



I have had the pleasure of knowing Mary Lou as a friend, colleague and peer for the past 25 years. The first 15 years as a nephrology social worker, the last 10 through the school of social work, and for the whole 25 with our connections and work with both CANSW and the Kidney Foundation. In every aspect of her life she was a leader, a mentor and a teacher. Mary Lou always gave 100% to everything she did, and she loved to be in control. She enjoyed the challenge and was never afraid to take risks or stand up and be heard for what she believed in and was passionate about. It is because of these attributes that she made such an impact on all our lives and she made such a difference in the lives of her patients, students and colleagues.

Mary Lou rarely, if ever said no, she always had time for you, regardless of how busy her life was. But she used her time wisely, was super organized and very practical. I don't think there was a time in the last 25 years when we didn't sit on a committee together. If she was going to be on a committee, she was either going to chair it or make darn sure the chair kept to the agenda and kept the meeting to an hour. She usually was able to arrange who the chair would be. Those of us involved in committee work are familiar with Roberts Rules – but I'm convinced that Mary Lou had Robert's Rules memorized and I'm sure kept a copy with her at all times.

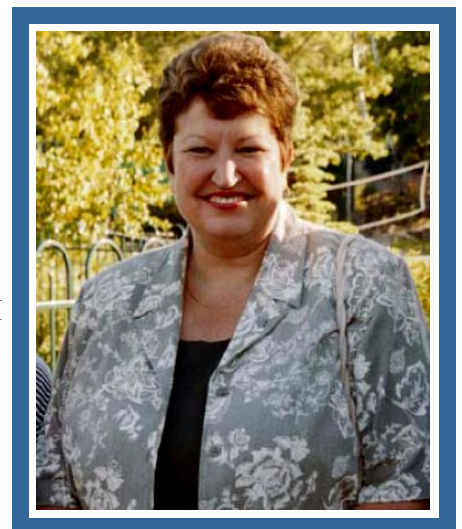
Some of her accomplishments to name a few were – President of CANSW, with the Kidney Foundation she was national President, Chair of the National Patient Services Committee, Chair of national Public Policy Council, Chair of the National Research Counsel, Chair of the Leading Change Team to name but a few.

In spite of all these accomplishments, Mary Lou was a humble person and very private. I recently found out that very few people knew that she received the Queen's Golden Jubilee Medal from the Governor General – I had known for years and just assumed she had shared such a great honor with all her friends and colleagues.

Mary Lou's smile lit up every room she walked into. Her laugh was contagious and she wasn't beyond having a laugh at your expense but more importantly could laugh at herself. I asked her last year if she wanted me to step down as the community rep on the practicum committee at the school of Social Work, I told her if others were interested I would be willing to step down to give them the opportunity of sitting on the committee. She broke out into that great big laugh of hers and said – you're it buddy – no one else will do it. I knew that really wasn't true, but Mary Lou wanted me to stay involved and I think wanted to maintain that connection we had at the school.

Remembering Mary Lou Karley

By Doug Parsons RSW



*...In every aspect
of her life she was
a leader, a mentor
and a teacher.
Mary Lou always
gave 100% to
everything she
did...*

Continued on page 3...

CANSW VOICE

Table of Contents

Mary Lou Karley Mentorship Award.....	3 & 4
Jane Dicks Award.....	5
President’s Message.....	6
2010 CANSW Conference.....	7
Call for Abstracts & Posters	8
Kidney Foundation of Canada	9
Renal Social Work Case Review	10
Relaxation Therapy	14
Renal News: Italy.....	18
Kidney March	19
Renal News: Norway	20
Renal News: Belize	21
Early Development of Dialysis and Transplantation	22
McGill Program in Whole Person Care	27
Drug Seeking Under a New Lens.....	28
Renal News: Atlantic Ocean	30
Employment Opportunity	30

Message from the Editor



Lyle Stockwell MSW, RSW

I hope you enjoy this edition of the CANSW Voice as much as I enjoyed putting it together.

I welcome your contributions (and for a select few, I **demand** it—you know who you are).

Let’s hear about what’s happening in your area, your research, or about interesting cases you want to share.

I also expect to have regular contributions from The Kidney Foundation, and reports from the CANSW Executive and Regional Reps.

I’d like to add a personal touch as well. In a section called **Member’s Milestones** I will report on big events in members lives. Getting married? Have a new job? A birth or adoption? New degree?

Please let me know!

Your feedback is also welcome.

Contact me at: lstockwell@lakeridgehealth.on.ca
(905) 576-8711 ext.6913

Mary Lou Karley... continued

A couple of days before she was admitted to hospital we were chatting. Negotiating over which of us would do what with the Kidney Foundation. We eventually got around to talking about my student. Mary Lou had supervised her for the first 7 weeks of her placement when I was off ill. I asked her what the heck did you do while I was off – she's a third year student and she's assessing her own process recordings – you can imagine the roar of laughter that produced.

Mary Lou was a terrific juggler. She was able to juggle work, family, community and volunteer work and make everyone feel like they were what was important to her. She always had whatever time they needed for them. But she also was able to keep parts of her life very separate. Although I had heard about her Spencer Hall girlfriends from university and her CAS friends for years, I had never met any of them except one mutual friend. I think Mary Lou kept us from meeting each other for fear of us sharing some of our stories about her – and probably there was a little part of her that knew she wouldn't be the boss of us once we'd all met!!

When Mary Lou died I had the privilege of being present with her. What immediately struck me was that the other 5 friends that were there were the friends from the other 2 long time group of friends that I had heard about all these years. Mary Lou's death reminds us to tell the people we love and care about how much they mean to us and how they've touched and impacted our lives – not to wait – because tomorrow might be too late. Mary Lou touched and had an impact on all our lives – I hope she knew just how big an impact she had.



Mary Lou Karley Mentorship Award

This award is being initiated in 2009 to recognize the outstanding Mentorship contributions made by a CANSW member in the field of Canadian Nephrology in the memory of the late Mary Lou Karley. Mary Lou was a pivotal person in the history of CANSW. She was a transplant social worker at London Health Sciences Centre-University Campus and one of the founding members of CANSW. Her career path took her to the School of Social Work at King's University College and she continued to be a devoted supporter of CANSW.

She was a part of the Executive of CANSW for many years, held the position of National President of the Kidney Foundation from 1999-2001, and had numerous leadership roles. She remained committed to helping patients and families with renal disease. Her compassion and caring nature extended as well to all of her colleagues, in the renal and teaching worlds. She was truly a remarkable presence and has made a difference in many lives. Mary Lou was committed to helping others achieve their potential. Sadly, Mary Lou passed away unexpectedly in March 2009. She has left a footprint on the hearts of many social workers across Canada.

The *Mary Lou Karley Mentorship Award* had its inaugural appearance at the 2009 London CANSW Annual General Meeting (see page 4 of this newsletter).



Congratulations to Karen Ahola—First Recipient of the Mary Lou Karley Mentorship Award

Karen Ahola worked as a Renal Social Worker for 27 years with the Southern Alberta Renal Program (SARP) until her retirement in April of this year. When Karen began her work she was the only Renal Social Worker for Southern Alberta. Her responsibilities were to work with Inpatients, Outpatients, PD, HD, CKD, Transplant and Living Donor. She traveled throughout the Region and her car was her office.

Using Statistics, questionnaires, and scales she made use of anything which would document what we do and the impact of Social Work. These efforts and her own credibility furthered the role of Social Work in Southern Alberta. Today there are 10 Social Workers involved in Renal Care.

She was a mentor to new Social Workers entering the Renal field and strongly committed to education and research. She partnered with Researchers at Southern Alberta Institute of Technology and the University of Calgary to develop Quality of Life Surveys and questionnaires which were sensitive and valid measurements. These are tools which are useful to the Patient and Social Worker for ongoing assessment.

