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# **HCCA Review of the Canberra Hospital and Health Services Inpatient Guide**

## **October 2012**

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## **Background**

The Health Care Consumers' Association (HCCA) of the ACT Inc. 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 involves consumers through:

- consumer representation
- consultations
- training in health rights and navigating the health system
- community forums
- information sessions about health services
- advocating for issues of concern to consumers

The HCCA is dedicated to the promotion of consumer-centred health care, which we believe can be successfully achieved through the application of five key principles:

- 1. Respect**
- 2. Choice and empowerment**
- 3. Consumer involvement in health policy**
- 4. Access and support**
- 5. Information**

It is with reference to these principles and in consultation with our membership that the HCCA have developed our review of the Canberra Hospital and Health Services Inpatient Guide.

## **Introduction**

The Inpatient Guide is potentially a most valuable source of information for consumers who need to access TCH services. As such, it is essential that the Guide be easily accessible and understandable to all health care consumers. Similarly, the Guide needs to present information in a way that is sensitive to the needs and situations of consumers, effectively addressing all of their concerns.

HCCA strongly believes that the most effective way to ensure that health care services meet consumer needs is to develop services in consultation with consumers themselves. While the Guide makes reference to TCH's commitment to collaboration with consumers, the document provides little evidence of any dialogue with consumers. HCCA is aware that no consumer organisations were consulted prior to the release of this most recent version. Some actual examples of issues raised by consumers, and how these are being addressed, would demonstrate a real commitment to effective partnership with consumers. For this reason, we are providing consumer feedback on the Guide in the expectation that a revised version will better reflect the principles of consumer-centred care.

Our membership was very keen to provide feedback for the Inpatient Guide and have raised a wide range of concerns and suggestions to improve it. HCCA has also consulted with other consumer organisations, such as the Mental Health Consumers Network (MHCN), The Women's Centre for Health Matters (WCHM), Women With Disabilities ACT (WWDACT), Self Help Organisations Uniting Together (SHOUT) and the Council on the Ageing (COTA ACT). Our submission therefore reflects the interests and concerns of a broad range of health care consumers in the ACT. We will raise a number of general issues which have been identified by our membership, then address specific sections of the Guide using the existing headings.

### **Burden of Responsibility**

In general, HCCA is concerned that the Guide places an excessive burden of responsibility on the consumer to organise their care and seek out the specific services they require. We think that this is an unreasonable expectation, given that consumers presenting for inpatient treatment are likely to be ill, anxious and stressed. The Guide needs to reflect an understanding of the difficulties associated with accessing hospital care, and assist the consumer with any anticipated complications.

### **Readability**

The language also needs to be revised to ensure that information is consistent and free from health jargon which many consumers will not understand. We have also noted a range of spelling and grammatical errors which need to be corrected in the next version. It may be worth conducting some research into the readability of the document for lay persons.

This information must also be accessible to CALD consumers. HCCA suggests that a separate version be made available for consumers with low literacy and/or limited knowledge of English. Although the Guide provides contact numbers for interpreting services, if CALD individuals are unable to understand this information in the first place, it is unlikely that they will be able to access these services.

The Accessibility section needs to be made more prominent, particularly as its target audience includes consumers who can only read in large print.

### **Gender Equality**

The images used portray doctors and specialists as all male, while nursing and support staff are all female. We urge the Health Directorate to consider gender equality when depicting members of the health industry. Our members have raised this issue with great concern.

### **Relevance**

We are concerned that some information is not relevant to all consumers, such as those admitted to TCH via the ED and mental health consumers. It is important to identify when information in the Guide is not relevant in all cases and ensure that consumers are made aware of it.

Separate information booklets could be provided to consumers accessing mental health services within the hospital. For instance, admission to the hospital is often involuntary for mental health consumers and they are not permitted to bring belongings with them. This is inconsistent with the information contained on pages 8 and 12. On page 20, there is information about 'leaving your ward', which is impossible for patients of the Acute Mental Health Unit (AMHU). Additionally, while pages 47 to 48 encourage consumers to speak up and ask questions, many mental health consumers fear retribution when they speak up and are often ignored when they try to seek information about their treatment and medications.

