PRIVACY ISSUES IN LONG-TERM CARE

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> *A long-term care home is primarily the home of its residents and is to be operated so that it is a place where they may live with dignity and in security, safety and comfort and have their physical, psychological, social, spiritual and cultural needs adequately met.*[1]

All legislation, regulations and policies governing long-term care homes must comply with this fundamental principle. To adhere to this principle, a resident's privacy must be maintained wherever possible. Unfortunately, due to the medicalized nature of long-term care which is provided in a congregate care setting, true privacy may not exist. This article will explore the rules regarding privacy, focusing on the rights of residents respecting personal privacy, visitors and cameras.

PERSONAL PRIVACY

The *Long-Term Care Homes Act* includes a Residents' Bill of Rights. Right number 8 states that "every resident has the right to be afforded privacy in treatment and in caring for his or her personal needs". This means that you are entitled to have medical treatments and personal care done in private.

This can be difficult in a long-term care home. For safety reasons, rooms in homes do not have locks. Sometimes fellow roommates, staff and visitors forget that this means they cannot simply barge into a room or leave doors open. You have a right to have the door closed if you wish, whether you are dressing, visiting someone, sleeping, or just want to have some peace and quiet. This can be difficult if your roommate wants the opposite. Hopefully, you will be able to come to an agreement; if not, you can ask for a room change.

Staff and visitors should always knock or announce themselves **before** they enter the room. If there are curtains, they should not be flung open without asking your permission. Staff are often so busy that they forget to get your permission to enter. You should gently remind them of your privacy rights and if this does not work, speak to the administration or your Residents' Council.

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[1] *Long-Term Care Homes Act, 2007*, SO 2007, c 8, s 1.

Because your room is open to everyone, it can be difficult to keep items safe. Although you may have a chest of drawers and a closet, these can be opened by anyone. You are entitled to ask for, and be given, a drawer with a lock so you can store personal or valuable items. Be sure that you have a way of safekeeping the key. Many residents wear their key on a chain around their neck or on a wrist-band.

PRIVACY AND VISITORS

You are entitled to meet with visitors privately, if you choose. The home is **not** entitled to know what relationship you have to your visitor or why they are visiting. For example, when I visit a resident I will often be asked if I am the resident's daughter or her friend. As legal counsel, I must ensure that I keep information confidential, especially since the resident may be complaining about the home! I will only divulge that I'm a visitor – that's all.

Homes can ask visitors to sign in for two reasons. The first is so they know how many people are in the building in the event of an emergency. The second is to be able to track people if there is an outbreak of a communicable disease or illness. It is not to track your visitors.

Resident Right 21 entitles residents the right to meet with a spouse or other person in a room that assures privacy. For instance, you might go to a meeting room so that you can discuss your personal affairs in private. It might also be a private bedroom so you can have privacy with an intimate partner who lives in the community. It can be difficult to be intimate in a room that you share with three roommates and that has no lock!

PERSONAL HEALTH INFORMATION

All of your health information must be protected pursuant to the *Personal Health Information Protection Act*. This means that all of your health information must be kept private by the home and its staff unless the law expressly allows it. Resident Right 11(d) stresses that the home must comply with the *Personal Health Information Protection Act*.

When you are admitted, you will often be asked to sign a consent form which would allow the home to share your medical information with a hospital if you required medical treatment. Even if you are not asked to sign such a form, this information could still be shared if you were sent to hospital in an emergency, as the treatment team at the hospital would be regarded as part of the "circle of care" and sharing medical information would be allowed in order to properly treat you.

However, the home may not simply include every health care provider in this circle of care to avoid having to get consent to disclose. For example, if you saw a specialist, such as a psychiatrist, the home would have to get your consent to obtain any information from the psychiatrist, as you may not have any interest in sharing this information.

If you are mentally capable, you get to consent to the collection, use or disclosure of your own personal health information. Capacity is defined in the *Personal Health Information Protection Act* as follows:

> An individual is capable of consenting to the collection, use or disclosure of personal health information if the individual is able,
>
> (a) to understand the information that is relevant to deciding whether to consent to the collection, use or disclosure, as the case may be; and
>
> (b) to appreciate the reasonably foreseeable consequences of giving, not giving, withholding or withdrawing the consent.[2]

If you are not mentally capable, your substitute decision-maker will make this decision for you. Your substitute decision-maker is the person highest in the hierarchy set out in the *Health Care Consent Act* who meets the definition of substitute decision-maker and is willing to act.[3] This may be a person you have named in a power of attorney for personal care, a family member, and if there is no one else, the Public Guardian and Trustee. Personal health information cannot be collected, used or disclosed without your consent or the consent of your substitute.[4]

The fact that you live in a long-term care home does **not** mean that you do not have control of your health information. As long as you are competent, you have this control. If you are incapable, your substitute decision-maker has control.

It is often reported to us by competent residents that long-term care home staff call their spouse or children to “report” incidents. In fact, staff sometimes will not even discuss the incident with the resident even though they are capable!

Resident Right 16 allows a resident to designate someone to be contacted if they are being transferred or admitted to hospital. This is not the same as authorizing the home to discuss all of your care with the designate(s) without your consent.

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[2] *Personal Health Information Protection Act, 2004,* SO 2004, c 3, Sched A (*PHIPA*), s 21.
[3] *Health Care Consent Act, 1996,* SO 1996, c 2, Sched A, s 20.
[4] Other persons may be able to consent in specific situations: *PHIPA*, s 23.

