The Benefits of a Family Advisory Team

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Patient and Family Centered Care

- Patient-and family-centered care (PFCC) is an innovative approach to the planning, delivery, and evaluation of health care.

The hospital recognizes that when a child is diagnosed with cancer, the whole family is affected.

While the first goal is to treat the child’s cancer, hospitals that provide PFCC provide psychosocial support to the entire family.
Family Advisory Team

- Formed to support the efforts of the Patient and Family Education Program.
- The FAT serves as the voice of the patient and family.
- We believe that the families' perspectives are able to impact and improve clinical care.

Family Advisory Team

- The goal of the FAT is to inform our practice by engaging families in a systematic approach to delivering and developing patient and family education materials and delivery systems.

Family Advisory Team

FAT has been asked to participate in a quality improvement project that explores how families are being educated after receiving a new diagnosis of cancer.
Benefits for Families and Professionals

- Fostering collaboration
- Increasing sense of social support among families
- Increasing families' knowledge of community based resources
- Empowerment – feel that they have influenced for future families

Benefits for the Professionals

- Patient and family members bring ideas and insight into the development of the programs and educational materials
- This insight can only be attained through personal experience and knowledge
- Collaboration/partnership – part of a team

Timeline

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
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<tbody>
<tr>
<td>August 23, 2017</td>
<td>Orientation for new parent advisors</td>
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<tr>
<td>October 19, 2017</td>
<td>Conference call for input on QI questions</td>
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<tr>
<td>December 7, 2017</td>
<td>Conference call to get parental input on two new documents</td>
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<td>February 15, 2018</td>
<td>Conference call to get parental input on disaster plan document</td>
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<tr>
<td>February 20, 2018</td>
<td>Phone call to verify Spanish translation of document</td>
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<td>March 6, 8, 14, 2018</td>
<td>Showcase Event in clinic</td>
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<td>March 21, 2018</td>
<td>Showcase debrief</td>
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<tr>
<td>April 1, 2018</td>
<td>Conference call to go over new accordion</td>
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<tr>
<td>June, 2018</td>
<td>Conference call to report findings on accordion</td>
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<tr>
<td>Sept 2018</td>
<td>School Guide</td>
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<tr>
<td>December 2018</td>
<td>Medical Fact Sheets (nutrition, oral care)</td>
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<tr>
<td>March 2019</td>
<td>Review New Accordion</td>
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Educational Materials Showcase

Showcase Specifics

- Jelly bean voting
- Survey regarding support services
- 58 participants
- 3 separate days/times
- 5 parent advisor (volunteers)

Style of Binder
Would like information | Would NOT want
---|---
School coordination/information about services | o | o
Educational materials regarding diagnosis, general medical topics | o | o
Talking with my other children about my child’s medical condition | o | o
Talking with my other family members about my child’s medical condition | o | o
Connection to support & resources for me (support groups, counseling, etc) | o | o
Connection to support for my child (camps, social events) | o | o
Information about food assistance programs | o | o
Information about how to manage medical bills | o | o

Support Services Requested

Patient and Family Education Nook
Patient and Family Education Nook

School Guide Feedback

ALSF School Guide: Supporting Families and Classmates Affected by Childhood Cancer
Evaluation of School Guide

• 5 parents participated
• 4 school teachers participated
• Evaluated book using evaluation tool adapted from Agency for Healthcare Research and Quality

School Guide Feedback

• Evaluated on 5 matrix
• Audience, Transition Back, Bullying, Sibling, Grief,
• Assessment of strengths and opportunities

Family Advisory Team

• What impact did being a part of the Family Advisory Team have on you?
• Please list three things you learned or gained as a result of your participation.
• What benefit do you see the Family Advisory Team provides to the hematology/oncology department?

Health Care Provider

References

• Institute for Health Care Improvement
  http://www.ihi.org