For people being admitted via the Emergency Department, it may not be practical to distribute information in the first instance, but this still needs to be provided as soon as the consumer is able to understand it. Again, a separate information booklet could easily help to address this problem.

### **Length**

While the Guide is clearly aimed at providing comprehensive information for consumers coming to TCH, a fifty page document is far too lengthy for consumers to absorb, especially when consumers are likely to stay at TCH for only a short period of time (eg. overnight). In this instance, an abbreviated form of the Guide would be more useful and likely to be read.

Some parts of the Guide could be deleted to make it more concise. For instance, the Canberra Hospital and Health Services chart on page 10 is unlikely to be of use to most consumers. Other sections, such as 'Tell us what you think' and 'How you can help the Canberra Hospital' contain important information, but are not essential for consumers who just need to know how to access inpatient services. A number of our members have commented that they would like to see a more concise version of the Inpatient Guide which provides only the essential information for consumers coming to TCH, along with separate booklets or brochures for other topics which can be accessed on request or in waiting areas.

It may also be useful to include a list at the end of the Guide of additional sources of information for any other questions inpatients may have, such as Advanced Care Planning or the Open Disclosure Policy. (It is important to tell consumers how this information can be accessed).

### **Ease of Reference**

The headings used in the Contents page make the Guide quite difficult to navigate. For instance, 'Life on the Ward' is an ambiguous title and it is unclear what kind of information is likely to be contained in the section. Similarly, 'Consumer/Patient Rights' is a more appropriate heading than 'Excelling in Care'. The checklist 'Common Questions to ask your Care Team Doctors and Nurses' is important but it is embedded in the section 'Your Treatment and Care Team' and consumers are unlikely to look there for this set of questions. Instead, this could be included under a separate heading between 'Admission' and 'During your Stay'.

When a consumer is preparing to go to hospital as an inpatient, they need to understand how their treatment is going to be organised and how they can be involved in the process. As such, there may need to be an additional section added to the Guide which describes processes such as pain assessment and management, treatment planning and consultation as well as options for Advanced Care Planning (if appropriate). This section might be a good place to include the Australian Charter of Health Care Rights (currently on page 35) as well as 'Common questions to ask your Doctors and Nurses'.

### **Introduction**

Throughout the Guide, many important phone numbers are listed for different hospital services. We recommend providing a list of them on the first page so that consumers can find them easily.

Welcome

The use of the term 'consultant' in the sentence "your care will be overseen by a consultant..." is meaningless to many consumers. We suggest using 'doctor' or

'specialist' etc. Consumers also need to know how they can identify ward managers or their delegates so that they can ask questions about their treatment.

### About Canberra Hospital

It would be helpful to explain the values of the ACT Health Directorate in more detail. In particular, it is unclear with whom the Health Directorate values 'collaboration'.

While HCCA welcomes the Health Directorate's statement that it is committed to working with consumers to meet the needs and expectations of the community, this needs to be demonstrated in practice, and real examples given to explain how this is happening. For instance, consumers were not consulted in the preparation of this document.

This paragraph could also be reworded where it says "the team we work with..." to "your health team" to indicate specifically that the Health Directorate will work with all health professionals involved in a patient's care. The next paragraph could include a statement explaining how feedback will be managed and acted on. If consumers are to be encouraged to provide feedback, they need to know that their comments will be taken seriously by the Health Directorate. The sentence about positive feedback could be revised to better convey the importance of all kinds of feedback, not only to give people a 'pat on the back', but also to give a clearer indication of what is working effectively and who is doing a particularly good job at meeting consumer expectations.

### Coming to the Hospital

Transportation – we suggest listing the platforms and numbers of the buses going past TCH from the Woden Interchange.

The map provided is small, and may be hard to read for many consumers, especially those with vision impairment. We suggest the legend be doubled in font size at least. It is also important to provide information for people who need overnight parking, such as which timed parking spaces are likely to be most appropriate.

In the section titled "Getting Ready for Hospital", we suggest that the word 'pleasant' be removed. It is somewhat naive to suggest that a consumer will enjoy their time in the Hospital, as they are there because they are unwell. This sort of language may be considered insensitive to consumers who are feeling apprehensive about their upcoming treatment.

