

Queen Elizabeth Hospital Department of Clinical Oncology, palliative care out-patient clinic*“Leaving with peace at home” questionnaire*

The aim of this questionnaire is to understand your expectation of the mode of care and place of death. “Dying at home” means you die in the place where you are familiar and you often live, which includes your home and residential care home for the elderly. We hope to understand your needs and some of the facilitating factors and barriers to fulfill your wishes, so that we can help you to fulfill your wish in the future.

All the information is for the use of research.

Your confidentiality will be the highest priority.

Questionnaires might be self-administered or written by your relatives.

Participation in the study is voluntary.

If you feel uneasy for the questionnaire, please skip it.

Thanks for your precious time

A. Personal data

Date: _____; Participant number: _____

If the one who fills in the questionnaire is not the participant himself/herself, please write down your relationship with the participant: _____

Sex: Male; Female

Age: _____

Education level: No access to education

Primary school level

Secondary school level

Post-secondary school level or above

Your present residential place: Home

Residential care home for the elderly (RCHE)

If you live in RCHE, you live for: <3 months; ≥3 months

Please ✓ in the box which indicate your most suitable answer.

B. Your preference

1. Ideally, do you want to die at home?

I want

I do not want

2. Ideally, do you want to die at residential care home for elderly?

I want

I do not want

3. Which of the following sentence can represent your wish most?

I wish to be taken care and die at home (please go to questions 4, 8-17)

I wish to be taken care and die at residential care home for elderly (please go to questions 4, 7-17)

I wish to extend the time to be taken care at home, but when symptoms cannot be controlled or rapid deterioration of the medical condition, I can be sent to hospital and die in acute ward (please go to questions 5, 12-17)

I wish to extend the time to be taken care at residential care home for elderly, but when symptoms cannot be controlled or rapid deterioration of the medical condition, I can be sent to hospital and die in acute ward (please go to questions 5, 7, 12-17)

I wish to extend the time to be taken care at home, but when symptoms cannot be controlled or rapid deterioration of the medical condition, I can be sent to hospital and die in palliative care ward (please go to questions 6, 12-17)

I wish to extend the time to be taken at residential care home for elderly, but when symptoms cannot be controlled or rapid deterioration of the medical condition, I can be sent to hospital and die in palliative care ward (please go to

questions 6-7, 12-17)

Others: _____

4. The reason(s) you wish to die at home or residential care home for elderly is/are: (you can choose more than one answer)
- More autonomy and security
 - More confidentiality
 - More sense of belongings at home
 - Hope to maintain the “normal” family life as much as possible
 - The previous experience in hospital is not satisfied
 - Religious activities can be carried out more easily at home after death
 - Can always be taken care and accompanied by my relatives or loved one at home
 - Familiar surroundings and relationships confirm the importance of the dying person and reaffirms to the dying individuals that they are still the same people they always have been
 - Others: _____
5. The reason(s) you wish to die in acute ward of hospital: (you can choose more than one answer)
- Do not know I can choose to die at home
 - Fear of depreciation of the property value of my house as it becomes “haunted house” if I die at home
 - If I die at home, I would bring a lot of pressure and become a burden to my family
 - My family or friends or old age home staff do not know how to take care of me, so I do not have enough security
 - I can receive the most suitable treatment in acute ward
 - Others: _____
6. The reason(s) you wish to die in palliative care ward of hospital (you can choose more than one answer):
- Do not know I can choose to die at home
 - Fear of depreciation of the property value of my house as it becomes “hunted house” if I die at home
 - If I die at home, I would bring a lot of pressure and become a burden to my family
 - My family or friends or old age home staff do not know how to take care of me, so I do not have enough security
 - The environment of palliative care ward is better than acute ward
 - Can provide palliative care which is more suitable to terminal cancer patients
 - Others: _____
7. The reason(s) you chose to be taken care in residential care home for elderly is/are (you can choose more than one answer):
- I live alone
 - My family or friends do not have enough time to take care of me
 - My family or friends do not know how to take care of me
 - The relationship with my family or friends is not close
 - If I die at home, I would bring a lot of pressure and become a burden to my family
 - Small house with limited space
 - There are not enough medical facilities in my house
 - Others: _____
8. If you wish to die at home or residential care home for elderly, which of the following factor(s) can facilitate you to fulfill your wish? (you can choose more than one answer)
- There is enough support to my carer (including the old age home staff), for example, the carer can contact palliative home care nurse whenever is needed or provide teaching courses to the carer on how to take care of the patient
 - Provide respite care services, so that the carer can have a break to reduce his/her pressure
 - Physicians and nurses can have regular home visit according to my needs
 - My family and I have the same expectation of my place of care and death
 - Symptoms can be controlled at home or residential care home for elderly
 - Palliative care team doctor can certify death at home and fill in a Medical Certificate of the Cause of Death and the medical certificate for the application of the cremation
 - Occupational therapist can assess the facilities of my home and make any adjustment when needed