While you may authorize the home to release information about your health and well-being to family members, for example, this is for information purposes only and does not allow them to take over your care.

A requirement of privacy under the *Personal Health Information Protection Act* includes privacy in treatment. The legislation is breached if you receive treatment in a public area, your treatments are discussed in a public area, or your information is available in a public area (e.g., your chart left open on a desk). It is fine for staff to provide you with your medication but not to announce details about the medication without getting your permission first. You control the flow of the information, not the home.

You also have a right to see your medical chart at no cost and to have copies at a reasonable cost.[5] The Office of the Information and Privacy Commissioner of Ontario publishes a fact sheet specifically about access to records in long-term care homes.[6] If you are prohibited from seeing your records, you should contact the Information and Privacy Commissioner or obtain legal advice.

CAMERAS

Security Cameras Used by Long-Term Care Homes

Many homes now have cameras in public areas for security reasons. These can be very helpful as they may allow monitoring of situations in many places at one time or enable the review of incidents that have been recorded.

However, there is a question about their legality. As the cameras capture residents of a health facility, it can be argued that this constitutes health information. If the camera captures the person receiving any treatment (e.g., being given medication in the hallway), it is definitely health information. Therefore, it could be argued that because the videotaping is not within the normal expectation of medical treatment, then specific consent must be obtained to both collect (record) and use the video. Homes should be cautious when considering using these cameras.

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[5] The Information and Privacy Commissioner of Ontario released an important decision that sets out their position on costs: Order HO-009 (2010), online: http://www.ipc.on.ca/images/Findings/ho-009_1.pdf. Health information custodians may charge $30 for the first 20 pages and 25 cents for each additional page.

[6] *Long-Term Care Homes: Consent and Access under the Personal Health Information Protection Act, 2004,* online: http://www.ipc.on.ca/images/Resources/fact-09-e.pdf.

"Granny-Cams" Used by Residents/Substitute Decision-Makers

We often get asked if residents or their substitute decision-makers can put a camera in the resident's room, especially if there are questions about the care being provided by staff. There have been several well-documented cases in the media where these "granny cams" have substantiated concerns which could not be proved otherwise. Since many residents have dementia and are unable to explain how they were bruised or why they are afraid, some families have turned to putting cameras in the resident's room.

Cameras cannot be used without the consent of the resident if they are competent. If the resident is not competent, only the resident's substitute decision-maker can consent to the use of the camera. Putting a camera in a person's bedroom is a very invasive process. The substitute decision-maker should carefully consider the advantages and disadvantages given the significant intrusion on the resident's dignity. The camera may pick up intimate care – is this what the person would really have wanted? Cameras should always be a last resort and only used when there are very serious concerns about abuse or neglect in care. There is also a potential risk of criminal prosecution under section 162 of the *Criminal Code* if the camera picks up nudity or sexual activity. While the defence of being in the "public good" is possible (e.g., prevention of abuse), it would be a question of law and fact in a court hearing.

Homes will often remove the cameras if they are found. We know of no authority that allows homes to remove such private property, unless it is a safety hazard. Staff sometimes refuse to enter a resident's room or cover cameras while providing care because they know they are being watched. Homes may claim that you cannot have a camera due to staff privacy concerns – ACE disagrees. We do not believe that staff have an expectation of privacy when providing care. However, there is a concern about roommates. Where possible, consent should be obtained for the use of a camera from the roommate or their substitute decision-maker. Cameras should strictly be limited to the space of the resident and not their roommate.

It is not recommended that "granny cams" have an audio function. It is an offence under the *Criminal Code* to record a private conversation without the consent of the party.[7] The audio component could potentially record a conversation between a roommate and their visitors or two staff members having a conversation in the room.

[7] *Criminal Code,* RSC, 1985, c C-46, ss 183.1 and 184.

OTHER PRIVACY ISSUES

Long-term care homes are allowed to disclose the fact that someone is a resident of the home, their general health status and their location (e.g., room number) in the facility. However, the home must give the person an opportunity to refuse to allow this information to be provided.[8]

Homes often ask residents if their photos can be posted to celebrate birthdays or used in newsletters. This is good practice. There may be residents who, for a variety of reasons, do not want it known that they live in the home. This may be because they have been in an abusive relationship and do not want the abuser to know their location or they may have been a high profile member of the community and they do not want their residence to be widely known.

While Residents' or Family Councils are not bound by the same privacy legislation as homes, they should be respectful of the privacy of residents and try to adhere to these rules. Residents should be asked in advance that their names will be printed in meeting minutes and posted. If the Council publishes a newsletter, consent should be obtained to include pictures and names.

Under the *Long-Term Care Homes Act*, Family and Residents' Councils may bring issues of complaint management. The Council should always have the consent of the resident/family member before releasing the name of the complainant. Conversely, homes may never release information about residents/families or their complaints to the councils without their express consent.

Both the *Long-Term Care Homes Act* and the *Personal Health Information Protection Act* have exceptions for the provision of personal health information to the Ministry of Health and Long-Term Care. For example, homes are required to provide otherwise protected information about residents to the Ministry if there are complaints or critical incidents and during inspections.

[8] *PHIPA*, s 38(3).