Before you come in – as it is so essential that hospital staff are made aware of all of the medications a consumer is currently taking, it would be good to emphasise this fact more clearly in the Guide. A short paragraph could be included to explain that some medications may be incompatible with one another and produce side effects.

The sentence about managing when you go home after surgery may fit better in the 'Discharge' section, as consumers are unlikely to know what their condition will be until after they have had surgery.

At the end of the section, consumers are advised to cease taking complementary and alternative medicines. There are many cases where this may not be an issue, depending on the medicines being taken and the reason for admission to hospital. It is important to respect the value that some consumers place on these types of medicine, and consider the possibility of including them as part of the treatment regime. Moreover, it would be good to explain what exactly falls under the category of complementary medicine, as this is a vague term.

HCCA is also concerned that the section 'what NOT to bring' is particularly directive and in some cases impractical. It is unlikely that people will be able to leave all their valuable items, such as wallets and mobile phones, at home. It would be far more reasonable if TCH was able to make some provision for securing valuable items in the wards. In cases where the consumer is particularly unwell, or has had little advance warning of admission to hospital, it is unreasonable to expect that they will be able to have their electrical equipment 'tagged and tested' prior to admittance. However, this could be included as a suggestion rather than a direct instruction.

In 'What you need to tell your doctor', we assume the term 'device in situ' is supposed to read 'device *in situ*'. This term may not be recognisable to some consumers, so it may be better to refer to these as 'internal' or 'implanted' devices.

Some of the responses in the list of frequently asked questions do not convey clear information or reflect a patient-centred approach. For the second question, it would be better to indicate that partners and some family members will be able to stay overnight in the hospital, particularly when the patient is a young child, but that this needs to be verified and arranged with the nurse in charge of the ward. On page 20, it states that 'there are no restrictions on parents visiting young children in ICU', and it would be good to mention that in this section too.

In regard to seeing ward reception prior to entering a room, this will not always be necessary, eg. in cases where the person has visited the patient before. In practice, this has often been observed to be the case.

The statement that flowers should not be brought into the hospital is inconsistent with the information provided on page 20, which states that flowers can be brought in to any areas of the ward except the ICU; in fact, contact details for a florist are included on page 40. Instead of saying that visitors should not bring flowers to wards, the Guide could simply advise people to consider that, in some cases, flowers may trigger allergies.

Finally, the answer to the last question states that GPs will be able to supply any long term medications. It is important to clarify that GPs only provide prescriptions for

medications, which may already have been provided by hospital doctors, and that medications need to be collected from a pharmacy.

## **Admission**

The stress associated with being admitted to hospital for treatment means consumers may become confused about where to go when they first arrive. It would be good to suggest that, in this instance, they can always ask at the main reception. Also, it is unclear where the pre-admission consultation occurs within this process.

This section also needs to state where volunteers can be found to assist with 'way-finding'. For instance, are they at the main reception and are they only available at specific times?

We are also concerned that responsibility for accessing interpreting services rests with the consumer. It is likely that some CALD consumers will be unaware of the options available to them. They may also find it difficult to ask for this assistance. If hospital staff feel as though a consumer or their family may benefit from having an interpreter present, they could easily suggest this to the consumer and tell them how this could be arranged. This issue goes beyond problems with communication; consideration also needs to be given to the potential embarrassment of asking for additional assistance. There may also be issues with trust, particularly where the consumer has had negative experiences with health professionals in the past. When discussing the need for an interpreter with CALD consumers, it is essential that they are fully aware of their rights as a consumer, including their right to participate in their own health care. However, CALD consumers also need to have the option of contacting the interpreting service directly, as some consumers have reported being told by staff that it is too much trouble and that they need to get a friend or family member to translate for them. While this may be a convenient option for staff, it puts a lot of responsibility on the person being asked to translate, and it is often impossible to ensure that the information they are passing on is accurate.

