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Personalising care for people who are blind or have low vision

Information for staff

This is a prompt sheet to help staff to identify the TOP 5 things required to personalise care for people who are blind or have low vision when they are in hospital.

Definitions of vision impairment

A person is considered **legally blind** if they cannot see at six metres what someone with normal vision can see at 60 metres or if their field of vision is less than 20 degrees in diameter. Legal blindness covers people from those who are totally blind through to those with some useful vision but are nevertheless below the threshold for legal blindness.

A person is said to have **low vision** when they have permanent vision loss that cannot be corrected with glasses and affects their daily functioning. Low vision can affect people of all ages and can have an impact on many aspects of a person's life. It may cause problems with recognising faces, reading the newspaper, dialling the telephone or seeing road signs. (Vision Australia, 2020).

Instructions for staff

As a staff member providing care to patients in hospital who are blind or have low vision, there are important steps you can take to ensure each patient experiences care that is person-centred and appropriate to their needs. You can start by ensuring you do the following every time you interact with patients who are blind or have low vision.

- Always check the patient record to find out whether the person is blind or has low vision and whether they have a TOP 5 in place.
 - Quote from a patient: **'They focused on my ability to read the signature on the consent form instead of whether I understood what I had consented to.'**
- Always introduce yourself to the patient. Let them know you are there by telling them your name and your job and why you are there. Be sure to let them know when you are leaving.
 - Quote from a patient: **'It's hard to ask all the time "Who is it?" You get sick of it, especially in a strange environment and when there's so many people that you can't put a name to a voice.'**
- Never introduce yourself by saying 'Guess who?' This is not funny, nor is it appropriate.
 - Quote from a patient: **'When I did ask who they were, they didn't take me seriously. Some people would respond with "guess".'**
- Always talk to the patient directly first and not to any other person with them. Only engage with the identified support person if that is requested as part of the patient's TOP 5 strategies.
- Always ask for the patient's permission before you touch or move them.
 - Quote from patient: **'Staff should always say who they are, and what they are doing. Gosh, that made a difference when they remembered to tell me every time.'**
- When you are moving around the patient or are close to them, explain what you are doing.
- Keep items in the same place and always ask before you move equipment or the patient's belongings.
 - Quote from a patient: **'They should not move your stuff. You want to find something but can't if they've moved it and haven't told you.'**
- If you are unsure what the patient might need, ask them. This will provide an opportunity to introduce or review their TOP 5.
 - Quote from a patient: **'I didn't shower for two days because of the extra help I need, and I didn't want to trouble them.'**
 - Quote from a patient: **'At home things are automatic and you're in your comfort zone. I need more support when I'm in hospital. You don't know how much extra help you need until you get there.'**
 - Quote from a patient: **'They took away my personal independence. Staff decided if I needed a wheelchair, but I may prefer to walk.'**
- At handover to new staff, always advise them that the patient is blind or has low vision and that they have a TOP 5 in place.
 - Quote from a patient: **'We need to break down assumptions about what people who are blind or have low vision do, and don't, need or want.'**
- Describe the location of objects using indicators that include 'right', 'left', compass points (north, south, east or west) or use clock directions instead of saying 'over there'.
- Keep the patient's bed in the same place within the ward and on the same ward, moving them only if you absolutely must.
 - Quote from a patient: **'No-one tells you where the call button is, where the button is to flush the toilet, or where the towels are.'**

Name	
Given Name	
Date of Birth	



Talk with patient and or support person
 Obtain information
 Personalise care
 5 Strategies recorded below

Requests for personalising care: patient's top 5 needs for support

Please keep this TOP 5 form in a central place where staff can access it. When the person is in hospital, always place the form in **front** of the bed chart notes. This TOP 5 form should travel with the patient if they are moved around the hospital and given to them when they are discharged.

1.	
2.	
3.	
4.	
5.	

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About the prompt sheet

Please talk to the patient, and if they agree their support person, about their needs and preferences so you can identify the TOP 5 strategies to effectively provide support for the patient in the setting in which the patient is being cared for.

TOP 5 stands for

T = Talk to the patient

O = Obtain information about patient's individual needs

P = Personalise care according to identified needs

5 = 5 strategies identified

This should take place as part of the admission and orientation to the ward, or as soon as the patient feels ready and able. Then it should be refreshed throughout the patient's hospital stay. It can be done in one session or in short bursts.

When initiating a TOP 5 with a person who is blind or has low vision, the following script can be used in your conversation as a prompt to obtain strategies from patients. You can adapt questions according to the needs of people who are blind versus those with low vision. When you document a TOP 5 strategy also document why each point is important to the patient.

