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18 September 2015

**RE: HCCA Feedback on Patient Information ACT Specialist Palliative Care Service – Clare Holland House Calvary Health Care ACT.**

Thank you for providing opportunity for consumer feedback on patient information ACT Specialist Palliative Care Service –Clare Holland House Calvary Health Care ACT.

The Health Care Consumers' Association (HCCA) of the ACT is a health promotion organisation that provides a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

In preparation for this feedback we circulated these documents to our members who have had a recent experience with palliative care, have an interest in this area or have an interest in health literacy and patient information. The feedback provided is the collated responses to each document. We would like to commend your team for developing this resource to increase understanding of how palliative care outpatients is run and what patients, families and carers can reasonably expect from their experience at Clare Holland House when attending the service. Our feedback is attached.

Thank you for seeking consumer input on these documents. We are pleased to provide feedback on this patient information. We look forward to seeing how our comments can help shape the further development of these valuable resources. If any aspect of this response requires clarification please contact Eleanor Kerdo by email [eleanorkerdo@hcca.org.au](mailto:eleanorkerdo@hcca.org.au) or by phoning the HCCA office on 6230 7800.



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## **Background**

HCCA welcomes the opportunity to provide feedback on the patient information ACT Specialist Palliative Care Service –Clare Holland House Calvary Health Care ACT. HCCA recognises the importance of documents like these in developing the expertise of health consumers to actively engage with our own health care, understand the health system and to be able to participate as equal partners with health professionals to make informed decisions about our own and our family's health. Health literacy is an essential right of a health care consumer as addressed in the Australian Charter of Healthcare Rights, particularly the charter rights of access, communication and participation.

## **General Comments**

In preparation for this feedback we circulated these documents to our members who have had a recent experience with palliative care have an interest in this area or have an interest in health literacy and patient information. The feedback provided is the collated responses to each document.

## **Structure of Patient Information**

There are some areas of the information sheets that do not read clearly due to wording and sentence structure. Whilst some of this is addressed in this document we presume there is an internal editing process to aid with this. An example of this is the sentence; *The Out Patient Clinic is one of the first-line of introduction for you to the CSPCS*. It is not easy to understand what *first-line introduction* means. It could perhaps be made clearer to say *The Out Patient Clinic may be your first point of contact with Clare Holland House and the CSPCS*. As a rule short sharp sentences are always better. We know acronyms are a part of complex health systems but it would also be very useful if you could refer to the services as the Specialist Out Patient Clinic, as CSPCS is very confusing.

We understand that these brochures are the main source of written information provided to patients attending the outpatient palliative care services. Ee wondered if this will be made available on your website?

Patient information fact sheets, developed by other hospitals could be used to help develop your patient information handouts. These could include the following which our members have found useful:

- What is Palliative Care? (ACT specific, 2008 part of the Palliative Care Resource Kit )

- What is Palliative Care ( Palliative Care Australia - PDF attached)
- Palliative Care in the ACT (2008 part of the Palliative Care Resource Kit -attached )
- Asking Questions Can Help: An aid for people seeing the palliative care team (2007 - attached)
- <http://www.pallcareact.org.au/index.php/palliative-care/more-information>
- <http://www.pallcareact.org.au/index.php/palliative-care/on-death-and-dying>

There are several clear resources that have been developed both in Australia and overseas that we think are valuable to improving consumer knowledge about palliative care. The ACT specific documents developed in 2007 for the Palliative Care Resource Kit with Calvary, and the ACT Palliative Care Society Inc are excellent resources and could be updated to reflect current services and models of care. These documents were developed with significant consumer involvement.

Another suggestion from members was the addition of version control and dates to all footers of the documents, along with page numbers. This is useful for consumers to keep track of the possible multiple pieces of information given to them in one session and check the relevance and currency of the information provided.

We suggest that you draw on number of other clearly developed patient information documents to inform your documents, after all there is no reason for you to have to reinvent the wheel.

### **Possible Additional Sections**

Many of our members who provided comment on the brochure felt that the information was quite dense and that dot points under shorter headings would make the information easier to comprehend when people are stressed and possibly feeling overwhelmed. There were several suggestions from consumers on information that could be added to the patient information sheets that would help inform those who attend your service.

We suggest the following sections;

- **What is Palliative Care and why do I need Palliative Care?**

This section was suggested by several of our members. This information is crucial in ensuring that consumers and carers can make active decisions about our health care.

Our members commented that they were glad that information about palliative care broadly was included, however they would like this to be much briefer and in dot point form to quickly move on to the actual services offered in palliative care outpatients. Members who supported someone through palliative care commented that there is a lot of information that is given during this time and it is crucial that people are specific about what information they are trying to relay.

Some people felt confused that only after reading half of the document do you find out it is regarding a specific service. They suggested starting with just one line on palliative care before specifically outlining services available through outpatients.