The care of CALD consumers needs to go beyond simply providing an interpreter, because they may have a different understanding of health care issues which need to be taken into account. As such, there needs to be open discussion with these consumers and their families to ensure that they fully understand the treatment they are receiving. They must also be fully involved in the decision-making process to the same extent as all other consumers.

Under 'Acknowledgement of Consent', we strongly suggest that the paragraph be rewritten to better describe the process of informed consent. It is important to explicitly state that all health care carries some degree of risk and that informed consent requires consumers to have an understanding of the risks involved before consenting to treatment. It is appropriate to make reference to the Australian Charter of Health Care Rights at this stage.



The last sentence is confusing to consumers who are unfamiliar with health care terminology. A better word could be used instead of 'consult', as it is unclear whether this refers to a regular appointment with a GP, or a specific meeting with hospital staff.

Our members have also requested that more information be provided regarding private insurance. For instance, it would be good to know what the benefits are for the consumers and whether there will be a gap payment for doctors' fees.

### **During your Stay**

We suggest the information at the start of this section would be more appropriately placed in the Admission section, or could be included as a separate section entitled 'Getting ready for surgery'. Things such as fasting and preparing X-rays are important to consider prior to coming to the hospital, and this could be made clearer.

Under 'Having an anaesthetic', it would be better to say that anaesthetics are given to prevent or stop pain during surgery, as no pain should be experienced when a consumer is under anaesthetic. Analgesics provided after surgery are given to relieve pain.

It would also be good to clarify that the 'pre-admission clinic' is for consumers about to go in to surgery, rather than consumers about to be admitted to the hospital.

On page 15, the section on recovery post anaesthetic says consumers need a 'responsible adult' to drive them home. In cases where a consumer lives alone or does not have any friends or family available at the time of their discharge, it would be helpful to advise that TCH can call a taxi or community transport service to take them home.

### **Life on the Ward**

This section covers a wide range of topics in addition to moving around the hospital ward. The title may need to be changed to better reflect this. Alternatively, some of the information could be included in separate sections. This is a prime example of where the Guide could be made more logical and concise.

HCCA strongly supports the prioritisation of quality and safety in health care and we are pleased the Guide has included a brief description of the ten National Safety and Quality in Healthcare Standards. This section could be expanded in order to demonstrate how these standards are being met at TCH. In particular, (2) *Partnering for Consumer Engagement*, says nothing about how these partnerships are created, such as through empathy and effective communication.

When discussing quality and safety, HCCA urges TCH to consider the importance of accurate pain assessments for inpatients, as this is an issue of high priority for our membership.

Hand Hygiene: although initiatives such as the 'Ask Me' badges for health professionals have made it easier for patients to ask their health care providers whether they have washed their hands, this is still a fairly difficult question for patients, as they may be afraid of offending or angering the staff. This could be addressed by explaining that all staff members are committed to maintaining excellent standards of hygiene and that any concerns regarding this matter will be taken very seriously.

Under 'Privacy', the last line should read 'unless we have the permission of the patient', but it may be worth explaining that 'we' refers to hospital staff in general and clarifying situations where people will be able to access the patient's information.

The information regarding mobile phones is difficult to interpret, especially considering that patients are told not to bring valuable items like phones with them (page 8). It would be good to include examples of where it is acceptable to use a mobile phone. 'Clinical areas' also needs to be explained in greater detail, as some consumers may interpret this to be the entire hospital or ward.

Page 18 explains that all biomedical devices brought to hospital by the consumer will need to be checked by the clinical engineering department. It is worth outlining here how this would be organised, and whether there are any steps that need to be taken by the consumer. For instance, would it be possible to organise this ahead of time in cases where admission is not imminent. Consumers may also be concerned as to how long this process would take, as these devices are often essential to their health and well-being.

'Accommodation/Overnight stays' – This section needs to go into more detail about the availability of accommodation for relatives of inpatients. For instance, what exactly are the criteria for eligibility and are there circumstances where the relatives will be given priority access, such as when the patient is seriously ill or a small child. It would also be good if the cost of this accommodation, or at least an approximation, were included in the section. In addition, a description of the disabled access available with the accommodation would be useful.