- Volunteer workers can provide psychological support to me and my family, or provide other support, like accompany with me during medical follow-up
 - Medical healthcare workers help me to set advance directive and advance care plan
 - Financial support
 - Others: _____
9. If you wish to die at home or residential care home for elderly, which of the following 3 factor(s) become the most significant factors to facilitate you to fulfill your wish? (please write 1, 2, 3 in the ; 1 represents the most significant factor)
- There is enough support to my carer (including the old age home staff), for example, the carer can contact palliative home care nurse whenever is needed or provide teaching courses to the carer on how to take care of the patient
 - Provide respite care services, so that the carer can have a break to reduce his/her pressure
 - Physicians and nurses can have regular home visit according to my needs
 - My family and I have the same expectation of my place of care and death
 - Symptoms can be controlled at home and residential care home for elderly
 - Palliative care team doctor can certify death at home and fill in a Medical Certificate of the Cause of Death and the medical certificate for the application of the cremation
 - Occupational therapist can assess the facilities of my home and make any adjustment when needed
 - Volunteer workers can provide psychological support to me and my family, or provide other support, like accompany with me during medical follow-up
 - Medical healthcare workers help me to set advance directive and advanced care plan
 - Financial support
 - Others: _____
10. If you wish to die at home or residential care home for elderly, which of the following factor(s) can become barrier for you to fulfill your wish? (you can choose more than one answer)
- My family members have too much pressure to take care of me and cannot cope with it
 - My family do not know how to take care of me especially when my condition deteriorates
 - My family and friends do not have enough time to take care of me
 - No family members or friends are willing to take care of me
 - Small house with limited space
 - There are not enough medical facilities inside my house
 - The Coroner Ordinance demands all deaths in residential care home for elderly need to be reported to coroner except for the deaths in nursing home
 - Physician must have attended patients within 14 days prior to death. He also needs to certify patient death at home. However, there is not enough organization or hospital in Hong Kong to support this service
 - Some private hospitals can facilitate patients to die at home, but the cost is quite high
 - I worry my symptom cannot be relieved at home or in residential care home for elderly
 - There is not enough staff in residential care home for elderly to take care of me
 - Relatives need to notify the funeral planner/agent to transfer the dead body to funeral parlor
 - Others: _____
11. If you wish to die at home or residential care home for elderly, which of the following 3 factor(s) become the most significant barrier to fulfill your wishes? (please write 1, 2, 3 in the ; 1 represents the most significant factor)
- My family has too much pressure to take care of me and cannot cope with it
 - My family do not know how to take care of me especially when my condition deteriorates
 - My family and friends do not have enough time to take care of me
 - No family members or friends are willing to take care of me
 - Small house with limited space
 - There are not enough medical facilities inside my house
 - The Coroner Ordinance demands all deaths in residential care home for elderly need to be reported to coroner except for the deaths in nursing home

- Physician must have attended patients within 14 days prior to death. He also needs to certify patient death at home. However, there is not enough organization or hospital in Hong Kong to support this service
 - Some private hospitals can facilitate patients to die at home, but the cost is quite high
 - I worry my symptom cannot be relieved at home or in residential care home for elderly
 - There is not enough staff in the residential care home for elderly to take care of me
 - Relatives need to notify the funeral planner/agent to transfer the dead body to funeral parlor.
 - Others: _____
-
12. Would you tell your family about your expectation of place of death?
- Yes
 - No
13. Do you and your family have the same expectation?
- Yes
 - No
 - I don't know
14. Would you tell the doctors or nurses about your expectation of place of death?
- Yes
 - No
15. Do you hope doctors or nurses enquire directly about your expectation of place of death?
- Yes
 - No
16. Do you think "dying in the place according to your wish" is important?
- Very important
 - Important
 - Fair
 - Unimportant
 - Very unimportant

~ The end, Thank you~