. <input type="checkbox"/> Vision screening by your eye doctor 1 time every year to check how well you can see <input type="checkbox"/> Because you have a history of GVHD, you may need to have eye exams more often. 	<ul style="list-style-type: none"> • Do I need to see an eye specialist? • How often should I have eye tests?

RECOMMENDATIONS FOR YOUR ROUTINE SCREENING AND PREVENTIVE CARE

<p><input type="checkbox"/> If you have eye pain, dryness, change in vision, sensitivity to light, or watery eyes, you need to have an eye exam. Your doctor will tell you if you need treatment.</p>	
<p>MOUTH</p>	<p>QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES</p>
<p>It's important that you brush and floss everyday to prevent infections. Also, your doctor needs to check your mouth to make sure your teeth, tongue and throat are healthy and there are no signs of oral cancer.</p> <p><input type="checkbox"/> General mouth, teeth, tongue, and throat exam at least 1 time every year</p> <p><input type="checkbox"/> Because you have a history of GVHD, you need to have mouth, teeth, tongue, and throat exams at least 2 times every year. Talk to your doctor and dentist about when you should have these check-ups.</p> <p><input type="checkbox"/> Because you had total body irradiation (TBI), you need to have mouth, teeth, tongue, and throat exams at least 2 times every year. Talk to your doctor about when you should have these check-ups.</p> <p><input type="checkbox"/> Dental exam and tooth cleaning by a dentist at least 1 time every year</p> <p><input type="checkbox"/> Tell your doctor and dentist if you have dry mouth. This could be a side effect of medications you are taking or a sign of GVHD.</p>	<ul style="list-style-type: none"> • Other than not smoking, and brushing and flossing every day, are there other things I can do to keep my mouth healthy? • Do I need to take medicine before I have any dental procedures?
<p>LUNGS</p>	<p>QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES</p>

RECOMMENDATIONS FOR YOUR ROUTINE SCREENING AND PREVENTIVE CARE

- Lung exam at least 1 time every year

If you have problems breathing or have had breathing problems in the past, you may need more tests such as:

- Pulmonary function tests**
- Chest x-ray
- CT scan
- Because you have a history of GVHD, you might need to have lung exams and pulmonary function tests more often. Talk to your doctor about when you should have these check-ups.
- Don't smoke or use tobacco. Stay away from places where people usually smoke.

- What can I do to minimize my risk of getting infections?
- What tests should I have and how often?
- What can I do to help me quit smoking?

HEART AND BLOOD VESSELS

QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES

Even many years after transplant heart problems can occur.

- Blood pressure checked every time you visit the clinic (also see Kidneys and Bladder section)
- Blood tests to check your cholesterol level at least 1 time every year. This includes triglycerides, **LDL**, and **HDL**

You may need these tests more often if you had heart or blood vessel problems before or after transplant.

- How can I minimize my risk of heart disease?
- My goals:
 - Blood pressure: _____
 - Cholesterol: _____
 - Weight: _____

RECOMMENDATIONS FOR YOUR ROUTINE SCREENING AND PREVENTIVE CARE

LIVER	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES
<ul style="list-style-type: none"> <input type="checkbox"/> Liver function blood tests (to see if your liver is working well) at least 1 time every year <input type="checkbox"/> If you had red blood cell transfusions, you may need to have a blood ferritin test to check the level of iron in your blood. <ul style="list-style-type: none"> • If you have too much iron in your blood or your test results are abnormal, your doctor might do more tests. • If you have a hepatitis B or C infection, your doctor will watch it closely. 	<ul style="list-style-type: none"> • Do I need any other tests to make sure my liver is working well? • Do I need to see a liver specialist?
KIDNEYS AND BLADDER	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES
<ul style="list-style-type: none"> <input type="checkbox"/> Blood pressure checked every time you visit the clinic. High blood pressure (hypertension) can damage your kidneys. <input type="checkbox"/> Kidney test at least 1 time every year which includes testing: <ul style="list-style-type: none"> • Protein levels in your urine • Nitrogen levels in your blood (BUN) and creatinine test <p>If your test results show that your kidneys are not working properly, you might need further tests such as:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Kidney ultrasound <input type="checkbox"/> Kidney biopsy <p>If you have kidney disease, you should:</p>	<ul style="list-style-type: none"> • What are things I can do now to keep my blood pressure in check? • If my blood pressure is high, what can I do to get it under control? • Do I need to see a kidney specialist? How often?