The conversation is a partnership between the staff member and patient, so both are equal and can lead the conversation at different times. The patient will take the lead on how many of the topics are discussed at any time. There is also a blind or low vision patient kit that contains items which the patient may find helpful.

Use this suggested wording in the conversation with the patient

The following questions are about you and your needs and they will assist us to personalise your care. I'd like to learn more about how we can help you move around and look after yourself. I also want to know how best to communicate with you and plan for you to go home.

Key mandatory questions on background of visual function or level

1. I understand from your notes that you are blind or have low vision, can you please describe your level of vision, telling me what you can see?
2. How can we help? Is there anything specific we need to know to make it easier for you, such as making sure there is no glare from the windows?

Possible guiding questions

Communication

- When clinical staff provide information about your treatment, how would you like us to give this information to you? These are some examples of what we can do; we can provide it in large print, or we can record this discussion on a dictaphone, or your own phone, iPad or laptop so you can access the information. We can provide you with a dictaphone, if you would like. We also have handheld magnifiers in our blind or low vision patient kit to assist you to read information if you would like to use one.
- Would you like information about what is happening around you in the ward environment?
- How would you like staff to give you information about your surroundings, such as the location of the toilet?

Strategies to support care and communication

- People vary in whether, or how, they would like to make other staff aware that they are blind or have low vision. If you would like to use it, we can give you an identification badge, so people know you have specific needs regarding your vision or blindness. Would you like a badge?
- There is the option to have your preferences for care flagged using a TOP 5 symbol in different ways. We can put it in your medical record, talk about it during staff handover at each shift, print it on your nursing care plan and handover sheets, put it on the whiteboard or patient care board above your bed, or on our electronic patient journey board. This doesn't reveal your condition but recognises that you have specific needs. Would you like us to use this symbol to identify that we have discussed your preferences?

Identifying a support person and process to provide consent while in hospital

- Do you have a person you would like to be involved in discussions about your care? How would you like them to be involved?
- If you have any concerns about your care, our hospital has a patient advocate and we can tell you how to contact them.
- How would you like to confirm that you have given informed consent for treatment?
- Would you like a signature guide as a way of signing a document after it has been read to you? We can provide one for you.

I'd like to know more about your needs and let you know about the daily routine on the ward

- **Daily routines** – would you like to know about the general day-to-day routines on the ward? For example, when shift changes, safety huddles and ward rounds happen, and what each of these things mean. Also, cleaning and meal routines.
- **Meals** – how would you like your meal orders to be taken? When meals are delivered, where would you like staff to place your tray table with your meal on it? Do you require any assistance in preparing for your meal? Would using a red non-slip mat be helpful? We can provide you with one. We have talking alarms available that can be set to let you know when to expect your meal to arrive. Would you like to use one?
- **Operating the bed and remotes** – would you like me to explain how to use the tools available to get the nurse's attention or to raise or lower the bed? Where can these be put so they are easy for you to reach? Would tactile dots be helpful?

Looking after yourself and getting around

- **Daily routine** – what is your normal routine? How do you like things to be set up? Are you an early riser? Do you want to be first or last in the shower? Or don't you mind when you shower?
- **Personal care** – do you require any specific assistance in using the bathroom and getting dressed? If so, how would you like staff to help you?
- **Equipment** – do you have any of your own devices or pieces of equipment that you would like to use while you're here?
- **Environment set up** – how do you normally like things to be set up? What is important to you? Would you like to use a red non-slip mat to assist with contrast for objects that can be placed on the tray table to help with cups and plates?

Getting relevant instructions before and after tests, procedures and operations

- How would you like to receive this information?

Discharge

- How would you like to receive this information?

Do you have any questions or is there anything else you can think of that you'd like us to know?

Confirming the patient's TOP 5

Based on our conversation, I will read out the points I have noted. From these, please let me know which ones are the TOP 5 most important things you would like staff to know and act on to meet your needs.

I will repeat this list when it's finalised to check I have listed what is important to you.

Using the TOP 5

I have documented your TOP 5 things on the form that I just read out to you. This will be placed in a central place, such as by your bed, where it can easily be seen by staff.

Would you like a copy for your own reference?

If you find that your TOP 5 requests are not being done, please ask to talk to the nursing unit manager or patient liaison officer.

There is always the opportunity to add, or change, your TOP 5 things if you think of something after this conversation.

Please continue to discuss your TOP 5 with staff throughout your hospital stay if there are any changes you would like to make.

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