Karen was a member of numerous committees. She was the Chair of the Social Work Education Committee for several years and a member of the Renal Executive Committee for Southern Alberta. She also had a key role in the development of Standards of Practice for Renal Social Work in SARP. Karen is a registered Family Therapist whose therapeutic skills with individuals, couples, and families, continues to set the bar for Social Work here in Alberta.

She maintained membership in CANSW and NANSW which she promoted as valuable resources to Renal Social Workers. She was a presenter at the Vancouver CANSW Conference, along with her Colleague Colleen McShea. They presented a High Risk Screening tool being utilized by SARP, to help determine the extent of Social Work intervention needed with Patients. She was instrumental when SARP went electronic with charting, in ensuring that appropriate Social Work fields were in place.

Karen also was engaged in promoting the Kidney Foundation. She would attend various social functions, particularly those that involved recognition of Patients or Colleagues.

2009 Jane Dicks Award Winner

Diane Boisjoli

Congratulations Diane!

The Jane Dicks Award is presented as an acknowledgement of significant achievement within the profession of

Nephrology social work in Canada.

It is a recognition, by the community of Nephrology social workers, of outstanding contribution made by an individual Nephrology social worker.

We have included a SMALL sample of the comments made by Diane's colleagues:



“Diane has been working in Nephrology at the Ottawa Hospital for over ten years.”

“Her contribution in enhancing the quality of life of transplant patients has been widely recognized by both the multidisciplinary team and the patients themselves.”

“Apart from being a great asset to the team, she has been very active with CANSW as a treasurer from 2005 to 2008, during which time she was also on the planning committee for the annual conferences. She took over as regional representative this year to fill a maternity leave, and has been CANSW regional representative previously as well.”

“She has been a supervisor for field placements for many university students.”

“Diane's generosity and commitment extend beyond the hospital walls. In her free time she mentors a young boy, in addition to assisting a woman with multiple challenges. Promoting equality and quality of life for people of all abilities, sexual orientations, ethnicities, genders and socio-economic levels is just part of who Diane is.”

“Diane is a caring and compassionate in her role as a transplant social worker as she assists patients and their loved ones navigate the health care system before and after transplant. She is extremely devoted to her work and goes beyond what is expected.

Her decisions and actions are always guided by what she believes is best for the patient. She ensures that patient needs are addressed.”

“Diane is a great advocate! She will not hesitate to go to great lengths for patients to get access to resources or services, including at the government level. It is not uncommon to see people lined up out her door as they wait to talk to her.”

Thank you Diane!

Welcome to the January 2010 edition of The Voice! I have missed our CANSW newsletter and am thrilled that Lyle Stockwell has taken on the role of editor and brought it back to us. Thank you so much Lyle for all of your hard work! It is very much appreciated.



Dianne Kurina RSW
President, CANSW—ACTSN

We have many things to look forward to in the year ahead, including:

The Development of a Joint Task Force on Transportation with the Kidney Foundation of Canada. This is a very exciting collaboration between the Kidney Foundation of Canada and CANSW! As we all know, transportation is an ongoing concern for patients living with kidney disease and their families across Canada. While there are many similarities in the obstacles they face on a national level, there are also some vast differences in the barriers they encounter from region to region. The goal of this task force will therefore be to address transportation concerns from both a national and regional perspective. While the task force is only in the early stages of its development at this time, it promises to be a very progressive approach to addressing a longstanding issue for us all. We will be looking for your assistance in the future... Stay posted for more news on opportunities of how you can become involved!

A New Look and Feel to the CANSW Website. Gary Petingola is hard at work as we speak with our website designer to create a new and refreshing site for us all. Included in this will be a bright, shinier, and easier to use Tool Box. Special thanks to both Gary Petingola and Corinne MacNab for all of their efforts... We can't wait to see our new place! Keep in mind though that this reconstruction will take a little time. We will be sure to let you know how things are progressing.

Our 32nd Annual CANSW Conference in Banff, Alberta. You just have to come see one of the most beautiful places in the world! Our annual conference is being held in the Canadian Rockies this year. Come join us for an amazing conference and even more amazing scenery. More details about the conference are included in this issue of The Voice!

CANSW members can also look forward to ongoing communication, networking and support amongst their colleagues over the CANSW listserver. So, if you haven't had a chance to renew your CANSW membership for 2010, what are you waiting for?

As always, the CANSW Executive and Regional Representatives are looking for your feedback and ideas. If you are interested in becoming more active in CANSW, looking for CANSW's support of a project you may be working on that has a national flavor, or just wanting to touch base with us, remember we are only an email or a phone call away. CANSW is what you make of it... Please make the most of it!

Dianne



2010 CANSW Conference
October 14 -16, 2010 Banff Park Lodge
More details in future issues.

We invite you to join us in beautiful Banff, Alberta to explore the Ethics we face in our daily work with renal patients and families within a complex health care system. **Please note the minor date change from previously advertisements.**



Our keynote speaker is Sara Davison, MD, FRCP(C), Nephrologist from University of Alberta who will help us investigate the process of how nephrologists, social workers and other multidisciplinary staff can work together as a team in fostering good decision making with renal patients and families. Dr. Davison will also present on ethical considerations in pain management and renal disease.

Also, we are privileged to have Bashir Jiwani, PhD, Ethicist and Director of Fraser Health Ethics Services in British Columbia. Dr. Jiwani will discuss bringing ethics to life in a renal program – from bringing ethics decision tools to clinical and system-level decision-making, to providing ethics education support to the various players within a renal program. Ethics in a multicultural society and pandemic planning are also some of the planned themes of his workshop.



In addition to these respected colleagues, we will be inviting our CANSW colleagues to submit oral or poster presentations to round out this thought-provoking conference.

Conference committee members include: Shirley Pulkkinen, Sault Ste. Marie, ON; Dianne Kurina, Lethbridge, AB; Gordon Smith, Edmonton, AB; Neil Thompson, Calgary, AB; and Lee Woytkiw, Calgary, AB

**CANSW 2010 Call for Abstracts for Oral
Presentations and Poster Presentations
DEADLINE: APRIL 30, 2010**



We are inviting CANSW members to submit abstracts for presentation at the Annual Conference in **Banff, Alberta, October 14-16, 2010**. Our conference theme this year is **“Ethical Mountains in Nephrology Social Work”**.

Our CANSW membership has voiced the wish to have more expertise presented from our professional group. A small honorarium of \$100 is provided for all accepted oral presentations and \$25 for original poster presentations. Presentations may be in any area of nephrology social work and do not need to be limited to an ethical focus. Oral presentations should be limited to ½ hour to 45 minutes. If you are interested in sharing with your peers, please submit the requested information to:

Lee Woytkiw, Nephrology Social Worker
Foothills Medical Centre
Clinical Support Services
1403 - 29th Street N.W.
Calgary AB T2N 2T9
Phone: (403) 944- 8790 Fax: (403) 270-3692
lee.woytkiw@albertahealthservice.ca

ABSTRACT AND POSTER PRESENTATION

Please indicate what type of presentation you are submitting:

- Oral Presentation in the area of _____
- Oral Presentation in the area of patient case studies
- Poster Presentation regarding _____.
- Poster Presentation in the area of patient case studies.

Title:

Synopsis of the Presentation:

Handouts:

Equipment Required:

Presenter:



The Kidney Foundation of Canada pleased to collaborate with CANSW on transportation



The Kidney Foundation of Canada is looking forward to collaborating with CANSW on the important issue of transportation for dialysis patients. I am very pleased that CANSW and the KFOC are in the process of establishing a joint task force to explore and strategize around the ongoing transportation issues faced by renal patients and their families across Canada. I am sure that many renal social workers and renal patients can help the task force understand the issues and identify solutions.

The mission of The Kidney Foundation is to reduce the burden of kidney disease. Travelling to and from dialysis appointments is certainly a major burden for many dialysis patients and their families, especially for those living in rural areas. Even patients living close to their dialysis centre may be overwhelmed by the challenge of getting to and from their appointments if they are frail or if they do not have a caregiver who can give them a ride.

