The Canadian Association of
Nephrology Social Workers

January, 2004

Cansw Voice

INSIDE THIS EDITION

The 25 annual CANSW AGM and Conference was held in Kingston in October, 2003. We have highlights and some pictures of the event.

Several new CANSW Executives were voted in to represent nephrology social workers in Canada. We will hear some of their thoughts on directions for CANSW.

The 26th annual CANSW Conference will be held at Camp Dorset in Ontario in 2004. In 2005, book your holidays to visit Vancouver and attend the conference.

The Jane Dicks award was presented to Pat Reed, this year's winner. This award was initiated in 1995 to commemorate the contributions made to Nephrology Social Work in Canada by Jane Dicks. Receiving the award is an acknowledgement and recognition by the community of nephrology social workers of significant achievement within the profession. We'll highlight some of Pat's work.

Membership renewals to CANSW can be found at the back of this edition of Cansw Voice.

From the Editor…

In British Columbia, as in many other parts of the country, we anticipate layoffs in the hospital in the weeks ahead. We worry for ourselves, our friends, our colleagues. It can be difficult to keep our thoughts, and our worries from interfering with our work. It can be challenging to focus on our clients when new rumours are generated and shared on a daily basis.

The language of work has shifted in recent years and terms such as "caregiver burnout" and "caring for the caregiver" are now being replaced by terms with economic connotations such as "value-added employees". Our own stress about the restructuring of social work in the hospital setting is compounded by the lack of resources that we are able to find and access for our patients. Our patients are struggling with more illness and less available government support.

It is within this context that I have read and included all the articles submitted for this edition of Cansw Voice. I'm amazed at the compassion and the dedication that is reflected in the writing. I see the social work values that are at the heart of the practice.

There are two articles about the impact of kidney disease on First Nations' patients, each one written from a different perspective, and yet both clearly show the burden on this community. There is an article about what it was like last year to work in the hospital where SARS was suspected in the dialysis unit. It's another testament to the kind of stress that we have in our daily work life and yet we carry on better prepared for the next crisis. There is an article from a community social worker about how addressing an issue in the dialysis unit directly can have many positive consequences.

Our new executive have written inspiring words and have obvious enthusiasm for the job ahead. Shirley's call for advocacy is one I hope we continue to focus on in the year ahead as more social programs are being cut and impacting our patients and families.

Thank you all for your encouraging words and actions.

Lorraine St-Martin, MSW
Vancouver General Hospital

Sault Ste. Marie, Ontario

From the President's Pen…

A New Year – A New Honour and Responsibility

Warm greetings to all CANSW members across Canada from Sault Ste. Marie, Ontario. Another year has started and a modified executive is on board with energy to carry on the works of our predecessors. Remaining on the Executive is Carolyn Maingot (secretary) from Vancouver, B.C. and Lyle Stockwell (treasurer) from Whitby, ON. The new Vice President is Lise Ross-Lalande who hails from Timmins, ON. The Regional Reps from across Canada include:

- Laura Devereaux (Thunder Bay, ON) Northern Ontario Rep
- Nathalie Innes (Red Deer,AB) Alberta, Saskatchewan, Manitoba and the Northwest Territories Rep
- Michaela Leicht (Vancouver, BC) BC and Yukon Rep
- Diane Boisjoli (Ottawa, ON) Southern Ontario Rep
- Maureen Brownlow for Quebec, Atlantic Canada & Nunavut

Gary Petingola, our past president will remain on for awhile to provide much appreciated guidance and reassurance to the new President who still believes that she has a lot to learn.

I have been in Nephrology for 14 years (with three maternity leaves and one secondment in Human Resources). I truly value the CANSW organization as a professional group of Renal Social Workers. Social Workers who individually and collectively can facilitate change on the macro level as well as positively impact change at the micro level—all to improve the quality of life for our patients and their families with kidney disease. I love my work. I feel I can make a difference in the life of my renal patients, however long their lives may be.

If you were in Kingston in October 2003, you know that Dr. Susan Watt threw down the gauntlet and challenged each renal social worker as well as the CANSW organization as a whole to ADVOCATE, ADVOCATE, ADVOCATE. Dr. Watt pushed a button that I had already activated this summer when I got frustrated with the lack of local resources available to my patients.

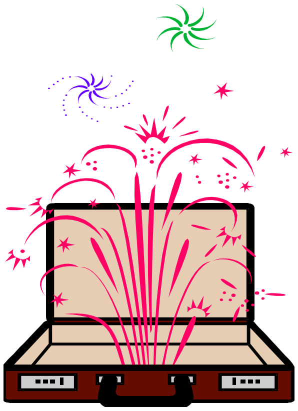
What can each of us do locally to Advocate for improvements for our patients and for health care as a whole? What renal departmental policies need to be challenged? Which hospital policies need to be changed? What community practices need altering? What regional issues need to come to the forefront?

