Figure 1: Description of the Care Planning Process

Child referred for enrollment in FOOTPRINTS by health care provider or parent

Is there a continuity MD identified? Yes

FOOTPRINTS office identifies time and location for advanced care planning conference. Notifies inter-disciplinary team (Team member notifies family)

Care planning conference is held (Facilitated by chaplain or FOOTPRINTS staff member)

Goals, values, and preferences of the family for their child are identified. Care plan is documented.

Document is signed by parent and continuity MD

Identify continuity MD

Identify Chaplain

Box 2
One physician should be identified to coordinate the care of the child and deliver a "singular" message to the family regarding the child's progress. Our experience has taught us the continuity physician is essential to the success of the process.

Box 6
Conference participants are: family members, continuity MD, primary nurse, chaplain, and other healthcare providers important to the family-social service home care/hospice personnel (if identified), primary care MD, etc. Our experience has taught us to limit the size of the conference as much as possible. If multiple physicians care for the child, have them meet in advance and allow the continuity MD to represent the MD viewpoint - "singul message. The child is always welcome to participate in the conference and is encouraged to do so if age is appropriate. Children over age 17 must sign the document if competent.

Box 8
Families are asked directly about their goals for their child. The healthcare provider team provides appropriate information to assure goals are realistic and potentially achievable. The team describes medically and ethically appropriate treatment choices and consequences. All child/family needs are considered-physical, spiritual, emotional and psychosocial.
Copies of the care plan are made and sent to all personnel/agencies involved in the care of the child.

(Original signed copy is placed in the orange tabbed sleeve and placed in the front of the chart including community personnel such as home health, hospice, fire department, police, ambulance, etc.)

No

Yes

FOOTPRINTS staff call each agency with explanation of care plan and appropriate information

Box 11
Calling each community agency caring for the child provides immediate opportunity to educate community care givers - "just in time" education.

No

Agency agrees to honor care plan? (during phone conversation)

FOOTPRINTS staff or chaplain informs family of agency status

Yes

Family satisfied

No

FOOTPRINTS staff work to coordinate services through other avenues

Yes

Family satisfied

No
Child/Family discharged

Child re-admitted

(No action can be taken)

FOOTPRINTS staff notified

Staff check to see if Advanced Care Plan is in place in the chart

Staff go to HIS dept. to retrieve care plan or reproduce office copy and place in patient chart

Continuity MD is notified patient has been readmitted

Care plans reviewed according to guidelines by continuity MD or designate

Care plan revision form completed

Changes

We have not yet identified a successful process for keeping the Care Plan with the current chart once the child has been discharged and re-admitted. We also lack a computer system to flag children in the program in a way that program staff can manually update the chart.
Copies made and distributed to all team members/family.

Personnel notified of changes made by fax or if major change by phone

Child/family discharged

Child/family follow up completed according to plan and when patient is readmitted or expires. (If patient has multiple admissions, process repeats until patient is withdrawn or expires)

Box 30
Follow-up calls are completed by FOOTPRINT nurse or chaplain for purposes of documentation. Other staff call, as often as needed.

Child dies.

Box 31
If the child is imminently dying at the time of the care conference, a specific plan may be developed addressing autopsy, organ donation, care and transport of the body, funeral, rituals, memorials, etc.

FOOTPRINTS™ staff inform all healthcare providers of the death (by phone).

Family is entered into the Bereavement Program and followed for 13 months. Families of children who die suddenly in the hospital are enrolled in the FOOTPRINTS™ program at this phase.
What does it mean to be a FOOTPRINTS<sup>SM</sup> continuity physician????

FOOTPRINTS<sup>SM</sup> is a program of advanced care planning and care coordination that helps children with life threatening conditions and their families live well until their journey ends. A continuity physician is key to the success in this effort.

Continuity physicians help children and families dealing with life threatening conditions.
- Suffering from pain and other symptoms is lessened
- Care is “seamless” and not fragmented
- By building a trusting relationship with the family and anticipatory guidance, ethical crises at end of life may be averted

What do FOOTPRINTS<sup>SM</sup> continuity health care providers have to say about FOOTPRINTS<sup>SM</sup>?
- 100% felt their department supported this effort
- 100% would place another child in FOOTPRINTS<sup>SM</sup>
- 67% felt FOOTPRINTS<sup>SM</sup> was very useful in helping them care for the child
- 85% felt FOOTPRINTS<sup>SM</sup> was helpful to the child and family
- 96% felt that the discharge order sheet was helpful to the child and family
- 92% felt that the discharge order sheet was helpful to them

What does the FOOTPRINTS<sup>SM</sup> continuity physician need to do?
- Agree to be the coordinating “continuity” physician for the child (this doesn’t mean you have to be the attending each time; only that you coordinate and direct the care) so that treatment is consistent with the child/families goals and values as documented by the discharge order sheet
- Provide (with the other physicians who share call with you) 24 hour a day/7 day a week availability
- Participate in the multidisciplinary care conference and completion of the discharge order sheet (similar to an advanced directive)
- Provide anticipatory guidance for the child/family
- Communicate with the child, family, hospital based physicians and other health care team members, and the community physician so that the care is “seamless” regardless of site of care
- Participate in periodic phone or physical follow up of the child and revise/update the care plan as needed or at least every 6 months
- Communicate changes in the care plan to the FOOTPRINTS<sup>SM</sup> staff

What does the FOOTPRINTS<sup>SM</sup> staff do to support the continuity physician? A staff member is available to:
• Coordinate and facilitate the multidisciplinary care conference and completion of the discharge order sheet
• Make sure that everyone potentially involved gets a copy of the discharge order sheet and any revisions
• Communicate with EMS and other community care providers to ensure that the child/family’s wishes are respected
• Help identify other community resources
• Provide phone and/or physical follow up and send you updates about the child and family
• Provide care coordination
• Notify you when we become aware the child is readmitted or comes to clinic
• Consult you for any identified problems or change in condition
• Provide continuing bereavement support after the death of the child

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