Following up on the discussion of this chronic issue at the CANSW Conference in October, we were pleased to explore with Dianne Kurina, CANSW's President, ways by which CANSW and The Kidney Foundation could collaborate on the challenge of transportation. We noted that in most provinces, the support for transportation is insufficient to meet the need.

We realized that The Kidney Foundation's short-term financial assistance program was not designed, and is not able, to adequately respond to what is often an ongoing need. Even the income tax deduction for medically necessary travel excludes many dialysis patients whose regular trip falls under the minimum length but proves, over a year, to be a major cost. We realized that in this era of large government deficits, we are going to have to be persuasive if we are to succeed in making a case to government. We will have to be creative in order to identify solutions, but we are confident that improvements can be made.

The new joint task force is an important collaboration for The Kidney Foundation, as we value our relationship with CANSW and with renal social workers across the country, and recognize that in many ways we have similar goals. We are very appreciative of the essential role played by renal social workers, and of the challenging circumstances in which many of you work.

If ever you wish to share suggestions or questions with me regarding The Kidney Foundation, please do not hesitate to contact me.

Yours truly,
Paul Shay
National Executive Director
The Kidney Foundation of Canada
514.369.4806 or 1.800.361.7494 x228
paul.shay@kidney.ca

**Kidney disease
can affect anyone.**

March is Kidney Health Month.
Please give generously.

Because we're
behind you all the way.

www.kidney.ca



The foundation of kidney care.

Renal Social Work Case Review: ETHICS: A Case of We're Damned If We Do, We're Damned if We Don't

Submitted by Shirley Pulkkinen RSW

John was a fellow in his early 60s, living in the chronic care section of our hospital. He had diabetes, an amputated leg, was visually impaired and was on hemodialysis three times weekly for about two years. Being a little "rough around the edges" was his usual persona. He was on disability from the mill where he worked, thus received a substantial pension along with his CPP. He was legally separated from his wife, although he had her listed as next of kin and she also had legal power of attorney for property for him at his request.

All John wanted was to get out to the river to go fishing from his wheelchair. He really had little in the way of pleasures left in his life as he was always fatigued. He was estranged from his daughter who lived out of town, however his ex-wife and his son regularly visited with him. He mentioned to me several times that he asked his ex-wife to get him a fishing rod, but, she was always too busy to accommodate his request. He was also anxious to get his income taxes completed, and, was continually asking the ex-wife to bring in the income tax receipts for the accommodation bills in order to get back his substantial taxes...or so he thought.

John finally asked me to contact the Patient Billing department to get copies of the receipts so he could file his income taxes.

Shortly after the request, the ex-wife happened to pop into my office to chat and share what was going on in her life. She cheerfully told me that she had bought herself a new refrigerator and bought her son a new used car...all with John's income over the past few months. The ex-wife was in receipt of her own disability pensions and had lived on her own for many years from John. She was quite exuberant in suddenly paying off all of her debts. She was finding great material comfort in this new financial lease on life. She proudly stated that she had told the hospital that she was reliant on John's income, so, according to government regulations, he did not have to pay for his accommodation. So she felt justified in spending his income as she saw fit as she had put up with his miserable nature for so many years.

Not only did she fully admit to committing fraud against the hospital, but, as the Power of Attorney for Property for her ex-husband, she had misinformed John of how she was spending his income.

As the ex-wife quite literally bounced out of my office, I sat there dumbfounded. Here was my patient who fully believed that he was paying rent and would receive tax receipts to finally get that fishing rod.

Do you have an interesting case to share?

CANSW Voice is accepting your cases for publication.

He had so little in the way of a quality of life, and here were trusted family members taking advantage of his vulnerabilities, who lied to him directly, and also lied to the system that cared for him.

Let me not forget in stating that John was VERY competent in managing and directing his own care. He just preferred to have the ex-wife take care of the banking end of things due to his difficulty getting around.

What to do? An ethical dilemma. I have information that is extremely important to two other parties.

Continued next page...

Renal Social Work Case Review continued...

Do I withhold the information from the patient to protect him from the realization that he is being stolen from? Do I inform him and jeopardize any relationship that he has remaining with these few family members? Will my information cause more harm than good? But will the family members continue stealing from him if I don't? Do I inform the hospital (who is my employer) of the fraud occurring? What will be the impact on the patient? Will there be charges put upon the family?

Because John had requested that I get a copy of the tax receipts, I contacted the Patient Billing department. My colleague confirmed my understanding, that, the patient had not been charged for the last 5 months of accommodation because of misinformation given by the family. And he would NOT be getting any tax receipts. And there went his dreams of a new fishing rod.

I continued to struggle internally with the knowledge of all of the wrong in John's situation. And truly felt that the information would be devastating to him. I reluctantly went to see him at dialysis and informed him of the ugly truth. I had never seen someone so crestfallen...there was no other word for it. Disappointment, disbelief, dejected all rolled into one. The look on his face as he realized that he had put all of his trust into this one person to have it so blatantly twisted into half truths and deception. His vulnerabilities were there for me to witness in its rawest form.

Over the next two weeks, we had some business to complete. John wanted to right the wrong with the hospital and ensure that he would be paying accordingly. He asked me to accompany him to the bank to remove the ex-wife from the books as cosigner. The ex-wife initially came into see me to angrily confront me with my handling of the information. When I calmly remarked that the hospital could be considering coming after her for the over \$6000 in arrears, she hastily retreated from the unit and did not darken my doors again.

John came into dialysis one day still feeling emotionally beaten by the deceptions and handed me a letter mailed to him. He was visibly fatigued, with very little energy or vitality. The piss and vinegar in him was gone.

The letter was from his estranged daughter who had not talked with him for many years. Because John had diabetic retinopathy, he could not see the words on the page. He had asked the hospital chaplain to read it to him, and, the chaplain refused. So John brought it to me. In reviewing the first few paragraphs, it seemed the daughter was doing some self-work in regards to her past relationship with her father and chose this time to confront her father. I did not need to read to the end of the two page document to realize that their relationship indeed had been a toxic one which some thirty years later was still causing anguish in the daughter.

I chose this time to gently refuse to read the letter to him. I explained that his daughter was very angry in the letter and I felt he had been through enough in the last two weeks to allow himself a break from the emotional attacks. I promised I'd read the letter after the Christmas holidays when he was stronger.

I continued to struggle internally with the knowledge of all of the wrong in John's situation.

And truly felt that the information would be devastating to him.

Continued next page...

Renal Social Work Case Review continued...

Three days later John was dead. Although medically John's death is not surprising when one considers his multiple co-morbidities, however instinct tell me that the ethics of disclosure had literally caused a broken heart, one that couldn't be repaired. He could conceivably have lived for another six months or so.

Instinct also tells me that NOT reading him the letter was the kinder thing to do; that hopefully any therapeutic benefit that the daughter received was in the writing and mailing of the letter and in BELIEVING it was read by Dad.

The ethics that confront us in dialysis life varies. Life and death. Truths and untruths. I periodically review this patient in my mind and ask if I would have done anything differently, and, sadly realize that there was nothing I could do differently. I just continue to stand and support each patient, no matter how wonderful or how miserable of a human they have been in the past. And try to balance this world with kindness when the world has a tendency to be so very harsh.

The Silent Cry

As I watched the life slowly fade away
I could see her desperately fight for her life,
Time was so precious as each moment went by
I was beginning to see the silent cry of the heart,
And the pain of all the loved ones that stood by
I was finding myself beginning to feel,
The pain deeper within my own heart
The many thoughts were rushing through my own
mind,
God, I wanted to cry out, when does all the pain
end
I knew I had to stop thinking about it,
But it was too late, the tears had already started
To run down the side of my face,
My throat was starting to get drier
As my heart began to pour out,

Wasn't there anything they could do
I couldn't stop thinking about it,
Oh God as I began to pray for the life that lay be-
fore my eyes
Where does all the answers lie,
When will all the pain stop
They were only the few questions asked,
The day was long and the night was near
And the hope for another day was only just a
dream,
Because the night had stolen the pain
We both had shared that day.