RECOMMENDATIONS FOR YOUR ROUTINE SCREENING AND PREVENTIVE CARE	
<ul style="list-style-type: none"> <input type="checkbox"/> Avoid medicines and substances (foods, herbs, vitamin supplements) that can hurt your kidneys <input type="checkbox"/> See a kidney doctor <input type="checkbox"/> Because you have a history of GVHD, you might need to have your kidneys checked more often. Also, you can get urinary tract infections (UTI) more often. 	
MUSCLES AND JOINTS	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES
<ul style="list-style-type: none"> <input type="checkbox"/> If you have myopathy (weak muscles), muscle pain, or joint pain, schedule an appointment with your doctor right away. Your doctor will check your muscles to find out if you need treatment. <p>Because you have a history of GVHD and have taken steroids (such as prednisone), talk to your doctor about clinical exam for:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Muscle strength <input type="checkbox"/> Range of motion in your joints 	<ul style="list-style-type: none"> • Do I need to see a physical therapist? • How can I build my muscle strength?
BONES	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES
<p>Transplant can cause low levels of bone density. You can develop bone diseases if your density levels get too low (such as osteopenia and osteoporosis). As a woman and because you've had an allogeneic transplant and taken steroids, you're more likely to have low levels of bone density. To help keep your bones healthy, you need to have:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Bone density scan (test) every year. If your scan is abnormal, you might need more scans. 	<ul style="list-style-type: none"> • Do I need a bone density scan at all? If so, how often? • What are the ways to help me prevent bone density loss?

RECOMMENDATIONS FOR YOUR ROUTINE SCREENING AND PREVENTIVE CARE

SKIN	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES
<ul style="list-style-type: none"> <input type="checkbox"/> Do a self-exam of your skin every month to check for any changes (for example, rash, unusual growth, or patch). <ul style="list-style-type: none"> • If you see unusual growth or patch on your skin, tell your doctor as soon as possible. Your doctor will refer you to a skin specialist. <input type="checkbox"/> Use sunscreen with SPF 15 or higher every time you go outside. Reapply at least every 2 hours, or more often if you're sweating or in and out of the water. <input type="checkbox"/> Avoid direct sunlight. Wear a broad-brimmed hat or use a large umbrella to protect your skin from the sun. 	<ul style="list-style-type: none"> • How do I do a self-exam of my skin? • Should I use any special soaps or lotions? • Do I have scleroderma? Fasciitis?
NERVOUS SYSTEM	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES
<p>The nervous system includes your brain, spinal cord and nerves. Sometimes after transplant, patients have changes or problems with how their nervous system works.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Clinical exam by your doctor at least 1 time every year to check for changes or problems <input type="checkbox"/> Tell your doctor right away if you have trouble with things like your memory, concentration, or making decisions. Your doctor will tell you if you need more tests and/or treatment. 	<ul style="list-style-type: none"> • How do I know when to call the clinic about symptoms I'm having?
ENDOCRINE ORGANS (THYROID, GROWTH AND SEX HORMONES)	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES

RECOMMENDATIONS FOR YOUR ROUTINE SCREENING AND PREVENTIVE CARE

To make sure your endocrine system is working well, you should have these tests at least 1 time every year:

- Blood test to check how well your **thyroid** is working
- Blood tests to assess your sex hormone levels
- Fasting glucose (sugar) test to check for Diabetes (where you do not eat or drink anything before the test)

You might need to see an OB/GYN (women’s health doctor) to talk about hormone replacement therapy.

- Do I need to see an OB/GYN specialist?

GENITALS AND SEXUAL HEALTH

QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES

- To stay healthy you should have a gynecology exam at least 1 time every year

Tell your doctor if you have any of these symptoms:

- Low sex drive
- Erectile dysfunction or impotence
- Hot flashes
- Vaginal dryness
- Vaginal pain or bleeding after sexual intercourse

These could be signs of low sex hormone levels, menopause or GVHD. You might go into early menopause after transplant, even if you’re young. Your doctor will tell you if you need more tests and/or treatment.

- Should I do a breast/testicular self exam? How often? What should I be looking for?
- Do I need to be tested for sexually transmitted diseases?
- How can I stay sexually healthy after transplant?

