



Asking Questions Can Help: An aid for people seeing the palliative care team





**Palliative
Care
Australia**

Asking questions can help: An aid for people seeing the palliative care team

ISBN: 0-9758254-3-7

First edition – December 2006

Palliative Care Australia

The opinions expressed in this document are not necessarily those of Palliative Care Australia.

© Dr Josephine Clayton, Prof. Phyllis Butow & Prof. Martin Tattersall, Medical Psychology Research Unit, University of Sydney, 2002. All rights reserved. Printed in Australia.



Contents

	<i>Page</i>
Introduction	2
About the palliative care service & team	4
- Available care	
- Contacting the palliative care team	
- The relationship between the palliative care team and other health professionals	
Physical symptoms	6
Treatment	7
- Medications	
- Morphine	
Lifestyle & quality of life	8
My illness & what to expect in the future	9
Support	10
- Support in the form of information	
- Practical support	
- Financial support	
- Emotional support	
- Spiritual & cultural support	
If you are concerned about your professional care	12
For carers	13
End of life issues	14
- 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 not responsive to curative treatment. Control of pain, symptoms, and psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care also apply earlier in the course of illness, together with treatment aimed at cure.

Most people who see a palliative care doctor for the first time have questions and concerns. Often these are forgotten in the rush of the moment, only to be remembered later. The purpose of this question list is to help you to get the information you want about palliative care and your illness.

The following questions have been asked by many people seeing a palliative care team. They have been developed after much discussion with people referred to a palliative care service, their families and with health professionals working in the area of palliative care.

Your palliative care doctor will be very happy to try and answer any questions you have. You can use this booklet while you are seeing the doctor. You may like to circle the questions you want the doctor to answer and add any of your own that are not listed, in the space provided. The doctor may answer some of your questions without you even asking, but this booklet can serve as a checklist so that you know that you have covered everything that is important to you.



Different people want different things at different times. You may wish to use this question list during this consultation. Or you may choose to use it later, or to discuss some of these issues with another member of the palliative care team (e.g. a nurse). You or your family may also find it helpful as a reference in the future, it is up to you. Please do not feel that you should ask any of these questions just because they are listed.

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.



About the palliative care service & team

Available care

- Who are the members of the palliative care 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 palliative care team both when I am at home and when I am in hospital?
- How much help is available at home (e.g. how often can I be seen by the palliative care team)?
- What do palliative care hospitals offer?
- Is it possible for me to be admitted to the palliative care hospital for a short time (e.g. 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 palliative care team?
- What is the cost involved with seeing the palliative care team?

Contacting the Palliative Care Team

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



The relationship between the Palliative Care Team and other health professionals

- Does the palliative care 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 palliative care 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

- If I have symptoms, what can be done to improve them? (e.g. pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)
- Can you help to control my pain?
- What are the different options available for controlling my pain?
- Can you help to control my other symptoms?
- What is the cause of my symptoms?

Additional questions:



Treatment

Medications

- Please tell me the side effects of any new medication you prescribe. How likely are they to occur?
- What can be done about these side effects?
- Will new medication affect any of my present medications or other medical conditions?
- Are there any tablets that I should NOT take whilst on this new medication?
- What is the cost of any new medication?
- Can I get the new medication from my local pharmacy?
- What are all my tablets for?
- Are all my old tablets still necessary?
- How and when should I take my medication?
- How can I manage to take all my medication?
- Are there any natural or complementary (alternative) therapies that may be helpful for me?

Morphine

- Will my body get used to morphine if I start it now?
- Will it still be effective in the future?
- Is it addictive?
- Can I stop taking it if my pain goes away?
- Will it make me confused or sleepy?
- Will it make me constipated?
- What are the different ways of taking morphine (e.g. tablets)?
- Are there other painkillers or alternatives available?



Lifestyle & 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 e.g. 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 & 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:



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 program of activities available through the palliative care service? (e.g. physiotherapy, massage, spa, breathlessness clinic, day centre)
- Can you provide equipment to make every-day living easier at home?
- Am I eligible for disability parking? How do I apply for this?
- Are there any volunteers available to help me? (e.g. to take me to an appointment or to do the shopping)

Financial Support

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



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 palliative care 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, such as my carer or my children?

Spiritual & 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:



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 palliative care 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 which hospital or palliative care team I am linked to?

Additional questions:



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 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?



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 palliative care ward or hospital?



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? 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 (e.g. what happens to their body, how do we arrange the funeral)?
- What support is available for the family after the person dies?



Acknowledgements

The authors would like to thank the following organisations for their support:

The Australian National Health and Medical Research Council – Medical Postgraduate Scholarship for Dr Clayton

The Cancer Institute of New South Wales – Career Development and Support Fellowship for Dr Clayton

The New South Wales Palliative Care Association in conjunction with “Pals of Palliative Care” – seeding grant

Background

This booklet was developed by Dr Josephine Clayton as part of her doctoral thesis, in collaboration with Professors Phyllis Butow and Martin Tattersall, in the Medical Psychology Research Unit at the University of Sydney. Focus groups, interviews and pilot testing with palliative care consumers (patients and their caregivers) and health professionals informed the development of this booklet.

The development and preliminary evaluation of this booklet is reported in Clayton et al. *British Journal of Cancer* 2003; 89: 2069-77. Formal evaluation with a randomised controlled trial was completed with 174 people who were referred for a consultation with a palliative care doctor. Fifteen palliative care doctors from nine Australian palliative care services participated. The results of the randomised controlled trial are reported in Clayton et al. *Journal of Clinical Oncology* 2007; 25: 715-723.

The authors would like to thank all the patients, caregivers and health professionals who gave their time and energy to participate in the development of this booklet. The authors would also like to thank the staff of the palliative care services who assisted with patient identification, and the research assistants who assisted with recruitment. For further information regarding the Medical Psychology Research Unit please go to www.psych.usyd.edu.au/mpru.

For further details on this publication:

Palliative Care Australia

PO Box 24

Deakin West ACT 2600

T: +61 2 6232 4433

F: +61 2 6232 4434

E: pcainc@palliativecare.org.au

www.palliativecare.org.au

This publication received funding assistance from the Australian Government Department of Health and Ageing.

Palliative Care Australia

PO Box 24
Deakin West ACT 2600

t: 02 6232 4433

f: 02 6232 4434

e: pcainc@palliativecare.org.au

w: www.palliativecare.org.au