

“The Impact of Live Discharge from Hospice on Patients & Caregivers”

Purpose: “The Impact of Live Discharge from Hospice on Patients & Caregivers” study will evaluate quality of life, health status, caregiver well-being, healthcare and service utilization during the six-months following hospice discharge.

Eligibility requirement: Adult patients, 18 years and older, and their primary caregivers, who are discharged alive from hospice care due to no longer meeting eligibility requirements. Patients can live at home or in a facility.

If a patient is unable to participate due to their condition, they are still eligible for this study! Their primary caregiver will be able to respond to questions on their behalf (with permission from the legally authorized representative/POA).

Note: If patients are discharged for a hospitalization, to seek curative care, or due to a move they are not eligible to participate in this study.

Referral and Participant Consent: See page 2 for referral form. Once a referral has been received by our team, we will reach out to the patient and/or caregiver to discuss study details, answer any questions, and to receive verbal consent. There will be no consequences if the patient or caregiver decides they do not wish to participate.

Incentives:

1. For each referral that leads to an enrolled participant, you will receive a \$25 Amazon gift card by e-mail. Your company will also receive one entry into a drawing for one of four \$500 hospice donations, designated for emergency patient needs.
2. Following EACH POINT of the study (0, 3, and 6 months), the patient and primary caregiver will BOTH receive a \$25 gift card.

Note: If the caregiver provides information on behalf of the patient (if a patient is unable to participate due to their condition), only the caregiver will receive a gift card after each survey.

You can use the script below to introduce this study to patients and caregivers:

“We recently learned about a research opportunity at Saint Louis University for patients and their caregivers who, like you, are being discharged from hospice care. They want to understand what happens in the 6 months following a live discharge from hospice care. Many people find that sharing their experiences for research is one way to contribute toward change for others who might face this same challenge in the future. Since you are eligible for the study, I wanted to share the opportunity with you.

To participate you will talk with a representative from the study to complete a survey either by phone or over zoom on three occasions: closely following the hospice discharge, and then at 3 and 6 months later. You and your caregiver will **both** receive a \$25 gift card after **each** survey.

Would it be okay for me to share your name and phone number with Dr. Cara Wallace and her research team? If so, they will follow up with you to go over further details for the study to see if you would like to participate. Participation is voluntary and you can say no at any time during the process.”

Study Contact Information:

Cara L. Wallace, PhD, LMSW, APHSW-C
School of Social Work, College for Public Health & Social Justice
Saint Louis University
314-977-2746
cara.wallace@slu.edu

IRB Information: This study has been approved by the Saint Louis University Institutional Review Board.

Protocol #31241
(314) 977-7730

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Study #: 1R21NR017978-01A1

Live Discharge from Hospice Study – Referral Form

Obtain permission from patient/caregiver prior to making a referral for this study.

Submit via e-mail to cara.wallace@slu.edu; Call Dr. Cara Wallace with questions 314-977-2746

PART 1: Patient & Caregiver Information

Patient Name: _____ **Phone Number:** _____

Primary Caregiver Name: _____ **Phone Number:** _____

Patient Capacity:

- Patient can participate independently
- Patient needs proxy due to medical condition

Patient’s Legally Authorized Representative & Phone Number (if different than caregiver above):

Most Recent Palliative Performance Scale (PPS) score (and Date): _____

Primary Diagnosis: _____

If Alzheimer’s disease or related Dementias (ADRD) is not a primary diagnosis, has this been given as a secondary diagnosis? Yes (Type if known) _____ No

Other Secondary diagnosis (if applicable): _____

Hospice Admission Date: _____ **Date of discharge:** _____

Please confirm that this discharge is due to extended prognosis of patient or because patient is no longer eligible for services due to stabilization of condition: Yes No

If no, why is the patient being discharged?

PART 2: Hospice Information & Demographics

Hospice Company*: _____ **Hospice Phone Number:** _____

Referring Clinician Name:** _____ **Referring Clinician Email:** _____

Our hospice agency is [check all that apply]:

- Free standing/independent
- Part of a hospital
- Part of a home health organization
- Part of a nursing home
- Other: _____
- For profit
- Not for profit
- Government owned and operated
- I don’t know

Average daily census: _____

*Referring agency to receive 1 entry to one of four \$500 emergency patient fund donations per every referral that enrolls in study.

**Referring clinician to receive \$25 gift card for enrolled participants.