John A. Gilbert . written after receiving kidney
transplant after being on hemodialysis.

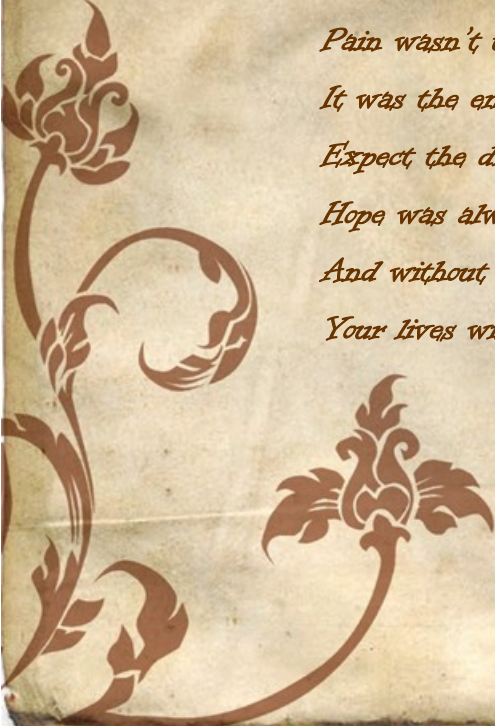


Hidden Pain

*Waking up feeling more alive
As if deep down inside of me
My spirit was telling me it's okay
My body was weaker than usual
But, knowing things were going to change
Maybe not today but in time
I knew we had to keep telling ourselves we could go on.*

*Days weren't always so easy
There were times we all felt like giving up
But, giving up was so easy to do
I was beginning to feel if it wasn't for the treatment
Life was slowly going to disappear and die.*

*I didn't like to think about my life or what I could do to change it
Because I easily felt that suicide was the best way to end the pain.*



*Pain wasn't the hardest part of the treatment
It was the emotional part of having to
Expect the different changes in life
Hope was always the best answer to turn to
And without that special kind of hope within yourself
Your lives will slowly burn away like the light of a candle.*

John A. Gilbert

*Written just after receiving a kidney
transplant after being on hemodialysis*

Fistulas, Fluid Restrictions, Frustrations and Phobias –Unleashing Relaxation Therapy Applications within the CKD Trajectory

Gary Petingola RSW

*I am scared.
I don't know what I am scared of,
I am just scared.
I am scared of imminent dialysis.
I'm scared of delayed dialysis.
I am scared of examining my
candidacy for peritoneal dialysis.
I am scared of doing dialysis
treatments at the hospital.
I am scared of losing the protec-
tion and security that exists in my
world as I know it by choosing
home renal replacement therapy.
I am afraid of being accepted for
Kidney Transplant.
I am afraid of being rejected for
Kidney Transplant.
I am scared of what
will happen if I do.
I am scared of what
will happen if I don't.
I am scared, scared, scared.
I am scared of everything.
I am scared of needles,
tubes, machines.
I am scared of my own fragility,
and dependence.
I'm scared of living.
I'm scared of dying.*

Frontline Nephrology Social Workers understand the complexity and issues that are faced by patients with Chronic Kidney Disease. These patients are often coined “the sickest of the sick”, referring to their co-morbidities and the psychological ramifications of their illness. They are indeed vulnerable.

- *They feel that their bodies and their lives are out of control*
- *They feel overwhelmed by fears and worries, often caused or compounded by painful family relationships*
- *They are suffering both physically and emotionally*
- *They are often frustrated with the medical system*
- *They are overwhelmed by feelings of anger and guilt*
- *They deeply lack self-confidence and self-esteem*
- *They have often been exposed to physical and psychological trauma*

(Adapted Frey 2003)

Kabat-Zinn 1990

Continued next page...

Relaxation Therapy continued....

Additionally Nephrology patients must learn to adapt to life with Chronic Kidney Disease, life sustaining treatment, uncertainty and obstacles that engulf them along their journey. They are distressed by:

Illness Effects

Family dynamics

Dietary constraints

Time restrictions

Functional limitations

Financial constraints, expenses and worries

Changes in employment

Complex relationships with staff

Role change / changes in self-perception

Change in sexual functioning

Medication effects

Awareness of impending death

Cukor , Cohen, Peterson, Kimmel 2007

It is therefore not surprising that depression is thought to be the most common psychiatric abnormality in patients with ESRD treated with Hemodialysis, with rates as high as 30% in some dialysis centers. Furthermore depression may be associated with worse medical outcomes, including increased mortality.

Kimmel, Cohen, Peterson 2008

Likewise the literature suggests that the rate of suicide is approximately 15 times greater than that in the general population for patients on Hemodialysis.

Neu & Kjellstrand 1986

Relaxation Therapy is a complementary therapy under the framework of mind body intervention. It is used together with conventional medicine and can be helpful with the amelioration of anxiety, sleep disturbance, fear, pain and symptomatology, often associated with Chronic Kidney Disease. Barnes, Bloom & Nahin 2008

The definition of Relaxation Therapy includes induction techniques which are targeted to induce a relaxed physical and mental state in the patient usually obtained by the implementation of deep breathing, progressive muscle relaxation with or without guided imagery/ visualization, hypnosis and autogenic training. Additionally the therapist may utilize Mindfulness meditation and Loving Kindness values to augment the intervention.

Relaxation Therapy techniques can be taught to patients, caregivers and staff affected by Chronic Kidney Disease in an effort to strengthen regime adherence as well as treat and prevent distress. Relaxation Therapy can be beneficial in promoting enhanced quality of life for many of our patients, caregivers and staff.

Relaxation therapy introduces our clients to a tangible skill which they can master and use independently, facilitating autonomy and control. Relaxation therapy provides the opportunity to experience profound life altering adaptation, affirmation and empowerment

Merighi 2004

At the Sudbury Regional Hospital's (HRSRH) Nephrology Program in Sudbury, Ontario Canada relaxation techniques have been successfully utilized to assist Nephrology patients and their support system throughout the Chronic Kidney Disease trajectory.

“Relaxation Therapy helped me to go onto the machine. At first I did not believe in it. After a while tried relaxing and realized it worked.”

(Nephrology patient)

Continued next page...

Relaxation Therapy continued....

At the HRSRH two separate qualitative studies were completed in 2006 and 2008 to examine the effectiveness and longevity of relaxation techniques over an extended period of time. Patients, caregivers and staff who had been taught relaxation skills were surveyed to determine if the relaxation techniques continue to be utilized, effective and recommended to others.

Survey results suggested that respondents were overwhelmingly pleased with Relaxation Therapy as an effective intervention to assist with the amelioration of anxiety, sleep disturbance, fear of needles, difficulty coping, fear of dialysis, pain control and caregiver stress.

(Petingola, 2006, 2007)

“I was terrified about having dialysis and I had asked for tranquilizers and my renal social worker helped me through with relaxations sessions... they helped me through it.”

“Relaxation Therapy helped me to relax before surgery and saved my life when I had severe depression and thoughts of suicide.”

“Relaxation should be part and parcel of overall treatment strategy”.

“After 3 sessions with my renal social worker I was able to relax more on my own and am sleeping better and longer now. The deep breathing and visualizations help to ease the stress I build up from worrying and care giving”.

Subsequently in October 2008 a survey (N=159) to the Council of Nephrology Social Workers (CNSW), Canadian Association of Nephrology Social Workers (CANSW) and American Nephrologists was conducted to investigate:

- Is Relaxation Therapy used as a psychosocial intervention by Nephrology Social Workers?
- Is there a fundamental belief that Relaxation Therapy is credible as an evidence based practice?
- Is there a willingness or interest in implementing relaxation therapy to frontline practice?
- What are the perceived barriers of implementation?

The majority of CANSW and CNSW respondents reported that there was an absence of health care professionals providing Relaxation Therapy techniques to patients and caregivers (62.6% of CNSW members and 73% of CANSW members indicated not providing Relaxation Therapy in their setting).

