



Otago Community Hospice | PO Box 8002  
293 North Road, Dunedin, New Zealand  
Tel: 03 473 6005 | Fax: 03 473 6015  
[reception@otagohospice.co.nz](mailto:reception@otagohospice.co.nz)

## ASKING QUESTIONS CAN HELP

An aid for people seeing the Hospice team

## ASKING QUESTIONS CAN HELP

An aid for people seeing the Hospice team

Reviewed: 1 September 2013

[www.otagohospice.co.nz](http://www.otagohospice.co.nz)



---

Published by:

*Medical Psychology Research Unit  
The University of Sydney  
Medical Psychology Unit, Blackburn Building DO6  
University of Sydney, Australia 2006*

*New Zealand Edition—Produced by the  
Otago Community Hospice with permission from the Publisher*



The University of Sydney

*Copyright © Dr Josephine Clayton, Prof. Phyllis Butow &  
Prof. Martin Tattersall, 2002. All rights reserved.*

*Notice: It is against the law to photocopy or otherwise reproduce this  
booklet without the publishers written permission.*



## other questions

---

You may wish to write any other questions that you have in the space below:

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

## table of contents

---

<b>Introduction</b>	<b>2</b>
<b>About the hospice service and team</b>	<b>4</b>
• Available care	
• Contacting the hospice team	
• The relationship between the hospice team and other health professionals	
<b>Physical symptoms</b>	<b>6</b>
<b>Treatment</b>	<b>7</b>
• Medications	
• Morphine	
<b>Lifestyle and quality of life</b>	<b>8</b>
<b>My illness and what to expect in the future</b>	<b>9</b>
<b>Support</b>	<b>10</b>
• Support in the form of information	
• Practical support	
• Financial support	
• Emotional support	
• Spiritual and cultural support	
<b>If you are concerned about your professional care</b>	<b>12</b>
<b>For carers</b>	<b>13</b>
<b>End of life issues</b>	<b>14</b>
• Questions that I may want to ask	
• Questions that my carer or family may want to ask	

## introduction

---

Palliative care is the active total care of patients whose disease is no longer responsive to curative treatment. Palliative care incorporates the physical (tinana), social (whanau) emotional (hinengaro) and spiritual (wairua) aspects of wellbeing to enhance the quality of life of patients and families/whanau.

Most people who see a member of the hospice team for the first time have questions and concerns. Often these are forgotten in the rush of the moment. You can use this booklet during your consultation to ensure your questions are addressed. You may want to circle the questions in this booklet to help you remember the topic, or you can add your own questions. This booklet can also serve as a checklist so that you know your concerns were covered.

Different people want different things at different times. You can use this question list at any time, the first visit and subsequent visits. You may want to discuss these issues with your family/whanau or other members of the palliative care team.

Do not feel you should ask a question just because it is listed here.

---

### Questions that my carer or family may like to ask

- If I cannot manage to look after my partner, relative or friend at home, how can we come to terms with this?
- What should I say when the person that I am caring for asks “Am I dying”?
- Will you be able to tell me when it is getting close to the time that he/she will die?
- When should I call the rest of the family/whanau? What should I say to them? Could you speak with them?
- How do I know when he/she has died?
- What happens after he/she dies (eg, what happens to their body, how do we arrange the funeral)?
- What support is available for the family/whanau after the person dies?

## end of life issues

---

*The following questions may not be relevant to you or your stage of illness. Please do not feel you have to read this section if you don't want to, but there may come a time in the future when you want to ask some of these questions.*

### Questions that I may like to ask

- How do I get my affairs in order and write a will?
- Who can I talk to about the medical care that I want in the future when I am no longer able to speak for myself?
- How can I cope when I get sicker and can no longer care for myself?
- How can I cope with becoming more dependent on others?
- What can I expect in the last days of my life?
- Will you be able to tell me when it is getting close to the time I will die?
- What happens if I go into a coma?
- Is it feasible for me to die at home rather than in the hospice inpatient unit or hospital?

We have organised the booklet into topics. You may find that some of the topics and some of the questions are not relevant to you or your stage of illness. There may also be some topics that you do not want to read about at the moment. We suggest that you look at the headings first and then decide whether you wish to read the questions about that topic.



You are welcome to bring a support person with you. If you would like a support person from within your own culture, please let us know and we can arrange this for you.



He pai mēnā he kaitautoko ōu e haere mai ana ki tō taha. Ki te hiahia he kaitautoko anō nō tou ahurea ake, whakamōhio mai. Mā mātou ia e whakarite.

## about the hospice service

---

### Available Care

- Who are the members of the hospice team and what do they do?
- What does the palliative care service offer that is different to the services provided by the other doctors/nurses that I see?
- Can I see the hospice team both when I am at home and when I am in hospital?
- How much help is available at home (eg, how often can I be seen by the palliative care team)?
- What does the hospice offer?
- Is it possible for me to be admitted to the hospice for a short time (eg, to get my symptoms under control or to give my family a break), and to then go home again?
- How do I access the services offered by the hospice team?
- What is the cost involved with seeing the hospice team?

### Contacting the Hospice Team

- How can I contact the hospice team?
- In what circumstances can I or should I contact them?
- How often can I contact them?
- Is the hospice service available after hours or in emergencies?

