Blood and Marrow Transplant Program
University of Minnesota Medical Center
University Of Minnesota Amplatz Children’s Hospital
Care for the caregiver: Addressing challenges and providing resources and support

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Blood and Marrow Transplant Program
I THINK IT'S STRESS!!
Description of the Caregiver Contract

Caregiver Requirements:

- Autologous: 24-hour caregiver for 30 days post transplant
- Allogeneic: 24-hour caregiver for 100 days post transplant

What does the contract include?

- Justification for caregiver requirement
- Description of the responsibilities of the caregiver
- Description of the training that will be provided to caregivers
- Space for patient to list designated caregivers and their phone numbers
- Signature line for patient and BMT social worker
Rationale for Caregiver Contract

Identified Problem:

- Most patients agreed with the concept of the caregiver requirement during work-up week, however, their plans often fell through, were tenuous, or they could not recall the caregiver plan/requirement when ready for discharge from the hospital
- Chaotic/last minute search for a caregiver increased stress and impacted length of stay

Identified Solution:

- Patients are required to sign a Caregiver Contract prior to work-up week close indicating their plan for a caregiver post-transplant
Caregiver Contract Benefits

- Provides education regarding the role and expectation
- Information is standardized and consistent
- Creates additional level of accountability and acceptance
- Caregiver plan is available for all team members to view in EMR
- BMT social workers had noticed increased lengths of stay (LOS) due to failed caregiver plans and patients denying knowledge of the caregiver requirement
How to get the medical team on board...

Identified Challenges:

- Introducing the Caregiver Contract concept
- Encouraging the medical team to incorporate it into their assessment of a patient’s readiness for transplant
- Describing positive impact to our patients and program

Identified Solutions:

- Conversation with Sr. Director and Medical Director one year before creation of the form regarding identified concerns re: lack of caregivers and delays to discharge on the inpatient unit
- Sought feedback from attending MDs and Nurse Coordinators on form prior to implementation.
Development of the Caregiver Contract

- Clarified the program expectations re: caregiver requirement for each transplant type with BMT medical director

- Contract written based on the BMT program’s existing guidelines for caregiver responsibilities

- Goal during development was for the contract to be clear and concise yet easy to read and not overwhelming
Protocol of the Caregiver Contract

- Patient is provided the Caregiver Contract at first BMT consultation

- Contract is again provided to the patient during workup week

- Caregiver contract documentation in PSA and EMR

- If no caregiver plan-team discussion for next steps
Assessment of Practice Change/Tool

PATIENT RESPONSE:

- Patients no longer stated they were unaware of the caregiver requirement at the time of hospital discharge

- Decreased number of examples of lack of caregiver plans and delayed hospital discharges

- Stress and anxiety for patients, family members, and healthcare professionals were observed to decrease
PHYSICIAN RESPONSE:

- 12/15 physicians completed an 8 question survey in 2010
- 4/12 had delayed signing consents based on an incomplete Caregiver Contract
- 6/12 indicated they would delay a transplant if the Caregiver Contract was not signed
- 7/12 stated they noticed a difference in the patients’ readiness for a transplant since the Caregiver Contract was introduced in 2008
“I believe patients and their families have been better prepared since the initiation of this contract. I have had to spend less time on discussing ‘caregiving’ during the close visit.”

“Patients seem to have the Caregiver plan worked out in advance more commonly than in the past. I think the contract system is working well. Thanks for all your hard work.”

“MDs are informed if there are no reliable caregivers, but not necessarily if the contract discussion identified the lack of support.”

“Not sure if I have noticed a huge difference in patients preparation for transplant, maybe a little?”
Who is the PRIMARY Person responsible for discussing the caregiver requirement with patients/caregivers?

- MD: 25%
- Nurse Coordinator: 8.30%
- Social Worker: 66.70%
- NP/PA: 6.00%
CAREGIVER CONTRACT
For Patients Receiving an Autologous Transplant

The Blood and Marrow Transplant (BMT) Program requires all patients who are having an autologous transplant to have a 24-hour caregiver post-transplant for a minimum of 30 days. This helps ensure the safety of the patient. Individuals who agree to be caregivers will receive training and ongoing support from the BMT team. The role of the caregiver is integral in the patient transplant journey.

The caregiver has many responsibilities. These include: helping with transportation to and from clinic appointments; assisting with daily activities (e.g., food, laundry, housekeeping); helping the patient to communicate with the medical team; monitoring and assessing symptoms; central line care; assisting with medications, and providing emotional support. The expectation of our program is that a responsible adult will provide the caregiver duties. This person must be trained by the BMT team before the patient leaves the hospital.

I understand that the Blood and Marrow Transplant (BMT) Program requires me to have a 24-hour caregiver for at least 30 days after my transplant. While I am in the hospital, my medical team will meet this responsibility. After I leave the hospital, my designated caregiver(s) will assume the caregiver role. This requirement remains in effect until I receive medical clearance from the BMT Team.

My caregiver(s) will be:

1. ___________________________ Phone: ___________________________
   cell: __________________    local: __________________

2. ___________________________ Phone: ___________________________
   cell: __________________    local: __________________

3. ___________________________ Phone: ___________________________
   cell: __________________    local: __________________

Patient Signature: ___________________________ Date: ___________

patient name

BMT Social Worker Signature: ___________________________ Date: ___________

PLEASE RETURN TO YOUR BMT PHYSICIAN
CAREGIVER CONTRACT
For Patients Receiving an Allogeneic BMT

The Blood and Marrow Transplant (BMT) Program requires all patients who are having an allogeneic transplant to have a 24-hour caregiver post-transplant for a minimum of 100 days. This helps ensure the safety of the patient. Individuals who agree to be caregivers will receive training and ongoing support from the BMT team. The role of the caregiver is integral in the patient transplant journey.

The caregiver has many responsibilities. These include: helping with transportation to and from clinic appointments; assisting with daily activities (e.g., food, laundry, housekeeping); helping the patient to communicate with the medical team; monitoring and assessing symptoms; central line care; assisting with medications, and providing emotional support. The expectation of our program is that a responsible adult will provide the caregiver duties. This person must be trained by the BMT team before the patient leaves the hospital.

I understand that the Blood and Marrow Transplant (BMT) Program requires me to have a 24-hour caregiver for at least 100 days after my transplant. While I am in the hospital, my medical team will meet this responsibility. After I leave the hospital, my designated caregiver(s) will assume the caregiver role. This requirement remains in effect until I receive medical clearance from the BMT Team.

My caregiver(s) will be:

1. ___________________________ Phone: ___________________________
   cell local

2. ___________________________ Phone: ___________________________
   cell local

3. ___________________________ Phone: ___________________________
   cell local

Patient Signature ___________________________ Date: ____________

patient name

BMT Social Worker Signature: ___________________________ Date: ____________

PLEASE RETURN TO YOUR BMT PHYSICIAN
Caregiver Companion Program

- A caregiver coach provides ongoing telephone support
- The caregiver toolkit includes:
  - The Caregiver's Companion book (introduction and six modules)
  - A wellness journal
  - Tote bag, water bottle and pedometer