- **What is the Clare Holland Outpatient Clinic**

In this section you could include the paragraph outlining the varied services managed by Clare Holland House, which is currently paragraph four. We again strongly suggest you avoid wordy sentences, rather using simple dot points to quickly convey information. For example;

*This pamphlet briefly outlines services and support available through the Community Specialist Palliative Care Service (CSPCS), or the Clare Holland House Out Patients Clinic.*

*The Out Patient Clinic is a specialist service that is available on referral from your General Practitioner Specialist or other health care professional involved in your care.*

*This service is for people in the Canberra and surrounding region, who have been diagnosed with a life limiting illness, requiring specialist consultation and/or intervention.*

*Other Services provided by Clare Holland House include;*

- *the Inpatient Unit,*
- *the Community Specialist Palliative Care Service (Home Based Palliative Care),*
- *Palliative Care Consultancy services to Residential Aged Care Facilities and the Public and Private Hospitals in Canberra.*

*Please ask feel free to contact Clare Holland House should you wish to find out more about any of these other services.*

- **Who can use the Palliative Care Out Patient Clinic**

Eligibility for services is often something that is poorly explained and can be confusing for consumers, carers and family. It is important to clearly articulate what requirements there are to attend Out Patients Clinics through Clare Holland House. It is not clear in the current brochure what this service is for and who can attend. There are many questions consumers may have around accessing palliative care services including but not limited to, Do you need to be an Australian Citizen, or hold a Medicare Card? Can I be referred by a psychologist or allied health professional? Is this a private or public service? Is there an out-of-pocket cost associated with using this service? Can I attend if it is likely I will be living for longer than the next two years?

- **What Happens when I Attend the Out Patient Clinic**

It is great that the current draft of the brochure includes three paragraphs about what to expect when you attend your out patient appointment. The paragraph that begins with *The*

*Out Patient Clinic is one of the first-line of introduction for you to the CSPCS, is slightly confusing as it seems to be discussing services that happen outside of services provided at the clinic. We suggest that information about how your referral is prioritised could be included under Who can use the Palliative Care Out Patient Clinic section. It would be great to include in this section how long you can expect the appointment to be for, what will be discussed, what being an outpatient means and possibly include other services you can access, what questions you may want to ask, and who you will speak to. This is also a good place to discuss the 'screening symptom questionnaire'. This was confusing to some who read it who did not understand what this was. Some rewording such as **'you will be asked to complete a 10 minute questionnaire that will ask you about your current symptoms at each session. This will be used to help guide the discussion in your appointments and ensure we are addressing your care needs.'***

We suggest moving the information about follow up and care plans to this section or under a sub-heading of; *After your initial appointment.*

- **What to Bring to the Outpatient Clinic**

This can be a short list of dot points including, your referral, medical history any tests, x-rays and so on, Medicare card, any current medication including any naturopathy, carer ect.

- **What to do if my Condition Changes between Appointments**

This section is vital as many of our members stated that they felt concerned about waiting time for appointments with a family member in palliative care. It would be useful to reiterate your triage process, emergency contacts, and after-hours services.

- **More Resources and Information**

We suggest including a section on *Useful Websites* or *Further Information*. These could provide links other patient information sheets or reputable websites.

- **Wayfinding, transport and parking to the Clinic**

Wayfinding to the Clare Holland House Outpatient Service could also be included in the forms and patient information. For many people navigating the multiple health service campuses in the ACT poses serious challenges, particularly given the changes due to the Health Infrastructure Program. We suggest the inclusion of a map pointing out the location of the service and parking. If this is not possible, due to space limitations or changing locations, we suggest at a minimum, including information suggesting people ask at main reception should you have trouble locating the service.

- **How to contact your treating team**

It would be useful to include a section in the patient information sheet on how to contact your doctor or palliative care specialist, phone numbers, emails or pagers.

- **Interpreter Services**

Information on how to access interpreter services both during consultations and if help is required to read the patient information or sign consent forms would be useful to include. HCCA understands that the ACT Health Multicultural Health Policy Unit can provide consistent language and symbols to be included. You can contact them on: (02) 6205 1011.

- **Information about Billing and Medicare Rebates**

It is often difficult for consumers and carers to navigate the Medicare rebate system or understand how a procedure like the ones explained in these forms are billed. For instance do I have any out-of-pocket costs? How do I claim a rebate? What about Private Health Insurance? Is there an extra cost for my sedation?

- **Calvary Values**

This section is important, along with the information provided in paragraph two about inclusivity of service. However many felt this could be at the back of the brochure to ensure that the most needed information is first.

*“The stuff about how compassionate they are and their values etc. could be somewhere on the edge or the back. It’s important but people in this situation don’t want to plough through text about how well they’ll be treated – they just want help. I simply expected that [name redacted] and I would be treated well when the Yass community nurses advised me to get [name redacted] on the books.” – HCCA member*