## for carers

---

*If you have a carer the following questions may be useful for them. Some of the questions listed here may not be relevant to your stage of illness.*

- What skills will I need as a carer?
- Do you think I can look after my partner, relative or friend at home?
- Can I get help if I cannot manage?
- What are the signs of not coping?
- What can I do if I am not coping?
- How can I best support the person that I am caring for?
- What should I do if my partner, relative or friend won't eat very much?
- If my partner, relative or friend eats more, will this make them live longer?
- How can I assist health professionals to talk to my partner, relative or friend in a way that respects their personality/culture?
- Who can I talk to if I am concerned about the care my partner, relative or friend is receiving?

## if you are concerned about your professional care

---

- Who can I talk to if I am concerned about the care that I am receiving?
- Is it possible for me to see someone else if I don't get along with my hospice nurse or doctor? How do I go about this?
- Can I get a second opinion about any aspect of my palliative care?
- Can I choose where I receive my palliative care?

*Additional questions:*

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

## The relationship between the hospice team and other health professionals

---

- Does the hospice team speak to or write to my GP and other specialists about my care?
- What is the role of my GP now that I have been referred to the hospice team?
- Which of my health professionals should I contact first if I am unwell or if there is an emergency?
- Who will see me on a regular basis from now on?
- Can you help me choose a GP or another specialist?
- Can you help me to work out questions I may wish to ask my other doctors/specialists?
- Can you give me advice about treatment decisions that I am discussing with other doctors? For example, whether to stop or start chemotherapy or other treatments.

*Additional questions:*

.....

.....

.....

.....

.....

.....

## physical symptoms

---

### Available Care

- Who are the members of the hospice team and what do they do?
- What does the palliative care service offer that is different to the services provided by the other doctors/nurses that I see?
- Can I see the hospice team both when I am at home and when I am in hospital?
- How much help is available at home (eg, how often can I be seen by the palliative care team)?
- What does the hospice offer?
- Is it possible for me to be admitted to the hospice for a short time (eg, to get my symptoms under control or to give my family a break), and to then go home again?
- How do I access the services offered by the hospice team?
- What is the cost involved with seeing the hospice team?

### Contacting the Hospice Team

- How can I contact the hospice team?
- In what circumstances can I or should I contact them?
- How often can I contact them?
- Is the hospice service available after hours or in emergencies?

### Emotional Support

- How am I likely to feel through this and what can I do to cope?
- How can I deal with depression if this occurs?
- Is there someone I can talk to about my fears and concerns?
- How can I cope with the changes in my body as a result of this illness?
- Is it possible for me to talk to a member of the hospice team alone or for my carer to do so?
- Are there any support groups available?
- Can someone help me to communicate with other members of my family about what is happening to me?
- What support is available for other people in the family/whanau, such as my carer or my children?

### Spiritual and Cultural Support

- Is there anyone that I can speak to about my spiritual or religious needs?
- Can you arrange for me to talk with someone from my culture, someone who may understand me better?

*Additional questions:*

.....

.....

.....



## support

---

### Support in the form of information

- What information is available about palliative care and my illness?
- Are books, videos or pamphlets available?
- Are there any other organisations that would be useful for me to contact?

### Practical Support

- Is there a programme of activities available through the palliative care service (eg, physiotherapy, massage, spa, breathlessness clinic, day centre)?
- Can equipment be provided to make everyday living easier at home?
- Am I eligible for disability parking? How do I apply for this?
- Are there any volunteers available to help me (eg, to take me to an appointment or to do the shopping)?

### Financial Support

- What costs will I have during my illness (eg, for my equipment required or medications)?
- Is there any way I can get medical equipment (eg, oxygen) or medications at a cheaper price?
- What financial assistance is available for my carer or me (eg, benefits)?
- Is there someone I can talk to about financial matters?

## treatment

---

### The relationship between the hospice team and other health professionals

- Does the hospice team speak to or write to my GP and other specialists about my care?
- What is the role of my GP now that I have been referred to the hospice team?
- Which of my health professionals should I contact first if I am unwell or if there is an emergency?
- Who will see me on a regular basis from now on?
- Can you help me choose a GP or another specialist?
- Can you help me to work out questions I may wish to ask my other doctors/specialists?
- Can you give me advice about treatment decisions that I am discussing with other doctors? For example, whether to stop or start chemotherapy or other treatments.

*Additional questions:*

.....

.....

.....

.....

.....

.....

.....

## **lifestyle and quality of life**

---

- What can I expect to be able to do?
- How much activity or exercise is too much and how much is too little?
- What activities may help me to enjoy life more, eg, massage, meditation?
- How can I make the most of my life?
- What kind of food should I eat?
- How important is my diet?
- Can you advise me if and when I can return to work?
- Can you advise me about the timing of a holiday or trip I wish to take?
- Is it OK for me to drive?
- How can I remain close and intimate with my partner (physically and/or emotionally)?

*Additional questions:*

.....

.....

.....

.....

.....

.....

.....

## **my illness and what to expect in the future**

---

- What is going on with my illness?
- What are the chances of controlling my illness?
- Will the illness progress?
- What can I expect in the future?
- What symptoms may occur in the future and what should I do if they arise?
- Will I be in pain?
- Will my pain and other symptoms be controlled in the future?
- What are the worst days going to be like?
- What are the best days going to be like?
- How long am I likely to live?

*Additional questions:*

.....

.....

.....

.....

.....

.....

.....