Overwhelmingly Nephrology Social Work respondents reported that they would like to see the implementation of Relaxation Therapy in the overall treatment plan (CNSW 92% and CANSW 97.6%).

66.3% of CNSW respondents feel well equipped to offer Relaxation Therapy to patients and caregivers.

28.6% of CANSW respondents feel well equipped to offer Relaxation Therapy to patients and caregivers.

Continued next page...

Relaxation Therapy continued....

The primary barriers to providing Relaxation Therapy to patients and caregivers as indicated by survey respondents are:

- Lack of time (79.4% CNSW and 67.5% CANSW)
- Lack of skill / knowledge (61.0% CNSW and 42.2% CANSW)
- Lack of a necessary quiet environment (77.3% CNSW and 80.5% CANSW)
- Lack of support / “buy in” from the nephrology team (44.8% CNSW and 50.0% CANSW)

(Petingola, 2009)

Nephrology Social Workers can implement Relaxation Therapy as a standard therapeutic intervention in clinical practice. At the HRSRH, this modality has been successfully utilized for Nephrology patients in preparation for and during surgical interventions (e.g. T- tube insertions, Femoral Access, Fistula creation, etc.).

When surveyed, Nephrology Social Work respondents made many comments suggesting the need for enhanced training and the opportunity to practice Relaxation Therapy techniques so as to develop skill and comfort.

A Pre-conference workshop at the upcoming National Kidney Foundation’s Spring Clinical Meeting (CM10), April 13th -17th, 2010 in Orlando, Florida, USA - **Fistulas, Fluid Restrictions, Frustrations and Phobias – Unleashing Relaxation Therapy Applications within the CKD Trajectory** will strengthen the skill set of Nephrology Social Workers in the application of relaxation techniques targeted towards adjustment, trauma and overall enhanced quality of life for persons affected by CKD.

This pre-conference workshop will provide the attendees with opportunity to:

- Practice Relaxation Therapy to improve current clinical practice with enhanced confidence and skill set
- Dialogue and reflect with Nephrology colleagues in understanding how Relaxation Therapy can be maximized as a strategic treatment option with diverse physical and emotional trauma
- Be introduced to the power of Relaxation Therapy as a mechanism for self care

Relaxation training is the most commonly investigated and clinically used intervention in this field. Advantages of relaxation training are that it is inexpensive and has few if any negative side effects (Lader and Mathews, 1970).

*It is generally easy to learn and readily accepted by the patient. (Luebbert, Dahme and Hasenbring,*2001)*



Fistulas, Fluid Restrictions, Frustrations and Phobias – Unleashing Relaxation Therapy Applications within the CKD Trajectory

Gary Petingola RSW

For information about the Pre-conference workshop, please visit:

<http://www.kidney.org/news/meetings/clinical/program/SW%20-%20Relaxation%20Agenda.cfm>

Renal News Around the World: Italy

Sexual Dysfunction in Women During Dialysis and after Renal Transplantation

Abstract:

Introduction Disorders of the reproductive system and menstrual abnormalities often associated with loss of libido and inability to reach orgasm are common in adults of both sexes with an end-stage renal disease. These symptoms may significantly contribute to depression and reduce the sexual activity of women.

Aim To determine if sexual function, as well as hormonal status, improves after kidney transplantation, comparing a group of pre-menopausal women during dialysis and after a successful renal transplantation.

Methods We enrolled 58 women that received kidney transplantation. Patients included were 18-45 years old, on hemodialysis for more than 6 months following a fully functioning kidney transplantation, and on a stable corticosteroids immunosuppressive regimen for at least 6 months. All women underwent a general and urogynecological examination, a hormonal profile determination, and filled out the Female Sexual Function Index (FSFI) and a Beck Depression Inventory questionnaire administered during dialysis and 12 months after transplantation.

Main Outcome Measures We evaluated the prevalence of Female Sexual Dysfunction according to the FSFI cutoff points, sexual hormonal status, and menstrual status during dialysis and 12 months after kidney transplantation.

Results Nineteen out of 58 women left the study prematurely. Thirty-nine women (mean age 36 ± 5.9 years) completed the study. A total of 74% of the patients had menstrual disturbances during dialysis, as opposed to 45% after transplantation ($P < 0.001$). Sixteen out of 39 (41%) patients acknowledged having an active sexual life during dialysis. Thirty-four out of 39 (88%) transplanted patients acknowledged having an active sexual life (Fischer's exact test $P = 0.000039$). The hormonal profile and FSFI results improved significantly after transplantation.

Conclusion This study demonstrates that a successful transplantation should improve the sexual life in women with chronic renal failure.

Filocamo MT, Zanazzi M, Li Marzi V, Lombardi G, Del Popolo G, Mancini G, Salvadori M, and Nicita G. Sexual dysfunction in women during dialysis and after renal transplantation. J Sex ed 2009;6:3125-3131.

Keywords: [Female Sexual Function](#); [Dialysis](#); [Kidney Transplantation](#); [Female Sexual Hormonal Profile](#); [Pre-menopause](#)

Document Type: Research article

DOI: 10.1111/j.1743-6109.2009.01400.x

Affiliations: **1:** Careggi University Hospital—Renal Unit, Florence, Italy; **2:** University of Florence—Clinica Urologica II, Florence, Italy; **3:** Careggi University Hospital—Neurourology, Spinal Unit, Florence, Italy

**WELCOME TO THE
FRONTIER OF HEROISM**



KidneyMarch

3 Days. 100 Kilometres. 1 United Front Against Kidney Disease.

www.KidneyMarch.ca
(866) 9 KMARCH



The Kidney Foundation is putting kidney disease and organ donation on the map in a big way and your CANSW President, Dianne Kurina is going to be there!



www.kidneymarch.ca

Stay posted for news of Dianne's progress or, better yet, join her by participating as a fellow marcher, volunteering at the event, or sponsoring your CANSW President on the website!

Renal News Around the World: Norway

Benefit of kidney transplantation beyond 70 years of age

Kristian Heldal^{1,2,3}, Anders Hartmann^{2,3}, Diana C. Grootendorst⁴, Dinanda J. de Jager⁴, Torbjørn Leivestad⁵, Aksel Foss⁶ and Karsten Midtvedt²

¹ Section of Nephrology and Endocrinology, Clinic of Internal Medicine, Sykehuset Telemark, Norway ² Section of Nephrology, Medical Department, Oslo University Hospital Rikshospitalet, Norway ³ Faculty of Medicine, University of Oslo, Norway ⁴ Department of Clinical Epidemiology, Leiden University Medical Centre, The Netherlands ⁵ Institute of Immunology, Oslo University Hospital Rikshospitalet, Norway ⁶ Division of Surgery, Section for Transplantation, Oslo University Hospital Rikshospitalet, Norway

Correspondence and offprint requests to: Kristian Heldal; E-mail: kristian.heldal@sthf.no ; kri-held@online.no

Abstract

Background. Kidney transplantation generally improves long-term survival in patients with end-stage renal disease. However, in patients older than 70 years of age, only limited data are available that directly compare the potential survival benefit of transplantation versus dialysis.

Methods. All patients aged above 70 years who started dialysis between 1990 and 2005 and were waitlisted for kidney transplantation were included in the study. They were categorized according to time periods of inclusion (1990–99 vs 2000–05). Survival rates of altogether 286 dialysis patients were analyzed with a Kaplan–Meier model, as well as with a time-dependent Cox model. Comparisons were made between those who received a transplant and those who did not, and further between the two time periods.

Results. Median age at inclusion was 73.6 years (interquartile range 72.3–75.6). Two hundred and thirty-three patients (81%) received a kidney transplant during follow-up. Transplant recipients experienced an increased mortality in the first year after transplantation when compared to waitlisted patients. Patients starting dialysis between 1990 and 1999 had no significant long-term benefit of transplantation; HR for death 1.01 (0.58–1.75). In contrast, there was a substantial long-term benefit of transplantation among those starting dialysis after 2000; HR for death 0.40 (0.19–0.83), $P = 0.014$.