RECOMMENDATIONS FOR YOUR ROUTINE SCREENING AND PREVENTIVE CARE

FERTILITY AND FAMILY PLANNING	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES
<p>Transplant can lower your ability to have children.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Ask your doctor about your chances of being able to have children after transplant. <input type="checkbox"/> If you want to have children in the future, ask your doctor to refer you to a fertility doctor. <input type="checkbox"/> Talking about fertility can be very emotional. See the Emotional Health section for ways to help you sort out your feelings. 	<ul style="list-style-type: none"> • Should my partner or I be using birth control? • What type of birth control is best for my partner or me?
EMOTIONAL HEALTH	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES
<p>Going through transplant is a very emotional experience. Your feelings and needs will change a lot, maybe even every day. It's important that you talk <u>openly and regularly</u> with your doctor, family and friends.</p> <p>Here are some questions to help you sort out your feelings and talk about them with people you trust:</p> <ul style="list-style-type: none"> • How do you feel overall? Better or worse than expected? How do you feel today? How is it different from how you felt yesterday? • Are you worried or angry about anything? • Are you eating well? • How is your energy level? Are you tired more often or do you easily become tired? Are you sleeping well? 	<ul style="list-style-type: none"> • What can I do to make sure I'm taking care of myself emotionally? • Should I see another doctor, therapist, or counselor about my emotional health? • Are there any counseling or support groups in my area that I could join?

RECOMMENDATIONS FOR YOUR ROUTINE SCREENING AND PREVENTIVE CARE

- Have you noticed if anything makes you feel better or worse?
- How are your relationships with your loved one/partner/spouse? Family? Close friends? Are you talking with them about any relationship problems?
- Are you asking for help when you need it?

DIET AND NUTRITION

QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES

To stay healthy and help your immune system fight disease, eat a healthy diet that includes many different foods. General guidelines for a balanced diet include:

- Vegetables, fruits and whole grains - 2-3 cups every day
- Protein - 3-6 ounces every day of cooked lean meats like fish and chicken (or 46-56 grams of protein)
- Dairy 3 cups every day (low-fat or fat-free)
- Drink at least eight 8-ounce glasses of fluid every day to stay hydrated. You need to drink more water when:
 - It's hot outside
 - You exercise or are more physically active
 - You have a fever or diarrhea or vomit (throw up)
- Avoid foods with lots of processed (fake) sugar or saturated (bad) fat like candy or soda

After transplant, you might experience changes in taste, loss of appetite, nausea or other symptoms that make it hard to keep a healthy diet. Talk to your doctor about your symptoms.

- Should I see a dietician (diet and nutrition expert)?
- Should I be concerned about any new allergies?
- If I have trouble with GVHD of my **GI tract**, can you help me make a plan to maintain a healthy diet?
- How can I keep a healthy diet and weight?

RECOMMENDATIONS FOR YOUR ROUTINE SCREENING AND PREVENTIVE CARE

GENERAL HEALTH	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES
<p>It's important to take care of yourself and follow your doctor's orders to stay healthy and well. To make sure you are staying healthy overall, follow these general lifestyle practices:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Use alcohol in moderation (less than 2 drinks a day) <input type="checkbox"/> Stay physically active (2.5 hours each week of moderate exercise) <input type="checkbox"/> Don't smoke or use chewing tobacco <input type="checkbox"/> Stay away from places where people usually smoke <input type="checkbox"/> Don't let people smoke in your house or car <p>Smoking cigarettes or using tobacco hurts nearly every organ in the body, especially your lungs and heart. It can also cause new cancers.</p>	<ul style="list-style-type: none"> • What are some exercises I can do to stay physically active? • Are medications to help me quit smoking an option? If so, which ones? How long will I be on them? What are the side effects of the medications? • Where can I go for counseling or a support group to quit smoking?
NEW CANCERS	QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES
<p>New cancers can develop because you've had chemotherapy and/or radiation, TBI and have a history of GVHD. You need to have screenings at least 1 time every year for:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Breast cancer (mammography every 1 to 2 years starting at age 25) <input type="checkbox"/> Cervical cancer <input type="checkbox"/> Colorectal cancer (starting at age 50 or earlier if you have a family history of colorectal cancer) <input type="checkbox"/> Skin cancer 	<ul style="list-style-type: none"> • What is my risk for getting new cancers? • How can I lower my risk of getting new cancers? • How do I do a self-exam of my skin? How often? What should I be looking for? • Would I benefit from annual skin exams?

