



Carer Experiences Survey

We would like to invite you to tell us about your experiences as a carer of a palliative care patient. Your views are important, as they will help our service gain an understanding of how we can improve.

Attached is a survey we would like you to complete. All of the questions relate to how you have been feeling over the last three days and should take no longer than 15 minutes to complete.

Your participation is voluntary and will not affect the services you receive. If you do not wish to participate in the survey, it will also not affect the services you receive.

If you complete the attached questionnaire, this will be taken as a sign of your willingness to participate. However, you may at any time stop filling in the survey if it causes you any distress.

Summary results from the survey (that will not identify you personally) will be given back to our clinical managers to assist them in continually improving the quality of services that they provide.

Palliative Care Outcomes Collaboration (PCOC) will work with our service to summarise the results of our surveys and will compare them with participating services nationally. With this in mind it is possible that the data will be published at a later date in presentations, book chapters or journals.

We appreciate your time to complete this survey. You may feel it would be easier to have someone work through these questions with you. If this is the case, please let a member of the palliative care team know.

IMPORTANT: If you feel that this questionnaire raises any concerns for you, including emotional issues, and you wish to talk to someone about this, please do not hesitate to contact a member of the palliative care team or your GP. Any concerns about this survey may be directed to the Ethics Officer, Human Research Ethics Committee, University of Wollongong NSW 2522, (02 4221 4457).

Carer experiences with palliative care

Office Use Only

Service:

URN:

Date:

About you

Your sex: Male <input type="checkbox"/>	Female <input type="checkbox"/>	Your age _____
Do you identify with a particular ethnic origin or cultural background?		Yes <input type="checkbox"/> No <input type="checkbox"/>
If yes, please specify your ethnic origin or cultural background: _____		

Think about the palliative care that the patient receives and the ways in which the palliative care team may assist or communicate with families or carers who support the patient. Please answer the following questions indicating how satisfied you are with this care.

Tick the box that best matches your experience.

How satisfied are you with:	Very satisfied	Satisfied	Neither satisfied or dissatisfied	Dissatisfied	Very dissatisfied	Not relevant to my situation
The patient's comfort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way in which the patient's condition and likely progress have been explained by the palliative care team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information given about side effects of treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way in which the palliative care team respects the patient's dignity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meetings with the palliative care team to discuss the patient's condition and plan of care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speed with which symptoms are treated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Palliative care team's attention to the patient's description of symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How satisfied are you with:	Very satisfied	Satisfied	Neither satisfied or dissatisfied	Dissatisfied	Very dissatisfied	Not relevant to my situation
The way in which the patient's physical needs for comfort are met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Availability of the palliative care team to the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional support provided to family members by the palliative care team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The practical assistance provided by the palliative care team (e.g. bathing, home care, respite)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The doctor's attention to the patient's symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way the family is included in treatment and care decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information given about how to manage the patient's symptoms (eg., pain, constipation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How effectively the palliative care team manages the patient's symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The palliative care team's response to changes in the patient's care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional support provided to the patient by the palliative care team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1. Have you had someone to help you with practical tasks?

Yes, I've had all the help I need yes, but not enough I haven't needed help No

2. Did anyone give you information on whether you would qualify for a Carer Payment or Allowance?

Yes, I was given all the information I need Yes, it was mentioned but not in any detail I haven't needed any financial help No