Conclusions. Survival after kidney transplantation in patients over 70 years has improved during the last decade and offers a survival advantage over dialysis treatment. Our experience supports the use of kidney transplantation in this age group if an increased early post-operative risk is accepted. This transplant policy may be challenged for priority reasons.

NDT Advance Access published online on December 27, 2009

Nephrology Dialysis Transplantation, doi:10.1093/ndt/gfp68

© The Author 2009. Published by Oxford University Press [on behalf of the ERA-EDTA]. All rights reserved.

This is an Open Access article of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by-nc/2.0/uk>) which permits unres distribution, and reproduction in any medium, provided the original work is properly cited.

• [Oxford Journals](#) > [Medicine](#) > [Nephrology Dialysis Transplantation](#) > [NDT Advance Access](#) > [10.1093/ndt/gfp681](https://doi.org/10.1093/ndt/gfp681)

Renal News Around the World: Belize

Dialysis patients, Kidney Association Cry for Help



[Author: Adele Ramos - adelescribe@gmail.com](mailto:adelescribe@gmail.com)

This is an edited version of an article that originally appeared in the December 16, 2009 **Ambergris Daily**, and is reprinted with permission from the author.

There is growing concern over the level of care being afforded to dialysis patients in Belize, particularly with very limited access to the government's subsidy program and further delays in bringing a new program on stream through the World Organization for Renal Therapies (WORTH).

On Friday, dialysis advocates and a representative of the Kidney Association of Belize met with management of Belize Healthcare Partners, a private hospital that has the only dialysis center in the country, to press their concerns, and they called the media to publicly plea for help, in what has become a worrying situation for them.

Andrea Cox, president of the Kidney Association of Belize (KAB) for the last five years, a kidney transplant patient and diabetic herself, lamented that patients are not receiving adequate care:

“Presently we are having some serious problems because the trained nurse, the dialysis nurse, has decided to resign from the unit, the only dialysis unit we have in Belize; and her main reason for this is that she has been asking for a doctor to work along with her all the years she had been there and did not get it. When the patients go into an emergency situation, everything is on her shoulders. We really asked for a nephrologist, but we are asking now for at least a doctor,” said Cox. ...

Publicly and privately, the KAB and the dialysis patients are pleading with BHPL to resolve the concerns so that they can keep ...[the nurse] who patients say has gone above and beyond the call of duty in caring for them. ...

The KAB's central concern continues to be the absence of a doctor to adequately monitor the condition of patients. ...

Apart from the 21 patients in the government program, said Montejo, there are 5 to 10 private patients who use the center, apart from occasional Americans who come on cruise tours to Belize.

The early development of dialysis and transplantation

From [EdREN](#), the website of the Renal Unit of the Royal Infirmary of Edinburgh

COPYRIGHT INFORMATION from EdREN - please use information from this site freely for non-commercial educational purposes, but attribute it to us, including our website address, www.edren.org This only applies to images and text that are ours, and some images may be excluded (this will be stated in the figure legend). Anything that is not our own should be clearly identified - and where material is credited to others, you must seek their permission if you wish to re-use it.

CANSW has reproduced this information with permission from the EdREN site "as is" for their content only (see above).

CANSW has been unable to locate contact information for all the owners of photos included that are credited to others.

If you are the owner of any images used and wish them removed, please contact the CANSW Voice editor.

Origins of dialysis



Thomas Graham

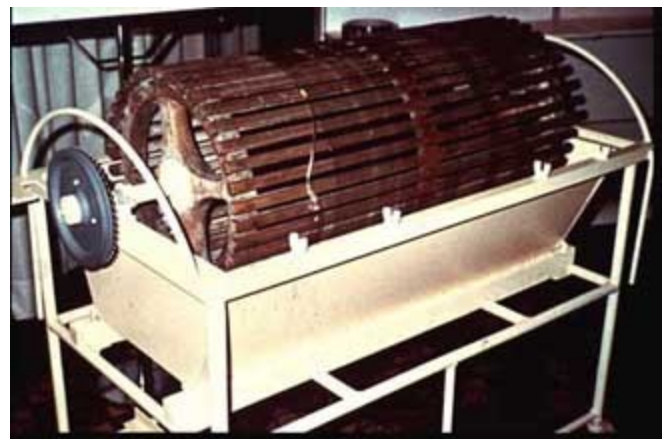
Thomas Graham, Professor of Chemistry at Anderson's University in Glasgow, coined the term dialysis in 1861. He noticed that crystalloids were able to diffuse through vegetable parchment coated with albumin (which acted as a semi-permeable membrane). He called this "dialysis". Using this method he was able to extract urea from urine (Maher JF, 1989).

The introduction of haemodialysis

In 1913, Abel, Rowntree, Turner and colleague constructed the first artificial kidney. They used hirudin, produced from leeches obtained from Parisian barbers, as an anticoagulant. They passed animal blood from an arterial cannula through celloidin tubes that were contained in a glass "jacket". The glass jacket was filled with saline or artificial serum. They coined the term "artificial kidney". Blood was returned into the vein of the animal via another cannula (Maher MF, 1989). The inventors wrote: "this apparatus might be applied to human beings suffering from certain toxic states, especially if due to kidney damage, in the hope of tiding a patient over a dangerous chemical emergency." The apparatus was never used to treat a patient (Robson JS, 1978).

George Haas from Germany performed the first successful human dialysis in autumn 1924. The dialysis was performed on a patient with terminal uraemia "because this was a condition against which the doctor stands otherwise powerless" (Maher MF, 1989). The dialysis lasted for 15 minutes, and no complications occurred.

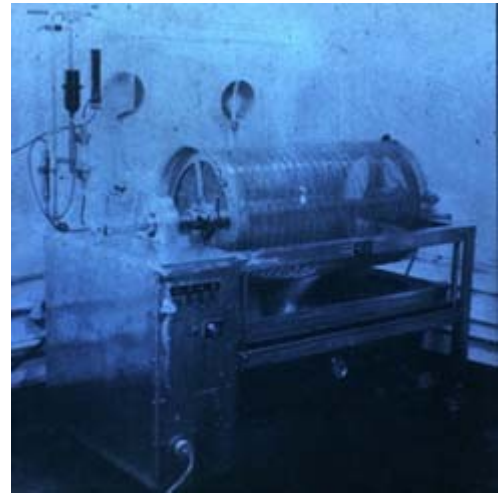
The first practical human haemodialysis machine was developed by WJ Kolff and H Berk from the Netherlands in 1943. This rotating drum artificial kidney consisted of 30-40 metres of cellophane tubing in a stationary 100-litre tank. It was Kolff who made clinicians and experimentalists interested in the treatment of uraemia, and this machine that delivered the effective haemodialysis treatments (Maher MF, 1989).



One of Kolff's first artificial kidneys (1946)
[origin of this picture not known]



An Alwall dialyser in the 1950s. The dialysis tubing was wound around the vertically mounted screen. Dialysate circulated round this at variable pressure. (Courtesy Dr N Hoenich)



The Kolff-Brigham dialyser, 1950, a modified version of the original rotating drum kidney.

In 1946 Nils Alwall produced the first dialyser with controllable ultra-filtration. It consisted of 10-11 metres of cellophane tubing wrapped around a stationary, vertical drum made of a metal screen (Maher MF, 1989) - resembling a rotating drum device stood on its end.



Modified Kolff twin coil kidney (Royal Infirmary of Edinburgh)

The original Kolff rotating drum kidney was modified in Boston to make the Kolff-Brigham kidney. In this form it was successfully used to treat renal failure in a few centres in the early 1950s, and in the Korean war.

In 1956 Kolff and Watschinger developed the principles of the Alwall machine to develop the "twin coil" artificial kidney (illustrated left), a modification of the "pressure cooker" dialyser developed by Inouye and Engelberg in 1952 (Maher MF, 1989).