YOUR CARE TEAM INFORMATION

Transplant doctor:	
Phone:	
Primary care doctor:	
Clinic name:	Phone:
Oncology (cancer) doctor:	
Clinic name:	Phone:
Ophthalmologist (eye specialist):	
Clinic name:	Phone:
OB/GYN (women's health specialist):	
Clinic name:	Phone:
Physical Therapist:	
Clinic name:	Phone:
Dentist:	
Clinic name:	Phone:
Other doctor:	
Clinic name:	Phone:
Other doctor:	
Clinic name:	Phone:
Other doctor:	
Clinic name:	Phone:

YOUR TREATMENT NOTES

Folder Cover

Individualized Care Plans for HCT Survivors

Study funding provided by the Patient Centered Outcomes Research Institute (PCORI) and sponsored by Be the Match[®]. This study is conducted by the Center for International Blood and Marrow Transplant Research (CIBMTR) Resource for Clinical Investigation in Blood and Marrow Transplant (RCI BMT).

Your study materials

Inside Left Panel

Congratulations on the one-year anniversary of your blood and marrow transplant (transplant), also known as HCT. Thank you for joining the Individualized Care Plans for HCT Survivors study. This folder contains your study materials:

- Your personalized care plan
- Glossary of terms
- Actions you can take to get the most out of your care plan
- How to get answers to your questions

A survivorship care plan includes a summary of your transplant treatment and plan for follow-up care. You and your doctors can use this information to make decisions together about your care. Transplant follow-up care is important to protecting your health, even many years after transplant.

Your transplant center reviewed the information in this care plan. For this study, treatments or issues that you might have had before transplant are not included in the care plan. Please contact your transplant center or hematologist/oncologist (cancer doctor) for your questions about treatment before transplant.

We will use your feedback to improve HCT survivorship care plans in the future.

Sincerely,

Elizabeth A. Murphy

K. Scott Baker

Navneet S. Majhail

Elizabeth Murphy, RN, EdD

K. Scott Baker, MD, MS

Navneet Majhail, MD, MS

Principal Investigator

Co-Principal Investigator

Co-Principal Investigator

Inside Right Panel

Glossary

Bone density scan — An imaging (picture) test that looks for abnormal (or unhealthy) areas in your bones. For this test, you are given a small amount of a fluid in your arm. The fluid is a radioactive contrast material (like a dye) that settles in abnormal areas of the bones. The dye can then be seen in pictures. When bone density is low, your bones become more porous (full of holes) and brittle. When this happens, you have a higher risk of breaking them.

Cytomegalovirus (CMV) — A type of herpes virus that can cause infections (for example, pneumonia).

Endocrine organs — Endocrine organs release hormones into your blood to manage body functions like your mood and growth. Endocrine organs include the thyroid, pituitary, and pancreas glands.

Fasciitis — Inflammation (redness and swelling) of the connective tissue that surrounds muscles, blood vessels, and nerves. Often patient get fasciitis and hardening of the skin (see **Scleroderma**) at the same time.

Fertility — A person's ability to have children

Gastrointestinal (GI) tract — Also called the digestive tract. It is made up of body organs that process the food you eat. The GI tract includes the throat, stomach, and intestines.

Graft-Versus-Host Disease (GVHD) — A post-transplant condition where the donor cells attack the patient's tissues or organs.

HDL cholesterol — High-density lipoprotein or HDL is known as "good" cholesterol because it helps to remove "bad" cholesterol (LDL) and keep your blood vessels healthy (see **LDL**).

Immunosuppressant drugs — Immunosuppressant drugs work to lower the strength of your immune system. The main use of these drugs is to lower the body's ability to reject the transplanted bone marrow, cord blood or peripheral blood stem cells. Immunosuppressant drugs are usually given to treat GVHD.

Kidney disease — When your kidneys don't properly filter toxins (or poisons) and waste products from your blood.

Kidney filtration levels test — Measures how much liquid flows through your kidneys. This test is used to see if you have chronic kidney disease.

LDL cholesterol — Low-density lipoprotein or LDL is known as “bad” cholesterol. When you have too much LDL in your blood, it can form a thick, hard deposit. If a clot forms and blocks an artery, you might have a heart attack or stroke.

Mammography — An imaging (picture) test to see if you have breast cancer.

Meningitis — Inflammation of the membranes covering your brain and spinal cord. This is caused by viruses, fungi or bacteria.

Myopathy — Muscle disease and weakness. Steroids are used to treat chronic GVHD, but might result in muscle weakness, especially in your lower body (for example, your legs and feet).