The section outlining smoking regulations would be a good opportunity to raise consumer options for accessing NRTs during their stay at TCH. In particular, services for pregnant women who smoke need to be made easily accessible to ensure the safety of both the mother and their unborn child.

It would be worth considering moving the two last paragraphs of the 'Visiting Hours' to just below the first paragraph. Currently, it appears as though the information in these two paragraphs refers specifically to the NICU due to the placement of the heading.

This chapter could also indicate whether there is any form of internet access such as wi-fi or computers for public use available to patients and their family members.

The section on 'Health records' states that patient's health records may be used for training and educational purposes. This statement seems quite vague and may be of concern to some consumers, who may not be willing to share their information for these purposes. It would be good if consumers could be given the option to refuse this sharing of information. In addition, the section makes no mention of the eHealth program and how this will affect their inpatient experience.

Again, on page 22, the Guide states that no valuables should be brought to hospital by consumers. HCCA strongly urges the Health Directorate to consider making some allowances for consumers who want or need to bring valuables with them to TCH. Often, consumers are likely to bring some valuables with them anyway out of necessity, so it would be good to provide lockers or something similar to help prevent them from being lost.

In the paragraph which describes the different lifting equipment available at the hospital, it is also important to consider that many consumers will be concerned about losing their dignity when they need to be assisted with movement by hospital staff. Often, an activity such as getting to the bathroom becomes highly distressing as the patient is unable to do this independently. It may be helpful to mention that staff are trained to be highly sensitive during this process and will discuss what needs to be done with the consumer to ensure they are comfortable.

### **Your Treatment and Care Team**

It is great to see that the Guide has included a list of 'Common Questions to ask your Doctors and Nurses', as this is an excellent means of assisting consumers to become involved in their health care. However, as this is such an important component, it would be worth moving it to another section, such as the beginning of the Admission chapter, where it would be more obvious. There are also a number of changes that could be made to this list. Firstly, the question 'What medications do I have to take?' could be changed to 'What medications are recommended for me and why?' One of either 'Will I be in pain' or 'Will it hurt' also needs to be deleted, as these essentially mean the same thing. The question 'What do you have to do?' is not particularly helpful, and could be made more specific. For instance, does this refer to the type of treatment the care team will administer or what the consumer needs to do to prepare for treatment? It might also be worth changing the heading to 'Common Questions to ask your Health Care Team'.

A number of additional questions could also be added to the list, such as 'are there any alternative treatment options I could consider' and 'what is likely to happen if I don't undergo this treatment'. While questions such as these may be uncomfortable, it is important that consumers are fully informed as to the reasoning behind their treatment so that they can be involved in their health care and remain in control of their own bodies.

We suggest that this section include a statement explaining that all hospital staff are required to identify themselves as well as their role. Consumers are often concerned that numerous staff come and go in the hospital without ever explaining what they are there for. This makes it very difficult for consumers to keep track of their treatment and to know who to speak to if they have any specific questions. It is also important that staff can be identified in the event of an incident occurring, so that the Open Disclosure process can be effective. The Guide could include a short description and pictures of the uniforms worn by different professions and how staff such as wards persons and administrators can be identified.

In the last paragraph of the section 'Our Nurses and Midwives', the Guide says that the nursing team liaises closely with other health care professionals. Nurses have the unique opportunity to be able to communicate regularly with inpatients, and so are well placed to facilitate liaising between health professionals and the consumer as well.

Under Allied Health, we note that the Guide only mentions how to access psychologists if required. It would be helpful if this could also be done for Occupational Therapists and Physiotherapists. Alternatively, a general comment that any of these allied health professionals can be accessed by contacting ward staff.

While it is good that pastoral care is being offered to all consumers regardless of their religious beliefs, this is unlikely to be acceptable to individuals who practice a religion other than Christianity. They may also be concerned that approaching pastoral care services will result in judgemental treatment and a lack of understanding. TCH needs to offer services specifically tailored to different religions, even if this means recruiting services from outside the hospital as required. The contact details for pastoral care services also need to be included on page 40 where it describes the Chapel services available.