What changes need to happen at the provincial level? Federal level? International level? And what part are we each individually prepared to entertain? And how can CANSW move the issues forward with all of the necessary partners?

These are questions I will be posing not only to myself, but to all of my colleagues everywhere. And I will be exploring this with the Executive as well. I encourage you to give feedback to your Regional Representative or to any member of the Executive on how we can make a difference. We have the expertise and the partners to facilitate change. We have a responsibility. And we truly have the honour and privilege to work with a unique population.

Looking forward to a New Year as your CANSW President

Shirley Pulkkinen, MSW, RSW
Renal Social Worker



A New Year, A New Project

As I sit here and write this piece, it still seems unreal to think that I now hold the position of Vice-President of an Association that has brought me so much. It was not that long ago that I made the transition from Mental Health to Renal Social Work. Fortunately, my entry within the renal world was simultaneous with my entry into the Canadian Association of Nephrology Social Workers. Somehow with the generous help and sharing of my colleagues throughout the country, what seemed initially like a huge task of setting up a new position within our program, became an exciting challenge of absorbing and coordinating a wealth of shared information and resources.

As time goes by, I remain fascinated by the depth and amount of tasks and responsibilities that come with our position of Nephrology Social Work. The list serve has truly been the biggest asset of CANSW members to share tools, thoughts and ideas. However if any of you are like me and don't have the perfect filing system, you have surely been caught asking yourself…"Where did that info on Renagel, parking or employment go?" Hence comes the desire to facilitate access to and sharing of such important resources.
Keeping in line with my vice-presidential task of "assuming responsibility for the ongoing development and maintenance of a CANW Resource Library", I have already initiated a discussion with the new executive about such. Recognizing the 'Information Superhighway' as the most accessible, timely and practical way to provide this service, we would like to look at the possibility of having all resources available through the CANSW website. We recognize the need to update and make the necessary changes that will permit us to expand.

Naturally this is an extensive project, which will require much teamwork and expertise, so…. I encourage all of you who may have an interest, experience or energy to put towards this worthy cause to be in contact at your earliest convenience. You will certainly be hearing our requests for documentation (…of all kinds) as we work towards collating and building our online resources. Thanks again to everyone who supported my nomination and candidature. I look forward to working with you. Have a happy and healthy New Year!

Lise Ross-Lalande, M.S.W., R.S.W.
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Working in Sault Ste. Marie & Northern Ontario

Laura Devereaux is CANSW's Northern Ontario Rep

To better appreciate the challenges of renal social work in Northern Ontario, one needs to appreciate the uniqueness of the geography itself. The following excerpt has been borrowed from the website http://142.51.17.253/jrp/nots/geograph.htm. "Unlike the provinces themselves, Northern Ontario isn't a strongly defined region…many people maintain their own definition of the region. Anecdotal boundaries include "anything north of Barrie", which is a bit of a stretch, unless you happen to live in Toronto".

"A big defining characteristic of Northern Ontario is scale. Until you travel across the region, it'' difficult to comprehend just how huge Northern Ontario is" it has been "a major element conditioning all aspects of the development process (Saarinen, 1986). It's had an impact on any number of political and social issues, from four-laning of highways to adequate access to health care".

To give one a visual as to how "big" Northern Ontario is – if you combined the total landmass of Finland, Sweden, Turkey, France, West Germany, Texas, and Louisiana, you would equal the Northern Ontario land mass.

The chart below indicates which social workers are responsible for the regional areas indicated.

Region	**Renal Social Worker**	**Land Mass Compares to:**
Thunder Bay	Laura Devereaux & Lori Byerley	Newfoundland, Hawaii and Tennessee
Timmins	Lise Ross- Lalande	Wisconsin
North Bay	Sonja Solman	Fiji Islands
Sault Ste. Marie	Shirley Pulkkinen	Costa Rica
Sudbury	Gary Petingola & Michelle Spence	Denmark, Northern Ireland, Cyprus and French Polynesia combined

Although Northern Ontario takes up to 88% of the land area of Ontario, only 7.7% of the total population of Ontario. (N. Ont population is 826,276 vs S. Ont 10,763,573; Stats Canada Census, 1996). We all know how much our renal numbers have exploded over recent years. The challenges of dealing with the increased numbers over such a vast geographic boundary pose many difficulties. It is my hope that Tileyla's story will reflect some of these challenges.

