COVER LETTER TEMPLATE FOR PATIENT QUESTIONNAIRE

(Date)_____

Dear Patient,

_____ Health System is a member of a group of Catholic health care organizations across the United States. The goal of this group is to improve care for persons who may be affected by a life-threatening illness.

We are inviting you to take part in a project. To help us improve care, we are asking people to answer questions about their experiences. The questions came from the reported experiences of people who were affected by life–threatening illnesses. The attached questionnaire asks you to rate your current health and symptom experience and your experience with healthcare. There is also a questionnaire that asks specific information about you.

The questionnaire takes about 25 – 30 minutes to complete. Please complete and return them within a week of receiving them. You will also be asked to complete the same form in another month, after three months six months, and every three months. Please complete each copy and return it within a week or as soon as possible. Answer the questions on each questionnaire from your experience **at that time**. Do not worry about your answers on the prior questionnaire when completing the next one.

We are developing a new service approach that will help health systems do an even better job serving those who come to them. Your answers on the forms will help them refine services available for you and others. It will also help us know if there is a need for more focused changes in health care or services for people affected by life-threatening illnesses.

You will work with the CALL Care project staff to have care and services matched to the information you share on the form. YOU ARE NOT REQUIRED TO COMPLETE THE QUESTIONNAIRES IN ORDER TO RECEIVE CARE AND SERVICES. With a completed questionnaire, however, the doctors and others can better provide you the care and services that you will benefit from most. The project staff will also review your records to determine the criteria used to refer you to this project and the services you actually received. Your information will be kept confidential.

The _____ Health system also wants to know how well their services are meeting the overall needs of people affected by life-threatening illnesses compared to other organizations. They will share the information from your questionnaires and records without your name with the Coalition office for analysis, report development and possible publication. This information will be entered into a computer file (EXCEL) before it is sent to the Coalition office. Your information will be identified by a code number only. The Coalition office will not be able to track your answers to you personally. Your name will not be used in any written project report or presentation. However, you may receive follow-up contact from

_____ Health System or _____ health service project staff.

Completing and returning these forms is voluntary and will qualify as your consent to take part in this project. You will not be paid to take part in this project.

If you have questions about this project, you may call _____ Health System or _____ health service. The contact person is:

(Name and title)
(address)
(phone number)
(e-mail address)

If you have questions or want additional information, about the Coalition, contact:

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Thank you in advance for completing the questionnaires.

Sincerely

Modified City of Hope** Patient Questionnaire

Please answer the following questions **based on your life at this time**. Circle the number from 0 – 10 that best describes your experiences:

Physical Area

To what extent are the following a problem for you:

1. **Fatigue**
   No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

2. **Sleep changes**
   No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

3. **Problems with dry mouth, change in food tastes, drooling or appetite changes**
   No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

4. **Intestinal problems of constipation or diarrhea**
   No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

5. **Nausea**
   No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

6. **Shortness of breath or difficulty breathing**
   No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

7. **Aches or pain**
   No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

8. **Please rate your current pain**
   No pain 0 1 2 3 4 5 6 7 8 9 10 *Worst pain you can imagine*

Emotional / Relationship Area

9. **How satisfying is your life?**
   Not at all 0 1 2 3 4 5 6 7 8 9 1*0 Completely*

10. **How much anxiety do you have?**
    None at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

11. **How free are you to express feeling of sadness, grief, and anger?**
    Not at all 0 1 2 3 4 5 6 7 8 9 10 *Completely*

12. **Do you have enough opportunity to talk about your illness, experiences, and possible death?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 *Completely*

13. **How much do you feel like you are a burden for your family?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 *Completely*

14. **How much do you worry about family and friends not being there for you?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

15. **Have family / friends given specific support without you asking?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

16. **Is the amount of support you are receiving meeting your needs?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 *Completely*

17. **How much isolation from others do you feel is caused by your illness or treatment?**
None at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

18. **How much of your treatment wishes and goals do your family / friends know?**
None at all 0 1 2 3 4 5 6 7 8 9 10 *Completely*