Haemodialysis in the United Kingdom

1946-47

Kolff gave away several rotating drum artificial kidneys after the Second World War, so that other clinicians can become familiar with dialysis. The Royal Postgraduate Medical School at Hammersmith Hospital, London was among one of those who received an artificial kidney. It was promptly used, but with limited success (Maher MF, 1989). Bywaters and Joeke published a report on 12 patients treated with the artificial kidney at Hammersmith in 1948. Despite their apparently favourable experience as described in their paper, the machine fell out of favour and use, and for a decade the weight of opinion in Britain was that dialysis was laborious, dangerous, and produced no better results than could be achieved by careful control of fluid balance and protein and calorie intake, as promoted in the UK by Bull.

In Leeds, Dr Frank Parsons had to explain to his professor of Medicine and the Board of Governors of the Leeds General Infirmary that he believed in the value of the artificial kidney, when they had already been told that there was no place in British medicine for artificial kidneys. Parsons had spent 3 months with Dr John Merrill in Boston, one of the pioneers of both dialysis and transplantation, learning about the Kolff-Brigham rotating drum dialyser. He convinced his colleagues to buy a Kolff-Brigham rotating drum dialyser for Leeds. He was left with the remarks, "Parsons, try it, but remember that the country is against you." (Parsons FM, 1989) A Kolff-Brigham machine was installed in the Leeds renal unit with the support of the British Medical Research Council.

The beginnings of dialysis for chronic renal failure

The first patients treated by dialysis were all believed to have acute renal failure. The methods in use for getting adequate flows of blood into the machine exhausted veins and arteries very quickly, and only a few dialysis treatments could be undertaken. The development of methods to use blood vessels repeatedly while preserving them made it possible to contemplate keeping a few patients alive for longer periods even though they had permanent renal failure. The arteriovenous shunt, as described by Quinton and Scribner (1960) was the key development. The first substantial programme for dialysis of patients with chronic renal failure began in Seattle in the same year.

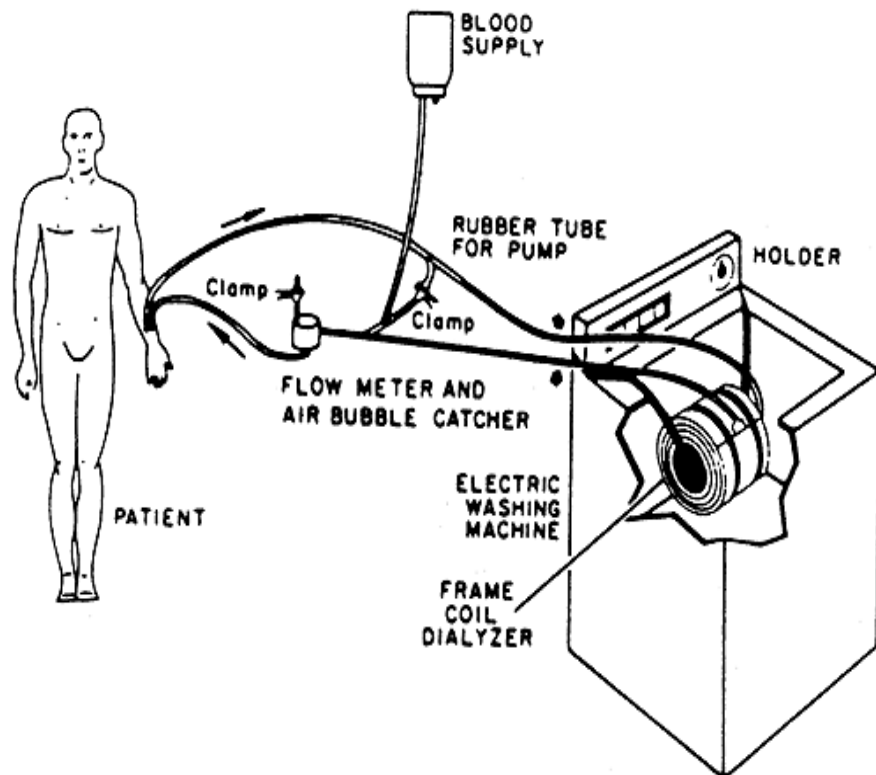
The Brescia Cimino forearm fistula (1966), which did not require exteriorised pieces of plastic, was another major advance. The growth of renal units was under way.

Home haemodialysis

Home haemodialysis was introduced to overcome the difficulties in providing adequate facilities in hospitals for the increasing number of patients being put forward for treatment. If a relative provided help for the patient, it could be carried out without the use of doctors, nurses or hospital premises, extending the number of patients that could be treated, as well as being better for the patient. However in 1965 at the American Society of Artificial Internal Organs meeting, reports of home haemodialysis of four patients in Boston (Hampers et al) and two in Seattle (Curtis et al) were supplemented by a report of two patients treated at home in London (Shaldon). All reported success and plans to expand their programmes.

In the UK outbreaks of hepatitis accelerated home haemodialysis programmes, as it became a priority to reduce the risk of cross-infection.

Also at the ASAIO meeting in 1965, Nose (supported by Kolff) reported the use of domestic washing machines to stir the dialysate, initially in hospitals in Japan. Surely one of the most homely of early accounts, but there are conflicting accounts of whether this amounted to 'home' haemodialysis in Japan in the early 1960s.



Dialysis using a domestic washing machine - Nose and colleagues in Japan in 1961 (above) and the similar programme established with Kolff at the Cleveland Clinic, USA (right) in 1965. The washing machine functioned in a very similar way to the Kolff-Travenol dialysis machine used in Edinburgh. Illustrations courtesy of Dr Y Nose.



Peritoneal dialysis

At the same time, a few patients with chronic renal failure were managed for quite prolonged periods by peritoneal dialysis - but this required repeated punctures of the abdomen each time treatment was given - usually once a week, each time for a prolonged treatment. This was possible because of improved techniques for puncturing the abdomen and maintaining the sterility of the dialysis solutions. The technique was also used for acute renal failure, though in most units peritoneal dialysis is now rarely used for this purpose.

At the same 1965 meeting at which home haemodialysis was first discussed (above), Tenckhoff described a patient treated for one year by home peritoneal dialysis using the repeated puncture technique. 20-22h (60l) of dialysis were carried out once or twice weekly after a visit by a physician to insert the catheter under local anaesthetic. At that time, all attempts to leave an indwelling catheter became complicated by infection. Tenckhoff and colleagues later developed a soft tunnelled catheter that could be left in place, making peritoneal dialysis a viable treatment.

The beginnings of renal transplantation

There has been a long history of the dream of replacing defective organs with healthy ones (Craps L, 1993). In 1933, the first recorded human cadaveric transplant took place in Russia. The first human kidney transplant from an allograft took place in 1936, by U Voronoy (Starzl TE, 1990). In 1954, the first successful kidney transplant between identical twins was performed by the surgeons Joseph E. Murray and J. Hartwell Harrison in collaboration with the nephrologist J.P. Merrill in the Peter Bent Brigham Hospital in Boston, USA (Starzl TE, 1990).

The first kidney transplant in the UK was performed in Edinburgh by Sir Michael Woodruff and his team on 30th October, 1960, between identical twins.

The first successful kidney transplant using an organ taken from a cadaver was in 1962 (Haeger K, 1989), made possible by the development of the first effective drug to prevent rejection, azathioprine.

Living with Kidney Failure: Video Essay from McGill Programs in Whole Person Care

Dawn Allen, PhD, Associate Director Palliative Care McGill & Research Associate, Programs in Whole Person Care, McGill University

Living with Kidney Failure is a film about the lived-experience of seven individuals of different ages, disease histories, and cultural backgrounds. The stories of their dialysis-dependency highlight some of the quality-of-life issues faced by people living with chronic kidney failure. While their experiences are in some ways specific to their disease and treatment, the issues of family strain, unemployment, uncertainty, vulnerability and mortality will be familiar to all those who live or work with chronic illness.