SHE WAS TILEYLA

by Laura Devereaux , a Renal Social Worker in Thunder Bay

(The name Tileyla is fictitious to protect patient confidentiality)

Tileyla was one of my first clients as a renal social worker. Her story burrowed a place in my memory and my heart that even today, lends me much strength in my work. This story belongs to many Aboriginal people living in Northern Ontario who live with kidney disease.

"Home", was the first English word I heard Tileyla speak. I was asked by her nephrologist to help her understand that home was not an option. When I first met Tileyla she was waiting in her hospital room dressed in a hand-sewn purple, blue, and yellow flowered cotton dress. Underneath she wore purple sweatpants; handmade wool socks and runners with velcro straps adorned her small feet. Covering her two white braids was a scarf of many colors. When she smiled it was almost like her face celebrated each memory held in the many wrinkles that covered her cheeks and around her dark eyes. Even though we had never met before, and I did not speak her language, she reached out her hand and held mine. She seemed to know that I was there to try and help. How could I possibly explain to this woman that she could not go home?

Tileyla lived in an isolated Aboriginal community, accessed only by plane in the winter and boat in the summer. If it was a good winter, the lake might freeze up enough to safely travel by snowmobile or by foot. A full day of travel even by plane was required to go to Thunder Bay. Tileyla was a recent widow having been married to her husband Simon for fifty-three years. Just prior to her illness she had moved from her small wood heated cabin where she had raised her children and had lived for over forty years to live with her daughter Agnes. Tileyla was the mother of eight children, one of whom died at birth, another committed suicide 6 months prior, and her eldest daughter drowned when she was seventeen. "Kokum" or grandmother was her name to her eight grandchildren.

Hemodialysis was started, a subclavian line inserted, and dialysis was now the only way Tileyla could be kept alive. In Thunder Bay, the closest satellite unit to Tileyla's home (even then nearly 900 km away and only by plane) had a waiting list of 8 other patients. Peritoneal dialysis was not an option as Agnes, her daughter's home, did not have running water or electricity. Her children, all fortunate enough to have jobs on the Reserve, could not leave to come and care for Tileyla. Doing so would result in job loss and guaranteed poverty which is the reality for many "relocated" Aboriginal people living in an urban city such as Thunder Bay.

After a family meeting based on the traditional way of consensual decision making, Teleyla decided that she would move to a Long Term Care Facility and remain on hemodialysis – conservative treatment was not a decision she or her family were prepared to make.

Over the two years that I knew Tileyla, she traveled home only once (for three days). Her family, being unable to afford frequent visits, only came to Thunder Bay three times. Tileyla, over time, became less engaging. She often became agitated on dialysis, yelling out "home" repeatedly. Effort was made to offer Aboriginal support in the form of friendly visitors, and some social circles. Tileyla spoke frequently of her deseased husband and three children who had died. She often cried and squeezed my hand telling me how lonely she was. The Long-Term Care facility where she lived housed over 150 clients, of whom only five were Aboriginal people. Very few people spoke Oji-Cree. She told me how frightening it was for her to eat amongst so many strangers in the dining room. Life for Tileyla had become only about survival. Over many short conversations interpreted by a translator, Tileyla and I talked about discontinuing dialysis. For her, it was the only way home. Shortly before her eighty- third birthday, I said good-bye to Tileyla. She was sent home by air ambulance to die. Once again, just as the first day I met her, Tileyla looked up at me from her stretcher, bundled tight in many blankets, with her head covered by a flowered scarf, and said "Home". Much later, after her death, the doctors and I say that Tileyla died of loneliness.

I will never forget Tileyla. The intensity of her suffering has deepened my understanding of true courage. The reality of those living in Northern First Nations communities such as those in this region is one of poverty, limited access to health care, and fewer choices when faced with End Stage Renal Failure. It has been found that social support is an important indicator of quality of life. Those who live with their families report better emotional adjustment to their illness, and less physical difficulties such as pain, decreased appetite, and fatigue (Valderrabano et al, 2001; Parkerson et al., 2000). In many First Nation's communities, a host of challenges exist. The housing conditions often limit individual treatment choice. A large majority of homes are not equipped with potable water, septic systems, or safe heat sources. Many homes are poorly insulated, have minimal storage and living space, and do not have running water or working toilets. A recent unpublished study conducted in Thunder Bay describes the difficulties faced by Aboriginal patients. Those First Nations participants described their social story as one of sorrow and destitution. They described, "loss of self – reliance…independence… separation from supports and loss of roles, alienation…stigmatization of illness, grief and loss, and uncertainty and loss of autonomy with treatment decisions" (Salvalaggio, 2001, p 6-11).