HCCA recommends that additional services be listed under 'Liaison Services' for CALD consumers who may find it difficult adjusting to the ACT health system. Following discharge, it would also be good to connect alcohol, tobacco and other drug users with social support services, particularly in cases where they have been treated for a condition related to their substance use. This may also be relevant for consumers likely to have difficulty readjusting to living at home due to disability or financial problems.

## **Discharge**

The discharge check list at the beginning of this section is very helpful for consumers. However, depending on the consumer, it may be necessary to provide more assistance with getting organised to go home. For instance, as mentioned above, consumers who live alone may need hospital staff to help them arrange appropriate transport home. It would also be good if nursing staff were able to ensure that all the necessary documentation and medication were given to the

consumer before they leave. We do acknowledge that the consumer needs to take some responsibility for this, hence the importance of the checklist, but we hope that hospital staff will not leave the entire burden on the consumer.

In addition to collecting all discharge medications, it is also important for consumers to be given a clear explanation of what those medications are and how they need to be taken. Where possible, this should be provided as written instructions. It may also be necessary for some consumers to know how their normal medication regime may need to be altered. Also worth noting would be how many days' supply of medication can be provided by the hospital pharmacy.

It is good to see that the Guide has mentioned community-based support services.

HCCA is concerned by the comment on page 30, stating that 'your views and expectations will be discussed and taken into consideration'. The phrasing used here is patronising, very vague and non-committal, making it appear as though the consumer has very little control over their discharge. This section needs to outline the specific conditions where it may be necessary to go against the wishes of the consumer.

### **Excelling in Care**

HCCA is pleased to see that the importance of partnership with consumers has been emphasised in this section and strongly supports the inclusion of consumer rights and responsibilities in the document as well as the Australian Charter of Health Care Rights. This information could be included earlier, as it is good for consumers to begin considering these issues prior to admission. To further demonstrate the Health Directorate's commitment to consumer rights, the Guide could provide advice for consumers should they feel that they are not receiving these rights. We note that the sixth dot point has been incorrectly divided into two points. When using this type of list format, each dot point needs to be followed by a semicolon.

Under 'Safe Care and Practices' it would be good to add that 'we aim to make your stay as comfortable *and safe* as possible'.

### **Tell us What You Think**

Page 37 states that 'all feedback is read by the Director-General of Canberra Hospital and Health Services'. It is important to clarify here that this is only for complaints. We are aware that positive feedback can be channelled back to the hospital staff involved, which might also be worth mentioning.

We also note that the section about HCCA does not include any contact details. We would like this to be included in the next version. The information included here provides a good overview of our mission and purpose, but does not explain how consumers can become involved with the Association. More information could be provided about how we engage in systemic advocacy. However, it is also important

to state that HCCA is unable to do individual consumer advocacy. Instead, it could be noted that the Consumer Feedback and Engagement Team of the Health Directorate can be contacted regarding matters of individual advocacy.

### **Facilities During Your Stay**

It would be good to explain exactly how consumers can contact the Pastoral Care office, such as with the help of hospital staff or by telephone.

Again, we note that the details for the hospital florist have been included in the Guide, even though page 9 states that flowers are not permitted in the hospital.

Under the section Radio and Television, it may be worth explaining what is meant by 'in most cases'. For instance, does the provision of television services depend on the patient's condition?

### **How You Can Help Canberra Hospital**

We feel that this section in particular may be unnecessary for consumers coming to the Hospital. While some consumers may be interested in becoming involved in volunteering services, it is unlikely that this will be the first thing on their mind when presenting for treatment. Instead, this section could be made available as a separate resource from Reception or the Consumer Engagement Office.

In the section about volunteers, information could also be provided about the role of volunteers in the Emergency Department.

The information provided about SHOUT needs to be amended to reflect the fact that they cannot provide advocacy or lobbying for individuals. However, they are able to refer people to groups which can assist them with advocacy.

We are also concerned that the '10 tips for safer health care' poster has only been included on the second last page. As this is an essential component of consumer-centred care, we strongly suggest that this resource be included earlier in the Guide, in a section such as 'coming to the Hospital' or 'During Your Stay'. Tip 4 needs to be amended to read 'keep *an up to date* list of all the medications you are taking'.