



Renal PFAC

Final Satellite Visit Report

Over the last year, from June 2015 to June 2016, 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 satellite patients, and rural PD, Home Hemo and CKD patients 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:

Staff in satellite unit:

The most common theme that emerged was the relationship that patients and family members were able to make with their care providers at each unit. Patients and families felt the staff got to know them very well, and that patients felt they were able to establish meaningful relationships with their care team. Patients and families suggested that staff were willing to go the extra mile for them and this was deeply appreciated.

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.

Renal Patient Website:

Most of the satellite units had Renal Patient Website posters hanging in the unit or waiting room, however, when asked many of the staff and patients were not aware of all the information that the Renal Patient Web has to offer. It was mentioned that little had been done within the satellites to advertise the website.

Transportation:

Transportation appears to be a problem with 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.

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.

Physician/Nurse Practitioner Visits:

Most of the patients indicated that they were happy with the frequency of nephrologists visits (physicians visit monthly, but patients are usually only seen once in two months. If they do need to be seen more urgently, the physician will see them monthly)

Social Work and Dietitian Access:

Some 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.

More Health Education:

Some patients discussed having more education once hemodialysis is started. They felt that they were either too ill, or too overwhelmed when starting treatment to absorb information. The request was made that the dietitian, social worker and the rest of the team visit the patient again within one to two months to cover what was talked about during the first few treatments so that the patient can have a review, and might be able to better absorb information at that time. The patients also suggested that they be asked to bring a family member with them for the first few treatments, so that person can listen to the educational information as well.

Appointment Times:

Some patients discussed getting to early appointments in London for dialysis catheter changes in radiology or other health related appointments at LHSC (at either VH or UH) could be a problem. Some felt that their long drive was not always taken into account when booking an appointment, and that it would be beneficial to offer later appointments to out of town patients.

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.

Satellite Unit Waiting Lists:

At the moment, most wait lists for the satellite dialysis units are not long, patients can be transferred relatively quickly to their own communities, with the exception of the Chatham dialysis unit. The waiting list for Chatham satellite dialysis unit had 19 patients on it at the time of the PFAC visit. The Chatham unit falls within 2 LHIN coverage areas (Erie St. Clair and South West), so they have both London area and Windsor area patients waiting to get into the Chatham unit. The wait can be disheartening; patients 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.

Local Transplant/CKD/PD Clinics:

Several patients who have experienced kidney transplants suggested that since the Nephrologist comes down to the satellite once a month, they could hold a kidney transplant clinic in the afternoon for the transplant patients in the area. They also expressed interest in being able to have their bloodwork drawn at a local lab and have the results sent to London. Lastly, they suggested the possibility of having a “telehealth” assessment done by the physician so they did not have to travel to London for this assessment when their bloodwork was within normal limits.

Other patients suggested having local or virtual telehealth CKD or PD clinics to eliminate travel for patients who live in the furthest regions from London.

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 issue of transportation for renal patients who live in rural communities should be referred to the PFAC transportation task group for further review, who may develop a formal recommendation from PFAC to the Regional Renal Program Steering Committee and to the ORN.

- The council recommends that no charge parking for dialysis patients be considered.
- 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, including more frequent face to face visits with the satellites.
- Some dialysis patients felt they would benefit from further health teaching once they had been on dialysis for several months. They felt they were too ill to absorb health information when they first started treatments. The PFAC recommends that the Renal Program offers further scheduled health teaching to all satellite patients when they feel ready. This teaching could be offered via telephone, or an in person clinic visit.
- Given the lengthy waiting list for patients to dialyze in Chatham, the Renal PFAC recommends that funding for more dialysis spots in Chatham 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.