It is with the shared knowledge that renal social workers in Northern Ontario have and throughout other areas of our country where populations are disenfranchised - that we are challenged to fight for greater access to health care. Sustaining human dignity and improving choice in treatment options must go hand in hand.

Cansw Voice is produced three times annually in September, January and June. If you would like to submit an article, a comment or ideas for the direction or layout, please email items to the editor at lstmarti@vanhosp.bc.ca or call Lorraine at (604) 875-5958 at Vancouver General Hospital.

ONE COMMUNITY SOCIAL WORKER'S EXPERIENCE

By Oi Man Chan in Vancouver

Almost two years ago, I went to work at the Community Dialysis Unit. This was a welcome change for me after working at the hospital's incentre unit for several years.

The dialysis schedule at the Community Unit is the same as at St.Paul's Hospital. We are open seven days a week with three shifts of patients doing dialysis daily during the week and two shifts during the weekends. There are a total of 90 patients at the Unit. Currently, I work three days a week, an equivalent of 0.6 FTE.

All patients at the community unit dialyze in chairs that are arranged in a semi-circle. Because of the intimate setting, patients can easily interact with each other during dialysis and often become bonded with each other. They often view each other as an extension to their families.

When I first started as a new member of the team, I discovered there was an ongoing issue among the staff and patients that related to the disclosure of patient information by staff members.

Quite often, when someone does not show up for dialysis during their regular shift, patients inquire, out of concern, as to what has happened to their fellow patient. However, the staff is not supposed to disclose information about a patient without their consent.

Therefore, the staff have been struggling with the need to protect patients' privacy with answering inquiries from other patients.

In fact, even though staff refuse to share information, patients usually find out through the "grape vine". From the patients' perspective, they want to know because they care about each other. They often assume that something bad has happened while in fact the patient may have been away on a trip.

The issue came up again after one patient who was well liked by others died suddenly of a heart attack at home. The staff faced the dilemma of whether or not to tell the other patients. Some staff felt the need to share the sad news with the patients so that they could grieve the loss together. Others were afraid to violate the policy. The patient's death finally became public knowledge after someone posted her obituary on the bulletin board a few days later.

This precipitated some discussion with the staff and patients. I decided to approach all the patients individually and discuss the issue of patient consent in this context. Would they want to give consent ahead of time to share information to other patients in their absence? If patients agreed, the staff could then feel free to share the information when asked. Everybody thought it was a good idea.

It took me several weeks to finally have the chance to meet with each patient regarding this issue. Not surprisingly, the response was overwhelmingly positive, out of the 90 patients, only two indicated that they did not want the staff to share any of their personal information. Everyone else was comfortable with it. In fact, the majority of patients stated that they would like others to know about what happened to them, be it good news or bad. Some even jokingly stated that, if they should pass away, they would like others to come to their funeral. In order to keep a written record of my conversation with the patients, I wrote a note in the patients' chart clearly documenting what was said.

This win-win solution definitely helped to reduce anxiety and frustration that both staff and patients were experiencing regarding the issue. The staff felt relieved that the issue was clarified with the patients. The patients felt respected by the staff because it was discussed with them and they were part of the process. I also benefited from this process because it gave me the opportunity to have a meaningful conversation with the patients about some sensitive issues such as end of life decision-making including living wills, DNRs, etc. I also identified whether there was a need for follow-up discussion with individual patients. What a good way to "get my feet wet"!

It has been a rewarding experience for me to work at the Community Dialysis Unit. The fact that patients at the unit are relatively medically stable allows me to focus more on promoting wellness and vocational rehabilitation. Not having to deal with urgent discharge planning issues gives me the opportunity to maintain regular contact with the majority of patients and to provide emotional support.

To me, it is a privilege to work with renal patients who teach me so much about courage and strength through their journey living with kidney disease. It is also gratifying for me to know that, in return, I can make a difference in their lives by providing support and encouragement as a social worker.

CANSW 25th ANNUAL CONFERENCE – Kingston, ON 2003

This summary of the Conference was written by Shirley Pulkkinen from Sault Ste. Marie, Ontario

The beautiful city of Kingston, Ontario. This was the venue for CANSW's 25th Annual Conference on October 20-23, 2003. Our hosts, Mary Joan Brinson and Sheridan Van Blaricom along with the 2003 Conference Planning Committee did a great job of the conference according to evaluations.