The film is the product of a two-year participatory action research project funded by the Kidney Foundation of Canada and the Donner Canadian Foundation. The project involved researchers from McGill University and patient-collaborators from two university-affiliated hemodialysis units. The film has several different goals: (a) raising awareness about kidney disease in the general public, (b) exploring quality of life and chronic illness issues with health care students and professionals, (c) providing chronically ill people with a larger sense of community (d) offering administrators and health-policy legislators a window into the needs of this rapidly growing patient-population.

In October 2008, we had the honor and pleasure of showing the film at the annual congress of the Canadian Association of Nephrology Social Workers in Quebec City. The audience was moved to laughter and tears during the screening and was full of praise and thanks in our discussion afterwards. In a generous gesture of support, CANSW donated \$1,000 to our project in order that the DVD be translated into French and distributed across Canada. Because of that initial gift from CANSW and the subsequent generosity of other local organizations, we have now distributed 280 bilingual copies of the DVD across Canada. We have sent copies to all of the Schools of Medicine, Nursing, and Social Work; to both the national and local branches of the Kidney Foundation of Canada; and to all of the dialysis units in Quebec. The film was screened as a plenary presentation at the 2009 CANNT congress in St. John and 30 copies were distributed through that organization. CANSW received 50 copies for distribution at its 2009 congress.

In addition to the CANSW and CANNT congresses, the film has been used in a variety of educational settings. For the second year in a row, we showed the film to the first-year cohort of McGill's medical students as part of their physicianship coursework which focuses on teaching healing practices. The film and subsequent discussion with the patients (some of whom were featured in the film) received a standing ovation, not something one often witnesses in required university courses. The film has also been shown in graduate-level research methods courses in schools of Social Work, Medicine, and Education. It was screened in the public seminar series of McGill Programs in Whole Person Care and has been shown in whole and in parts to dialysis nurses and other health professionals in various Montreal hospitals.

The film is currently viewable (though in a somewhat different format) on our website: www.mcgill.ca/wholepersoncare/esrdqualityofliferesearch. - includes French language version.

Drug Seeking: Under A New Lens

Allison Potts, MSW, RSW

Concurrent Disorders System Integration Consultant Pinewood Centre, Lakeridge Health
apotts@lakeridgehealth.on.ca (905) 723-8195 ext. 219

In providing on-site consultation in a hospital regarding substance use related issues, I have frequently been asked to assess patients regarding their “drug seeking behaviour”.

Specifically, what is being called “drug seeking behaviour” or DSB? As frustrating as it may be to the nurse, social worker or discharge planner on the other end of the phone, I usually begin by asking what specific behaviours have been noted as concerns to defend the use of the term.

Bias and stigma may influence descriptions of patients and have an impact on our treatment.

Without consensus about the term, we risk utilizing and documenting a label which instigates a domino effect which could impact the patient’s pain management, alter treatment protocols, and serve to stigmatize (rather than treat) possible substance use concerns.

Health care professionals do need to be aware of signs of possible risk of misuse or abuse of prescription medication and certainly should document these signs as appropriate in order to facilitate effective treatment options being offered to patients and to avoid contributing to the development of a substance dependency.

As well, from an addictions perspective, there are times when an individual with a history of substance use may actually require more medication to alleviate pain due to the tolerance they have developed from their use. Experiences I have had being called to consult on palliative care units have convinced me of this.

In most cases where medical staff are treating patients whom they feel may be at risk of drug seeking, there are questions that can inform the use of this terminology and our approach, including:

- What does it mean when we refer to a patient as being drug seeking or showing drug seeking behaviour?
- If the label is documented and not the behaviour, how is it interpreted?
- What are our responses to working with individuals who have already been characterized as “drug seeking”?

Of note clinically are cases where I have been asked to see patients about DSB who have no history of substance misuse, have health conditions explaining their pain and no documentation of the behaviours supporting the label of DSB they have been given.

Bias and stigma may influence descriptions of patients and have an impact on our treatment.

Continued next page...

Drug Seeking: Under A New Lens continued...

Mosby's Medical Dictionary definition of Drug Seeking Behaviour is:

“...a pattern of seeking narcotic pain medication or tranquilizers with forged prescriptions, false identification, repeated requests for replacement of "lost" drugs or prescriptions, complaints of severe pain without an organic basis, and abusive or threatening behavior manifested when denied drugs...”

Mosby's Medical Dictionary, 8th edition. © 2009, Elsevier.

However, there is currently no “gold standard” screen for risk of prescription drug misuse or abuse.

Although there are some screens available, they are seldom utilized. Without a screen or standard way to assess for this risk, are we relying on personal judgment?

This is cause for concern when the Mental Health Commission of Canada has stated that **Health Care Professionals** are a priority target population for their anti-stigma initiative because, **“the medical front lines eg. Doctors, nurses and emergency room receptions, are where people seeking help say they experience some of the most deeply felt stigma and discrimination.”**

(Mental Health Commission of Canada website)

<http://www.mentalhealthcommission.ca/English/Pages/OpeningMinds.aspx>

Another aspect of pain management and a strategy for determining if an individual is “drug seeking” that provides us with an opportunity for improvement is the judgment of what is often called “legitimate pain”. Again, without an unbiased mechanism to measure this very personal construct of physical pain, how are we determining its legitimacy?

The 1-10 scale is still widely used and it has questionable efficacy given that individuals have different thresholds for pain and varied past experiences with pain management.

Having a screening tool for risk of misuse of medication and a check list of established signs of “drug seeking behaviour” are part of a response which would reduce the personal judgment used to determine care for pain management.

Ultimately, one of the most significant aspects of our response is tested when a person being treated is living with a substance use concern – our ability to provide treatment in an empathic, compassionate and non-judgmental manner.

Renal News Around the World: somewhere in the Atlantic Ocean

PD Patient Sailing Solo Across the Atlantic

Reprinted with permission from The Kidney Foundation of Canada web site: www.kidney.ca

Jean-Louis Clemendot, a 59 year old sailing enthusiast and continuous ambulatory peritoneal dialysis (CAPD) pa-



Mr. Clemendot loves the sea of course but he also has a mission: to demonstrate to other kidney patients that peritoneal dialysis (PD) has not taken away the freedom to sail. He hopes to be an inspiration to the 1,700,000 dialysis patients around the world and show that you can continue to live life to the fullest despite kidney disease.

You can follow his adventure, the first of its kind world-wide, on his website www.jeanlouisclemendot.fr



The foundation of kidney care.

Employment Opportunity:

The Kidney Foundation of Canada National Director of Programs and Public Policy

The Kidney Foundation of Canada is one of the country's most respected and successful national health charities. Through a network of Branches across Canada and with the support of its dedicated volunteers, the Foundation is committed to kidney health and to improved lives for all people affected by kidney disease. Today, the Foundation provides a range of programs and services to reduce the burden of kidney disease, and to educate people about risks and better management of the leading causes of kidney disease.

A key member of the senior team, the National Director of Programs and Public Policy works closely with colleagues from across the country, helping influence national health policy and developing new and exciting programs for the Foundation. Through new technologies and interactive web-based tools, and in collaboration with the Foundation's communications team, the National Director helps promote greater engagement and connectivity with patients, stakeholders and the public. The National Director also plays a central advocacy and external relations role, advancing the importance of ongoing education, healthy living and kidney screening, and raising the Foundation's profile with patients, partners, donors and governments.

As the ideal candidate, you display initiative, entrepreneurship and creativity. You have a solid foundation in advocacy and federal health policy, and an appreciation for the role of new media in promoting an organization's message and brand. You are the consummate professional and team player. You have extensive experience in program management and service delivery, and can manage multiple projects within a collaborative and consensus based national environment. You build relationships based on trust, respect and transparency. Your knowledge of kidney health gained as a clinician, healthcare manager, or leader within a related health discipline or health charity is a desired asset, as is your ability to communicate in both official languages.

For further information or to apply, please contact Michael Naufal (michael.naufal@odgersberndtson.ca) or John Caminiti (john.caminiti@odgersberndtson.ca) in our Ottawa office at 613-742-3202.