19. **If you are still working, has your work place been supportive? (leave blank if not still working)**
Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

Spiritual Area

20. **How important to you is your participation in spiritual or religious experiences (e.g. meditation, spiritual traditions or rituals, praying, or going to a place of worship)?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 *Very important*

21. **To what extent has your illness made positive changes in your life?**
None at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

22. **Do you sense a purpose / mission for your life or a reason for being alive?**
None at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

23. **How hopeful do you feel?**
Not at all hopeful 0 1 2 3 4 5 6 7 8 9 10 *Very hopeful*

24. **How much opportunity have you had to reflect on your life?**
None at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

25. **Do you view time as precious and value each minute of life?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

26. **Have you experienced healing in spiritual, emotional, relational areas of your life?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

Please share other comments about your experience

_____

Modified City of Hope** Patient Questionnaire

July 2003

Please answer the following questions **based on your life at this time**. Circle the number from 0 – 10 that best describes your experiences:

1. To what extent are the following physical symptoms a problem for you:

- **Fatigue**

No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

- **Intestinal problems of constipation or diarrhea**

No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

- **Nausea**

No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

- **Shortness of breath or difficulty breathing**

No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

- **Aches or pain**

No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

2. **Please rate your current pain**

No pain 0 1 2 3 4 5 6 7 8 9 10 *Worst pain you can imagine*

3. **How much anxiety do you have?**

None at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

4. **Is it a problem obtaining adequate help for meeting your physical needs at home?**

No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

5. **Have you been given enough information about your care and treatment choices to prepare you for your experience with care and treatments?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *Completely*

6. **Do you feel that you have appropriate control over your care choices and health care experiences?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *Completely*

7. **Do you have enough access to professional counselors or support groups or are you put in touch with others who have similar experiences?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

8. **Have you been given a choice to have chaplains or others to pray with and for you or to say no to their praying with or for you?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

9. **Do people consistently follow through on your care wishes?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

10. **Do you feel caring, respect, and genuine presence from your doctors, nurses, and other health care providers?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

11. **Is your doctors' communication with you easy to understand and consistent?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

12. **Is your nurses' and other health care professionals' communication with you easy to understand and consistent?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

13. **Do you your doctor(s) are available for you as you need them**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

14. **Do you feel nurses and other professionals are available for you as you need them**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

15. **Do you feel supported by your doctors if you looked for second opinions and other care choices?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

16. **Do your doctor(s) provide you the opportunity to discuss possible death?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

17. **Do your nurses, and others provide you the opportunity to discuss possible death?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

18. **Please rate your overall experience with the quality of your health services**

Very inconsistent 0 1 2 3 4 5 6 7 8 9 10 *Consistently high*

Please share other comments about your experience

_____

_____

_____

_____

_____

**Modified by Supportive Care of the Dying: A Coalition for Compassionate Care

Information About You

Please complete the following questions about you. This information will be kept strictly confidential.

Age _____ **Gender**: ____Male ___Female

Diagnosis or illness that seems to be life – threatening:

_____

Race/Ethnicity

___White/Caucasian
___Black/African American
___Asian or Pacific Islander
___Hispanic
___Native American
___Other

Current Living Arrangements:

___Living alone at home
___Home with family / friends
___Living with family / friends in their home
___Assisted Living
___Nursing Home

Health Services you are receiving:

___Home Health
___Hospice
___Parish Nurse
___Church based ministries, e.g. Stephen Ministries
___Visiting Nurse
___Other (specify): _____

Please call me about my care or this questionnaire ___yes___no
Date Questionnaires completed _____ I.D. number_____

Place of Care Environment (Health Care Experience)

1. **Experience receiving effective and timely pain management**
   No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

2. **Experience receiving effective and timely symptom relief, e.g. difficulty breathing, nausea, constipation.**
   No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

3. **Adequate help for meeting your physical needs at home**
   No problem 0 1 2 3 4 5 6 7 8 9 10 *Severe problem*

4. **Were you given enough information about your care and treatment choices to prepare you for your experience with care and treatments?**
   Not at all 0 1 2 3 4 5 6 7 8 9 10 *Completely*