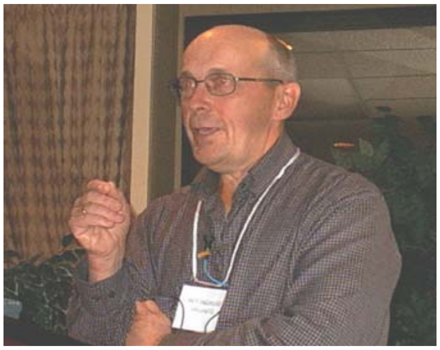
Mary Jane Jacobson, RN discussed a Decision-Making Tool to assist patients and families with the process of making difficult decisions. Many of the attendees expressed appreciation for the hands-on tool. Dr. Susan Watt presented on "Aging Dialysis Patients – Old Lessons, New Challenges". Her inspiring presentation challenged renal social workers to review our approach and "step out of the box to examine our practice" and "return to our roots". Susan McMurray from Baxter discussed the concept of "Integrated Care", approaching renal education as a continuum of options and promoting peritoneal dialysis as an initial treatment option for many different reasons. Dr. Toffelmire, a leading nephrologist in Canada celebrated the profession of renal social work and was an enjoyable dinner presenter.

Sheridan Van Blaricom thanking Keynote Speaker, Mary Jane Jacobson at CANSW Kingston 2003

CANSW Kingston 2003 – Cathy Mosher speaking with Keynote speaker Dr. Susan Watt

As always, we were very fortunate in having our own CANSW members give presentations from their own experiences: Sheridan Van Blaricom on "The Elderly on Dialysis: What Happened to the Golden Years"; Stephen Giles on the "Antidote to Emerging Two-Tier Organ Donation Policy"; "Just Because We Can, Should We" a review of initiating dialysis on an incompetent patient by Rachel Belway,; "Patient Withdrawal of Dialysis" a masters thesis review by Laura Devereaux,; and "End of Life Issues" presented by Anita Pudlik. We never seem to have enough time for discussion with our peer presenters: we all have so much to share about our own experiences and can truly relate to the challenges.

For those of you who weren't fortunate to partake in the welcome dinner at the restaurant "Casa Domenico"— well we shouldn't really gloat about the marvelous dinner that allowed us to connect with our peers in "an intimate setting" and the "Wonderful gastronomique experience" along with the kidney trivia from 25 years ago. A great thanks again to our Conference Committee for a wonderful job getting sponsorship as well as a superb opportunity to meet the faces with the names that show up on our list server.



Sheridan Van Blaricom presenting "The Aging Dialysis Patient" at CANSW Kingston 2003

THIS YEAR'S WINNER OF THE JANE DICKS' AWARD IS PAT REED. PAT REED WORKS AT SUNNYBROOK IN TORONTO COLLEAGUE, AMY CANTER WROTE THE FOLLOWING IN HER NOMINATION LETTER….

Pat started her professional life as an X-ray technician. She later became an office manager in a psychiatrist's office which inspired her to help people in a more direct, professional way. She went back to school to get her BSW while at the same time managing her responsibilities as a wife and mother of 2. But if you know Pat, you know that she does not do things in half measure so she went back to get her Master's in Social Work. She has worked in the Children's Aid society, a Neonatal Intensive Care Unit, an Employment Assistance Program, a GI surgery program and finally settled down in Nephrology. We are all fortunate that she did.

When one looks for examples of clinical excellence among our staff in the Nephrology program, one does not have to look far. Pat Reed stands out among many as a health care professional who is known for going the extra mile. During the SARS crisis, Pat was at the front door early almost every morning to ensure that the dialysis patients were able to come into the hospital for their treatments. Knowing that many of our patients would be frightened, or would not be able to understand the screening questions either because of language barriers or cognitive impairment, she was there to trouble shoot and to help them negotiate the system. She also took off her heels, put on her runners and portered patients up and down when there were no volunteers. She came early and stayed late, often coming in on weekends to help. As a result of her work, she has been awarded a prestigious "Star of Sars" award at Sunnybrook.

Pat's clinical practice embodies patient-focused care as it was taught to us in social work school. She develops care plans that are patient-driven, strives to protect the dignity of our aging renal population and is one the best advocates in the community for renal patients. She has that uncanny ability to make fast, enduring, therapeutic connections with her patients. Her world view is that people are basically good and she lends her perspective to those who are in need of strength and wisdom, patients and staff alike. She has helped develop the Nephrology Patient Council at Sunnybrook, which means coming in on weekends because that time is the most convenient for the patients. She is an editor for the SUNDIAL, the dialysis newsletter and organizes countless social events as she sees her role as a social worker is to enrich the lives of dialysis patients, families and staff.

Her work at the Kidney Foundation is another example of her boundless energy and her belief in the need for community organization. She co-chairs the Patient Service Committee at the Kidney Foundation, and is a tireless fund raiser for that organization. She has twice received the KF Patient Services Professional award for her ongoing commitment to helping the dialysis community. She is a superb organizer and strong advocate for Camp Dorset, for dialysis patients and families.

