Detailed FAMCARE and FAMCARE-2 Guidelines for Use, developed by the Edmonton Zone Palliative Care Program, consist of eight key sections: (1) Background, (2) Versions, (3) Translations, (4) How to Administer, (5) How to Interpret, (6) How to Report, (7) How to Implement, (8) Frequently Asked Questions. These guidelines may be accessed at: http://www.palliative.org/NewPC/professionals/tools/famcare.html

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The FAMCARE-2 tool was originally developed for administration to family members of advanced cancer or palliative non-cancer patients receiving palliative care services in settings that include acute care, hospice and home care. The tool can be administered to family caregivers while the patient is receiving palliative care or after a patient’s death.

In June, 2012, the Edmonton Zone Palliative Care Program (EZPCP) adopted the FAMCARE-2 for use on the tertiary palliative care unit and hospice sites in Edmonton. The Covenant Health palliative care units in Lethbridge and Medicine Hat will also adopt the FAMCARE-2 as of January, 2013. In the EZPCP and Covenant Health palliative care sites, the FAMCARE-2 is mailed to family caregivers approximately one to two months after a patient’s death. Completed surveys are returned by mail to the palliative care sites. An additional section has been added for family caregivers to provide comments. If a family caregiver is very dissatisfied and if contact information is available, then it would be important for a staff member to contact the family caregiver to go over the issues experienced.

How satisfied are you with:

1. The patient’s comfort
2. The way in which the patient’s condition and likely progress have been explained by the palliative care team
3. Information given about the side effects of treatment
4. The way in which the palliative care team respects the patient’s dignity
5. Meetings with the palliative care team to discuss the patient’s condition and plan of care
6. Speed with which symptoms are treated
7. Palliative care team’s attention to the patient’s description of symptoms
8. The way in which the patient’s physical needs for comfort are met
9. Availability of the palliative care team to the family
10. Emotional support provided to family members by the palliative care team
11. The practical assistance provided by the palliative care team (e.g. bathing, home care, respite)
12. The Doctor’s attention to the patient’s symptoms
13. The way the family is included in treatment and care decisions
14. Information given about how to manage the patient’s symptoms (e.g. pain, constipation)
15. How effectively the palliative care team manages the patient’s symptoms
16. The palliative care team’s response to changes in the patient’s care needs
17. Emotional support provided to the patient by the palliative care team

The FAMCARE-2 is shorter and more concise than the FAMCARE. FAMCARE-2 refers more to a team approach to palliative care, rather than focusing primarily on physicians and nurses. FAMCARE-2 makes reference to more symptoms than pain alone and offers more response options. The FAMCARE was developed for inpatient advanced cancer care, while the FAMCARE-2 was developed for use in diverse palliative care settings, with both advanced cancer and non-cancer patients. Both tools may need to be modified for care of other illnesses such as end stage organ failure and neurodegenerative diseases. Each FAMCARE-2 item is rated on a five-point Likert-scale: very satisfied, satisfied, undecided, dissatisfied, very dissatisfied. Family caregivers may select a sixth option, “not relevant to my situation.” They may also choose not to answer some questions. FAMCARE-2 has 17 questions.