5. **How difficult was it to find out information about your illness, care, and treatment choices?**
   Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

6. **If there was a conflict over your care, did you feel supported in having your care wishes honored?**
   Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

7. **Did you feel that you had appropriate control over your care choices and health care experiences?**
   Not at all 0 1 2 3 4 5 6 7 8 9 10 *Completely*

8. **Did you feel free to refuse care or treatments?**
   Not at all 0 1 2 3 4 5 6 7 8 9 10 *Completely*

9. **Did your family feel welcomed 24 hours a day and with each appointment?**
   Not at all 0 1 2 3 4 5 6 7 8 9 10 *Completely*

10. **Was your privacy and confidentiality respected?**
    Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

11. **Were you given information about support groups or put in touch with others who had similar experiences?**
    Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

12. **Do you have enough access to and opportunity to talk with professional counselors?**
    Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

13. **Were you given the opportunity to have chaplains or others pray with and for you or to say no to their praying with or for you?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

14. **Did the health care team ask about your Living Will or advance care planning?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

15. **Please rate your overall experience with the quality of your health services**

Very inconsistent 0 1 2 3 4 5 6 7 8 9 10 *Consistently high*

16. **Have those caring for you had a good understanding of your illness, treatment, and care wishes?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

17. **Have people consistently followed through on your care wishes?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

18. **Did you get enough help obtaining and completing applications and financial forms, e.g. insurance, social security, disability?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

19. **Did you get enough help finding needed resources and support, e.g. transportation or homemaker assistance?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

DOCTORS, NURSES / OTHER HEALTH CARE PROVIDERS COMMUNICATION

20. **Have you felt caring, respect, and genuine presence from your doctor?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

21. **Have you felt caring, respect, and genuine presence from your nurses and others?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

22. **Was your doctor's communication with you easy to understand and consistent?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

23. **Was your nurse's communication with you easy to understand and consistent?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

24. **Did you feel supported by your doctors if you looked for second opinions and other care choices?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

25. **To what extent has communication with healthcare personnel assisted you to maintain hope?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

26. **How much do you worry about physicians and other professionals not being there for you?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

27. **If you had questions about "complementary therapies", did your doctors' answer your questions to your satisfaction?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

28. **Have your doctor(s) provided you the opportunity to discuss possible death?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

29. **Have your nurses / others provided you the opportunity to discuss possible death?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 *A great deal*

Please share other comments about your experience

_____

_____

_____

_____

_____

**Modified by Supportive Care of the Dying: A Coalition for Compassionate Care

Information About You

Please complete the following questions about you. This information will be kept strictly confidential.

Location Where Questionnaire Completed:
___Home ___Hospital ___Long Term Care ___Dr's Office
___Other (*please specify*) _____

Age _____ **Gender**: ____Male ___Female

Diagnosis or illness that seems to be life – threatening:

_____

Race/Ethnicity
___White/Caucasian
___Black/African American
___Asian or Pacific Islander
___Hispanic
___Native American
___Other

Religion
___Jewish
___Catholic
___Jehovah's Witness
___Christian Scientist
___Seventh Day Adventist
___Protestant
___Native American
___Muslim
___Buddhist
___Bahia
___No religion
___Other (*specify*):
_____

Insurance:
___Private/Commercial insurance
___Medicare
___Medicaid
___No insurance / self-payment
___Other insurance

Health Maintenance Organization (HMO) ___yes ___no

Yearly household income before taxes:
___less than $25,000
___$25,001 - $50,000
___$50,001 - $75,000
___$75,001 - $100,000
___more than $100,000

Current Living Arrangements:
___Living alone at home
___Home with family / friends
___Living with family / friends in their home
___Assisted Living
___Nursing Home

Health Services you are receiving:
___Home Health
___Hospice
___Parish Nurse
___Church based ministries, e.g. Stephen Ministries
___Visiting Nurse
___Other (specify): _____

Please call me about my care or this questionnaire ___yes___no
Date Questionnaires completed _____ I.D. number_____