When Pat entered the world of Nephrology Social Work, she quickly became involved with CANSW as an offshoot of her strong belief in the importance of peer support. She served as secretary for 4 years. She was also a key organizer of the GTA Nephrology Social Work group. She is a strong advocate of networking and collegial support. Among her peers, she is widely known as a mentor to new Nephrology Social Workers and gives generously of her time and expertise to help others develop their own skills and resources. She believes strongly in field instruction for social work students and in addition to supervising students, she participates in the Mentoring Program at University of Toronto Faculty of Social Work.

Pat is constantly reminding me that she will retire in a couple of years and while she looks forward to a busy life spent enjoying her leisure time, I cannot imagine the time when she will not be here by my side. Her sense of humour, her energy and her wisdom are a constant source of inspiration to me and to many others!

CONGRATULATIONS, PAT!

First Nations Patients, Diabetes and Renal Disease

By Michaela Leicht, a Social Worker at St. Paul's Hospital in Vancouver. Michaela is also the CANSW rep for BC and the Yukon

While being diagnosed with chronic kidney failure and requiring dialysis has a major impact on the lives of all renal patients, those of aboriginal heritage often face particularly challenging obstacles in their efforts to manage and integrate this treatment into their lives. As renal social workers we witness the suffering and attempt to alleviate some of the fallout and effects this illness has on our patients' lives. Although the illness has typically progressed too far by the time we see our patients, the biggest hope in this regard – particularly in the case of diabetes, the fastest growing cause of renal failure for First Nations patients – are initiatives which aim to prevent the onset of diabetes in the first place.

Until the 1940s, diabetes was virtually unknown in Canada's Aboriginal communities. However, during the last few decades this chronic condition has reached epidemic proportions. The prevalence of diabetes amongst First Nations populations is now at least three times the national average. In the wider Canadian population more men than women are affected by diabetes, yet the disease strikes over five times more First Nations women than other women in Canada.

There are many theories as to why diabetes has become so widespread among First Nations populations. As a consequence of colonization, aboriginal people no longer engaged in physically demanding work such as setting trap lines, etc but were forced into a sedentary western lifestyle with diets high in fat, sugar, white flour and processed foods. In many remote areas the availability and affordability of healthy food choices became increasingly limited, and health care services are inadequate. A further explanation is the "thrifty gene" theory, which refers to an adjustment of the metabolism during alternating periods of feast and famine. While this "thrifty gene" protected ancestors from starvation, it is believed to be partly responsible for today's aboriginal populations' predisposition toward obesity.

Another contributing factor regarding vulnerability to diabetes may be ongoing emotional stress in response to yet other consequences of colonization. For instance, the last *residential school in Canada closed its doors two decades ago, but the devastating and demoralizing aftermath of physical, sexual and emotional abuse endured by First Nations people will linger for a long time to come. Generations of children had been wrenched from their parents, brought up to be ashamed of their culture, abused physically, emotionally and sexually, returned home unable to trust and bond, only to find elders who had lost their reason for existence, as nobody was around to receive their wisdom. Spiritual alienation and poverty lead to a context of alcoholism, the inability to parent, children with fetal alcohol syndrome, unstable lives in foster care, continued cycles of pain and abuse, separation from community and family, and so on.*

Some of our aboriginal patients at St. Paul's Hospital come from as far north as the Yukon, or they may be Haida Kwaii from the Queen Charlotte Islands, Nisga'a from the Prince Rupert area or they might come from bands in closer proximity to the Greater Vancouver region. Typically patients are accompanied by at least one other family member or perhaps a paid escort from their reserve, and this emotional support and community connection is certainly of critical importance for the mental well-being of the patient who might otherwise feel "lost" in the alienating environment of an urban hospital.

Hemo-dialysis is unavailable in the Yukon or other regions in northwestern British Columbia, leaving PD as the only option allowing a patient to return to their home community. If a patient is capable of doing PD on their own, or if the family is very supportive, life on dialysis may not differ much from that of other renal patients. However, if alcoholism is an ongoing problem, if FAS presents a barrier to learning, if caregivers quickly reach the threshold of burnout due to flashbacks of sexual abuse brought on by close physical contact when assisting with PD exchanges, crisis situations are quick to flare up and escalate.

For aboriginal patients who have been ruled out as PD candidates, relocation to an urban centre brings along a host of other dilemmas. Although native housing can be procured after some period on waiting lists, and patients may connect with others through friendship centres, it is not uncommon that the separation from the familiar community brings about complex mental health problems such as profound existential angst, severe depression, even psychosis.