Osteopenia — Thinning of your bone tissue. Bones are weak with Osteopenia, but not as weak as with Osteoporosis. Patients develop Osteopenia before Osteoporosis.

Osteoporosis — A lot of thinning of your bone tissue, causing very weak bones. Osteoporosis can cause pain and lead to broken bones.

Oral cancer — Cancer of the mouth.

Pneumonia — Inflammation of the lungs caused by viruses, fungi, or bacteria.

Pulmonary function tests — A group of tests to measure how well the lungs are working.

Range of motion — A test to find out if a joint (such as elbow, hip, wrist) can move properly and in all normal directions.

Scleroderma — When your skin becomes hard, thick, and tight. This can lead to weak muscles, stiff joints or pain in your joints.

Thyroid — A gland that controls your body’s metabolism. Metabolism is how quickly your body uses energy from the food you eat.

Fold-in Panel

Take action

- Schedule twelve-month check-up appointments with your transplant doctor or your hematologist/oncologist.
- Review the tests, procedures and questions to ask your doctor listed in the care plan inside.
- Write down questions or issues you’d like to discuss at your appointments.

PSCORI SCP template mock up text

- Ask your doctor if there are other recommendations unique to your situation.
- Bring this care plan to all of your appointments.
- At your appointment, ask your doctor if you need to schedule appointments with other health care providers (for example, eye doctor, dentist, physical therapist, OB/GYN, counselor or other specialists).
- You might have more than 1 doctor. Talk with your doctors and encourage them to speak with each other. This will help you know who to call when you have new symptoms or to schedule checkup appointments.

Share with your doctor

- Review this guide with them at your next appointment.
- Ask them to make a copy for your medical record.

For questions or more information

You might have questions about your care plan. For answers to these questions, contact your transplant center. The name and phone number for your transplant center are listed on the care plan inside.

You might have questions about this study. For answers to these questions, contact the Investigator at your transplant center. This information is provided in your consent form and the patient information sheet. You can also contact the Center for International Blood and Marrow Transplant Research (CIBMTR) study team by:

Phone: 1-800-526-7809 Ext. 4368 (toll-free)

E-mail: SCP_SRGTeam@nmdp.org

Randomized controlled trial of individualized treatment summary and survivorship care plans for hematopoietic cell transplantation survivors

Navneet S. Majhail,¹ Elizabeth Murphy,² Purushottam Laud,³ Jaime M. Preussler,^{2,4} Ellen M. Denzen,^{2,4} Beatrice Abetti,⁵ Alexia Adams,⁴ RaeAnne Besser,⁴ Linda J. Burns,^{2,4} Jan Cerny,⁶ Rebecca Drexler,⁴ Theresa Hahn,⁷ Lensa Idossa,² Balkrishna Jahagirdar,⁸ Naynesh Kamani,⁹ Alison Loren,¹⁰ Deborah Mattila,⁴ Joseph McGuirk,¹¹ Heather Moore,² Jana Reynolds,¹² Wael Saber,^{3,13} Lizette Salazar,¹⁴ Barry Schatz,¹⁵ Patrick Stiff,¹⁵ John R. Wingard,¹⁶ Karen L Syrjala¹⁷ and K. Scott Baker¹⁷

¹Blood and Marrow Transplant Program, Cleveland Clinic, OH; ²National Marrow Donor Program/Be The Match, Minneapolis, MN; ³Medical College of Wisconsin, Milwaukee, WI; ⁴Center for International Blood and Marrow Transplant Research, Minneapolis, MN; ⁵Leukemia and Lymphoma Society, White Plains, NY; ⁶UMass Memorial Medical Center, Worcester, MA; ⁷Roswell Park Comprehensive Cancer Center, Buffalo, NY; ⁸Regions Hospital, St Paul, MN; ⁹AABB, Bethesda, MD; ¹⁰University of Pennsylvania, Philadelphia, PA; ¹¹University of Kansas Medical Center, Kansas City, KS; ¹²Baylor University Medical Center, Dallas, TX; ¹³Center for International Blood and Marrow Transplant Research, Milwaukee, WI; ¹⁴Haledon, NJ; ¹⁵Loyola University Medical Center, Chicago, IL; ¹⁶University of Florida, Gainesville, FL and ¹⁷Fred Hutchinson Cancer Research Center, Seattle, WA, USA

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Received: August 6, 2018.

Accepted: November 23, 2018.

Pre-published: December 4, 2018.

Correspondence: NAVNEET S. MAJHAIL majhain@ccf.org
