- Once a story has been written and pictures or video taken, they become the property of the media outlet. This means that neither you nor the UHN will have any control over their current or future use.
- UHN will ask the patient and family member to sign a consent form which will note that they agree that pictures and recordings may be taken.
- The care team will be asked about whether an interview or recording is in the best interest of the patient at that time. Their answer; 'yes' or 'no' will be final at the time of the request. Their only interest is the health of the patient.
- If the team in Public Affairs & Communications would like to ask a patient to tell their story to a reporter, they will make the request through the Most Responsible Physician (MRP). The MRP will ask if the patient is interested and then, will give the patient name and contact information to Public Affairs & Communications. It is the patient's choice if they would like to work with the media and they should not feel forced to do so.
- The team in Public Affairs & Communications will not give any member of the media any information about an individual patient without the express consent of the patient or their Substitute Decision Maker (SDM).
  - This includes whether the patient is in hospital or not, whether they have had a transplant or not, and any other details which may be requested. The team will ask that one family member become the contact person for Public Affairs & Communications. We will need to know that the patient agrees with this.

- As a patient waiting for transplant, you need to inform your loved ones about your wishes with regard to social media and the general media. Once images and details of your care are posted on a social media site or on the general Internet, you have no control over the information and images.
- From time to time, patients use the media and social media to raise funds to support their transplant expenses. This is entirely up to you, your family and friends. UHN cannot take part in fundraising for individual patients.

For more information or, if you have questions about the use of media and social media as a transplant patients, please call Public Affairs & Communications at 416-340-4636.

Media, social media and your transplant at University Health **Network (UHN)** 



Toronto General Toronto Western Princess Margaret Toronto Rehab

## You have been given this pamphlet because you are waiting for a transplant.

Many people waiting for transplant use social media sites to blog about their experience, search for an organ donor, or keep their friends and family in touch with what is happening to them.

Social media sites, such as Facebook<sup>™</sup> and Twitter<sup>™</sup> have helped many people through their transplant, but there are some things that you should think about when using social media:

- When you share your story using social media, you offer intimate details of your health and family life to everyone. You have no control of how these details are shared and used at the time of your transplant, or in the future.
- In the province of Ontario, the act of organ donation is anonymous and the identity of donors and their family members is protected for the benefit of the donor and recipient.
  - By publishing details of your transplant

     the time and date of your surgery, the organ(s) you have received and other additional details, this may make it easy for someone to identify you.
  - This may also mean that the donor family may be able to identify you as the recipient of the organs that they have donated from a loved one. It has happened and, it has resulted in comfortable and uncomfortable situations for the donor, the recipient and for their loved ones.
- If your story is on a social media site, you may be called by members of the general media (such as a news team) and asked to share your story.

- If you choose to share your story, you should be aware that the UHN has restrictions on how the members of the media may enter any of our hospitals. This is because UHN is concerned about your privacy, the privacy of other patients and their family members, and the privacy of our staff. At UHN, your health is the prime focus of your stay in the hospital.
- If the media will be following your story, you must call the UHN Public Affairs & Communications team at 416-340-4800 ext. 4636. One of our team members will work with you and the media.
- Every person who shares their story does so in the very positive frame of mind that everything will go well. Once you share your story, people will want to know the details – the good and the bad – and members of the media can be very persistent. This may be very difficult for you and your family during the most difficult times in your transplant journey.
- If you want to use your camera to take pictures, video or recordings to post on a social media site, there are three questions you must ask yourself:

1 Do I have the permission of everyone who appears in the picture or recording to capture their image or voice? no

- 2 In giving that permission, do they know that I intend to post these pictures or recordings on a social media site? no
- 3 Will taking pictures or recordings interfere in any way with my yes care, or the care of my family member? no

The answer to the first two questions must be "Yes." There is the expectation of privacy for all patients and family members while at UHN. You must have their permission to use their picture, video, or voice on social media. Staff members also have the right to privacy if their image or voice is going beyond the walls of the hospital on to social media.

The answer to the final question must be "No." Nothing can interfere with care at UHN. The patient's health care team must be consulted and agree to any requests for pictures or recordings. They will make the decision in the best interests of the patient at the time of the request.

## **General media requests**

If your story has attracted the attention of journalists, you will need to meet with a member of the Public Affairs & Communications team at UHN. They will help in any way they can, while making sure that the privacy of other patients, family members and staff is respected.

Here are some things to know and think about when working with the media:

- No reporters can come in to UHN without making arrangements through Public Affairs & Communications.
- Requests for reporters and camera crews in the ICUs, Emergency, inpatient units and outpatient clinics are looked at on a case-by-case basis, depending on the care needs of the patient, the privacy of others in the area, and whether it will disrupt the work in the area. It will also depend on whether a member of Public Affairs & Communications can take part.

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