Not only are aboriginal populations at high risk for developing renal failure secondary to diabetes, they are also genetically more susceptible to other diabetic complications compared to the average population. The overwhelming consequences and challenges of adapting to co-morbidities like retinopathy or neuropathy significantly add layer upon layer to a patient's distress and truly seem to test a human being's ability to cope. It is truly inspiring to witness the inner strength of some of our patients and their strong spirit to survive even in the face of extraordinary obstacles.

* * *

Health Canada's ABORIGINAL DIABETES INITIATIVE funds projects which are designed and managed by First Nations living on and off reserves (as well as Inuit and Metis communities):

The Vancouver Native Health Society runs a program called ADAPT (Aboriginal Diabetes Awareness Prevention and Teaching). Its focus is on prevention and awareness of diabetes and involves weekly activities such as sharing circles, lectures or movies about diabetes, etc. This organization is located in Vancouver's Downtown Eastside (notorious as the poorest postal code in Canada). However, economically deprived individuals are dependent on food agencies and have very limited choice in terms of nutrition.

British Columbia also operates a Mobile Diabetes Telemedicine Clinic, which screens for diabetic retinopathy. This pilot project is run by the Chiefs' Health Committee in partnership with First Nations and Inuit Health Branch, CNIB and the Vancouver Hospital and UBC Eye Care Centre.

Alberta's SLICK (Screen for Limbs, I-Sight, Cardiovascular and Kidney) program, a partnership initiative between the University of Alberta, First Nations communities and Alberta's health care providers. Two vans with information and communications technology visit isolated aboriginal communities to screen for diabetes and related complications.

Just as sweat lodge rituals, spiritual counseling and reconnecting with one's culture are critical steps on the journey to recovery in general, a broadening base of innovative First Nations diabetes prevention programs will hopefully slow down or prevent the occurrence of Type 2 diabetes, which is starting to affect even children and teenagers. Exercise, *particularly walking programs are being set up in various communities. Women from the Nuxalt band in Bella Coola, BC have developed their Nuxalt Food and Nutrition Handbook promoting the benefits of traditional nutrition practices including growing their own food.*

Non-Insured Health Benefits provide a limited range of medically necessary items and services for Status Indians/Inuits. The information booklet of this benefits program can be obtained on the web @ www.dsp-psd.communication.gc.ca/Collection/H35-4-23-1-20003e.pdf. (Please note: this website is case sensitive)

SARS BLUES

This article is written by Lyle Stockwell who works at Lakeridge Health Whitby, in Whitby Ontario. Lyle is also the Treasurer of CANSW

China first reported 305 cases of atypical pneumonia on February 15, 2003. Toronto recorded its first SARS death on March 13. By March 23 Scarborough Grace Hospital was closed. At that time, infection control procedures were being tightened at health care facilities, and we began screening and tracking people entering our units. Dialysis staff at our unit were gowned and masked for several weeks during March but this was soon relaxed since our main dialysis unit is not located in an acute care hospital. We initially escaped some of the more stringent procedures imposed on emergency rooms and other dialysis facilities throughout Greater Toronto Area. The directives from the Ministry allowed us to work without being masked, gloved & gowned so long as people entering the facility were screened for symptoms. Only the screeners were wearing masks, gowns, gloves and goggles.

The impact on patients during this phase was fairly minimal and involved little more than a delay in entering and exiting the building. The delay resulted from patients needing to answer several questions designed to screen out anyone feeling unwell, having a fever, or having recently traveled to or visited to certain destinations or locations considered to be SARS hot-spots. There were many barriers involved in this process – hearing and vision problems, cognitive difficulties, fatigue, fear and frustration.

The initial scare passed quickly. We were congratulated for our hard work and primed with stacks of information about living with “the new normal”. However, deaths from SARS continued to mount throughout April and May. Suspected cases of SARS exposure caused closures of schools, workplaces and several health facilities.

Our second incident occurred on the morning of Thursday June 5, when two nursing home residents passed through the screening process for their morning dialysis. Unknown to the screeners, both of these patients had cognitive problems and may not have really understood the importance of the screening questions. It was soon discovered that each patient was carrying a note from the nursing home informing us that they were symptomatic and should be treated as potential SARS cases. This should have required that they be immediately transferred to an acute setting in full isolation precautions for assessment, but instead they were sitting in the middle of a busy dialysis unit.

Very quickly, all staff entering our dialysis units were in gowns, masks, gloves and goggles. All patients were wearing masks and told not to remove them through the entire treatment. The masks are hot and uncomfortable. Anyone wearing glasses often had problems seeing due to fogging. Communication was not easy when facial expression is covered and sound is muffled. Stress levels were high because we were dealing with a new and unknown threat.

