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**Allison Turner**  
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**Division of Cancer, Ambulatory and Community Health Support**  
**The Canberra Hospital**  
Email: [Allison.Turner@act.gov.au](mailto:Allison.Turner@act.gov.au)

Dear Ms Turner,

**RE: HCCA Feedback on the Chemotherapy Education Checklist**

The Health Care Consumers' Association (HCCA) of the ACT was formed over 30 years ago to provide 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.

HCCA welcomes the opportunity to provide feedback on the Chemotherapy Education Checklist. HCCA recognises the importance of documents like these in fostering clear communication between clinicians, consumers and their families. Clear communication and health literacy develops the expertise of health consumers to actively engage with our own health care, understand the health care 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. This document supports the essential rights of a health care consumer as addressed in the Australian Charter of Health Care Rights, particularly the charter rights of access, communication and participation.

**General Comments**

The document is extremely comprehensive, highlighting areas that many patients indicate they have lacked information on when using cancer services. HCCA applauds the creation of this document as an important part of insuring adequate support and information is given to health care consumers and their families. Broadly many consumers were concerned given the in-depth nature of the document that it may be initially overwhelming to the patient and their family. Implementation of this education plan would need to be executed over several sessions and at a pace that suits both the patient, family or carer and the clinical team. Timing was also highlighted as a potential issue in making sure information is given at a useful time for the patient and carers. For example support services should be highlighted in an early session to ensure that these programs are accessible from early on within treatment. It would be useful to know if written material is available covering relevant

topics discussed for patients or carers to take home to aid comprehension. If written material is provided then it must be simple and concise and conform to the Health Literacy Guidelines. Again HCCA wishes to highlight the high quality of this document and commend Division of Cancer, Ambulatory and Community Health Support in the proposed implementation of this tool to support patients and their carers when commencing chemotherapy.

## Specific Comments

The document does not include information about the lowered immune system of a patient undertaking chemotherapy and the need to avoid those with infectious illnesses, even the common cold. We suggest including a section in *Side Effects Management* highlighting the role of the patient's immune system and further precautions that need to be taken. It may also be good to include information about the possibility of developing lymphoedema as consumers highlighted this as an area that is often overlooked in education.

In the *Treatment* section, please include information about the need to tell the onsite Pharmacologist and treatment team about any naturopathic options, medicines, or supplements the patient may be taking.

HCCA suggests section on *Support Services* should include more detailed information about community support groups. Many cancer patients and their families expressed a need to highlight these groups as an important part of the patient journey. Listing particular support groups both nationally, and within the ACT region is suggested. Community group members also highlighted the need to provide brochures or written materials from each group to the patient and carers. In relation to hair loss and wig services the addition of Colleen's in Phillip is recommended. The topic of hair loss should be covered in detail before commencement of chemotherapy with one consumer suggesting;

*'My only suggestion would be to recommend, when advising the patient about hair loss and places to visit for wigs etc. that the patient should perhaps purchase some form of head covering prior to the commencement of chemo. In my case, my hair fell out very quickly and almost all in one day. Although you are prepared for hair loss, it is still very confronting and would be more so if you were not prepared and had to go looking for something to cover your head after the event. Apart from that, the document is a great step forward'. –Cancer Services Consumer*

HCCA recommends that the first dot point under *Support Services* be amend to clarify what follows up the home assessment. In particular the need for the patient and the treatment team to identify carers or people in the carer role throughout the treatment who can provide support for the person receiving chemotherapy. Consumers stressed that for some patients, reliable and consistent carers are not

available throughout the treatment process, it is essential that the treatment team work with the patient to insure that support is available perhaps emphasising the role community support groups can play.

In the section *Patient acknowledgement of information* the form states that they patient should know who to contact should a problem arise within business hours and after hours, please include in the document, information about who these contacts are.

In conclusion, we are pleased to provide feedback on the Chemotherapy Education Checklist and would like to highlight again how important the role documents like this play in patient and family centred health care.

We are happy to discuss our submission further.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Darlene Cox', with a stylized flourish at the end.

Darlene Cox  
Executive Director  
Health Care Consumers' Association

Date 31/03/14