



# Renal PFAC Final Satellite Visit Report 2017/2018

Over the last year, from September 2017 to May 2018, representatives from the LHSC Renal PFAC have visited the following 8 satellite dialysis units situated around the Southwest LHIN:

- Chatham Satellite Dialysis Unit
- Goderich Satellite Dialysis Unit
- Grey-Bruce Satellite Dialysis Unit (Owen Sound)
- Hanover Satellite Dialysis Unit
- Bluewater Health Satellite Dialysis Unit (Sarnia)
- Stratford Satellite Dialysis Unit
- Ed DeSutter Satellite Dialysis Unit (Tillsonburg)
- Woodstock Satellite Dialysis Unit

## Goals

- Promote Renal PFAC
- Meet rural satellite patients and their families from the area
- Gather feedback and suggestions from the rural patient population
- Generate interest from satellite patients who might be interested in joining council

## Findings

In general, most of the patients in satellite units are very satisfied with their care. They are happy to be dialyzing in their own communities, and close to home. Some of the findings include:

**Television and WIFI Availability:**

All of the satellite dialysis units had free television available for the patients, which patients were very happy about. One unit even had lap tops for patients to go on the internet, or to watch movies. The majority of the dialysis units either have free Wi-Fi available for patients, or are working on getting free Wi-Fi. Patients were appreciative of this. Patients in units that did not have free WIFI would be appreciative of having free WIFI provided.

**Transportation:**

Transportation and its cost continue to be huge burden for many satellite patients. If a patient can not provide their own transportation, most satellite units have reliable transportation available to get them to their local dialysis unit, but the service is costly if patients don't qualify for government funding.

When patients need to travel to London for healthcare, and family can not provide transportation, service is sometimes not available or not affordable.

The travel costs and problems with travel vary depending on the area of the province that patients live in.

Many patients mentioned they were on a limited income due to their illness and the financial burden of transport costs for dialysis created financial hardship.

**Parking:**

Parking costs for patients who drive on their own to dialysis varied. Some satellite units had free parking for dialysis patients, while other hospitals charged up to \$40 per month for dialysis parking. Some patients suggested this cost created more financial burden to patients living on a limited income.

**Social Work and Dietitian Access:**

Most patients mentioned that they are able to communicate with the social worker and dietitian by phone, and their needs are met sufficiently that way. Other patients thought more frequent in person clinic visits with the dietitian and social worker would be more likely to meet their needs. Some patients had the availability of contacting allied health via facetime with an iPad, however there were mixed reviews about the use of the iPad. Some patients were intimidated by

the technology, and others felt this mode of communication was not private enough.

### **Physical Environment:**

A number of satellite dialysis units visited did not provide sufficient space for staff to work efficiently, or for patients to have their treatment comfortably. Some units were required to have their patients wait in the hall way instead of in a designated waiting room.

Some of the satellite units provide space or lockers for patients to store personal belongings, such as blankets and some don't. This appears to be important to most patients. There is also variation on items supplied to patients such as blankets.

### **Satellite Unit Waiting Lists:**

Over the last year, wait lists for most of the satellite dialysis units have increased. The majority of patients PFAC spoke to waited at least 3 to 4 months before service, but recent stats indicate wait times are longer. News that the Chatham and Owen Sound Dialysis units are expanding is encouraging to patients. The patients were very happy with this and feel they should be able to get treatment in their own community instead of travelling for a life sustaining treatment, which causes significant financial burden and stress to already unwell patients.

### **Fistula Needles (update):**

Given that the PFAC had received complaints from patients about the newer fistula needles in use, PFAC reported this to the vascular access team. The team had received complaints about the needles at in-centre sites as well. A working group was completed which included a patient member, and new fistula needles were trialed in the fall of 2017, with positive results and have been selected for use in the program.

## **PFAC Recommendations:**

Based on the above findings the Renal PFAC would like to make the following recommendations to the LHSC Renal Program:

- Transportation and parking: transport to and from dialysis, whether in a patient's own community or within London can represent a significant cost to a patient who may no longer have an income related to illness. Based on this information, the PFAC recommends that funding bodies such as the ORN account for transportation costs for dialysis patients and provide increased funding for patients who have to travel outside of their own community for treatment.
- The council recommends that no charge parking for all dialysis patients be considered given their frequency of visits it high. PFAC also recommends that all dialysis patients be given priority parking spots close to a hospital entrance.
- WIFI: all dialysis units within the LHSC Renal Program should consider offering no charge WIFI for patients and family members
- Renal Patient Website and PFAC Page: the renal program should consider further advertisement of the Renal Patient Website, as many patients and staff in the satellite units are not aware of the website.
- Although some patients were satisfied with talking to a social worker or dietitian via telephone or iPad, not all patients felt comfortable with this method. The Renal PFAC recommends that several different options for meeting with social work and dietitian should be offered.
- Given the increasingly long wait lists for patients to dialyze in their own communities, the Renal PFAC recommends that funding for more dialysis spots throughout the London catchment area be considered.

The Renal PFAC would like to extend thanks to all of the renal patients, family members, staff and leadership for welcoming us into your satellite dialysis units.