The situation got much worse the following week when a “respiratory outbreak” was identified involving a total of fifteen patients. They were to be investigated for SARS. By the end of that day we were informed that all staff, patients and visitors having any contact in the building over a 4 day period were to be quarantined for ten days from the time of potential exposure. For staff, this was a “working quarantine” which meant that we were to report to work, but that we were not to leave our homes for any other purpose. Like patients & visitors, we were directed to sleep and eat separately, and to wear a mask at home whenever another person was in the same room. Everyone was to take their temperature twice a day and report the results when asked by public health.

Living and working under quarantine was very difficult. No patients at our unit had been identified as having SARS, and we were aware the quarantine was a precaution. Nevertheless, the fear of possibly taking a deadly disease home to your family was always present. Communication issues were also stressful. I found I had to juggle the hospital’s official announcements with news media reports, rumors and gossip. Patients and families were in the same position and looking to us for clarification.

The absolute worst moments occurred on day two of the quarantine when problems piled on problems. We were masked, gowned & and gloved all day long. The media were camped just off site. There was an *unfounded* rumor that SARS had actually been confirmed in one of our patients. Calls were received from nursing homes saying they would send patients for treatment but not accept them back after their dialysis. Patients were furious or depressed after being informed that their ten day quarantine period was to be renewed every time they came for dialysis. On top of this, I received a phone call informing me that Public Health had ordered all local buses, including the accessible service to stop providing rides for dialysis patients out of fear of contaminating the vehicles. Many of the local taxi services had already refused drop-offs & pick-ups at our facility. At that moment, it really felt like events were spinning out of control and that we were in serious, serious trouble.

Most of the big issues were resolved over the following day or two thanks to very hard work by senior management and the cooperation of Public Health, the Ministry of Health and the ambulance services. In the end, there were no cases of SARS found among our dialysis patients or the nursing homes were some of them live. We were released from quarantine in just under ten days.

The SARS experience left me with some lasting lessons. The first is that in a crisis, communication is vital, and misinformation can cause a situation to seem to be more out of control than it really is. Second, quarantine had a big personal impact, and the temporary stresses I was feeling reminded me of the ongoing experiences of my clients. These include: FEAR OF THE UNKNOWN: we didn’t know a lot about SARS or what crisis would hit us next; LOSS OF CONTROL: under quarantine you lose some of your freedom and new rules are imposed on you by others; STRESS: even though I had no trouble separating myself at home and lived very comfortably while quarantined, I found that I was sleeping poorly night after night, likely due to stress. I noticed that I became irritable and was resentful of the faceless professionals who were making decisions about my life. It affected my relationships at home, and my wife was faced with picking up all those tasks that I could no longer do. I even lashed out at a co-worker in a way that seemed very out of character; OVERWHELMED BY THE COMPLEXITY OF THE INFORMATION: At times there seemed to be too much information, and at other times, too little information or conflicting information.

CANSW

Canadian Association of Nephrology Social Workers
Membership Application/Renewal
January 1, 2004 - December 31, 2004

Name: ____

Business Address: ____

____

____

____**Postal Code**_________________

Business Tel# (____)___________________Fax#(_____)______________________

E-Mail Address ____

Education: MSW____ BSW____ Other____

Members of Professional Social Work Association /College: Yes____ No____

Name of Association / College:____

Areas in which you work: Pre-dialysis____ Hemodialysis ____ Peritoneal ____

Transplant ____ Adults ____ Children ____

Years in Nephrology: ______ Other Experience: _____________________________________

____

____

Committee Work (eg. working committee on renal services, Kidney Foundation, etc...)

____

____

How can CANSW assist you to meet your professional goals and objectives?

____

____

____

Activities you are willing to assist CANSW with:

___ Mentorship for new Renal Social Workers
___ Renal Social Work Standards/Guidelines
___ Advocacy for renal patients
___ Submissions for the Voice newsletter
___ Developing a resource library for the website
___ Assist in redeveloping CANSW website
___ Any other activity ____________________

Active Membership Fee **$60.00 due by March 1, 2004, $75.00 thereafter. *Any Social Worker currently working in a dialysis/transplant program in Canada. Active members may vote and hold office and act as a chairperson of a committee. The immediate Past President will be considered an active member.**

Associate Membership Fee **$65.00 due by March 1, 2004, $75.00 thereafter. *Those eligible for Associate Membership include the following: Social Workers practicing Nephrology Social Work in any area outside Canada; professionals practicing in a related field of Nephrology; laypersons from related organizations; previously Active Members. Associate Members may attend meetings, conferences, participate on committees, receive significant mailings. Associate Members may not vote or hold office in the Canadian Association of Nephrology Social Workers.**

Please make cheques payable to CANSW and return to:

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