

CANSW

Canadian Association of Nephrology Social Workers

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Deputy Minister Kevin Costante
Ministry of Community, Family & Children's Services
Ontario Disability Support Program
Hepburn Block 6th Floor
80 Grosvenor Street
Toronto, ON M7A 1E9

Dear Mr. Costante:

The Ontario regional representatives of CANSW have identified a number of concerns related to client accesses and support services within the Ontario Disability Support Program. We need your help. Within this letter, we will outline the challenges renal patient's experience with ODSP as well as recommendations that we hope you and your team will consider.

As nephrology social workers, we provide clinical intervention for individuals who suffer from kidney disease. The majority of individuals that we work with suffer from end stage kidney failure (ESRF) – a life threatening degree of this illness. Those with ESRF must choose to receive life support dialysis in order to maintain their lives. This treatment is offered in a number of forms including home – based and patient delivered peritoneal dialysis or hospital-based and health care professional delivered hemodialysis. Peritoneal dialysis is a treatment that the patient performs on themselves at a minimum of 4 x per day (for the rest of their life). Individuals receiving hemodialysis must travel to a hospital or medical centre 3 x per week (for the rest of their life) for a 4 to 4.5 hour treatment per visit. Some patients are successful in receiving live or cadaveric kidney transplants, although, the waiting list for cadaveric transplants is well over 5 years. In this respect, the treatment regime for ESRF patients is extreme and severely interferes in their ability to find and sustain employment as well as in their ability to maintain a good quality of life.

The social burdens of ESRF are significant. Several studies including one recently conducted in Northwestern Ontario, found that a large majority of patients live well below the poverty line. In order for patients to receive treatment, they must often relocate to an urban setting for treatment, travel exceptional distances 3 times per week for dialysis, leave family and friends behind, or move into Long Term Care

Facilities. The financial cost of these scenarios is exceptional and in most cases, the assistance that is available is inadequate. As I expect you are aware, affordable housing is difficult to secure waiting lists for subsidized housing is remarkable, and locating barrier free housing is next to impossible. Although we recognize the C-SUB entitlement under ODSP, it is in most cases insufficient.

It has been our experience that the majority of renal patients are unable to afford the social costs of their illness and suffer tremendous indignities. Many describe choosing to not purchase their vitamins (not covered by ODB drug card), or defer eating in order to pay for rent and utilities. Others describe being separated from their children and spouses, as they cannot afford to pay for relocation transportation. Even with the diet supplement, many struggle in their ability to follow their restricted renal diet due to the extra costs associated with it. Patients express difficulty negotiating for travel assistance both locally and outside their treatment centre when they have additional medical appointments. Patients experience difficulty communicating and eating, as they cannot secure funding for specialized dental work or dentures.

The emotional impact of living with ESRF is significant. Many patients suffer from depression, anxiety, and a severe reduction in their quality of life. Coping with government systems is a burden many cannot cope with. Often they may suffer from other illnesses in addition to their kidney failure such as heart disease, blindness, multiple limb amputation, and symptoms such as anemia, generalized fatigue, confusion, and memory loss.

Treatment for ESRF as explained is a form of life support. When social stability is shaken, patients often consider stopping treatment. Discontinuation of dialysis for social reasons is the second leading cause of death for dialysis patients. We are appealing to you to assist us in both identifying and addressing those barriers that contribute to hardship or result in lack of treatment accessibility for kidney patients.

The Benefits of Collaboration

Patients suffering from kidney disease frequently find themselves involved with ODSP. We hope that this collaborative effort will help to achieve the best quality of care for clients across Ontario living with disabilities.

1. Service Continuity

The shift away from a case management model of service has created significant difficulty for patients and health care providers. The following are the challenges many have faced:

- Stressful interactions as patients must repeat their concerns to different workers
- The response by workers can vary significantly, which lends to the belief that there is room for preferential treatment
- Voice mail and phone ‘line-ups’ are a permanent feature of our society. However some people must call from a pay phone and stand for 20 minutes or more waiting for someone to answer (this is a hardship with many physical disabilities)
- People who are unwell and on limited income find the process intimidating
- Time consuming for a community professionals – we cue up along with our patients, waiting to finally speak with a person (often 20-30 minute wait)
- The letters, sent out ‘anonymously’ and threatening to cut off income because of some vaguely worded transgression, truly frighten this vulnerable population. They can’t sleep; their blood sugars and blood pressures often escalate to dangerous levels from the stress. For a sick person to feel that they risk

being on the street because their cheque won't come in and they can't pay their rent is horrible. These people live from one social assistance cheque to another disability paycheque.

2. Responding to the Unique Needs of Clients

The discretionary aspect of some benefits is a double-edged sword. As social workers we have all experienced the variations of workers who go from the sympathetic to the antagonistic. We are concerned about the lack of consistency with discretionary benefits such as the following:

- Dental health is an essential element in keeping a person healthy. Although it is easy enough to access clinics for dental extractions there is almost no assistance for dentures. Often the discretionary aid provided is insufficient and the patient is unable to afford to purchase dentures. This further impacts their nutritional status negatively, compromising their health.
- Anecdotal reports find that the mileage allotments and medical travel assistance does not appear to be consistent across the province
- There are inconsistencies in access to specialised financial assistance for assistive devices, vehicle maintenance for medical travel, diet supplements reflective of true cost, an increase of C-SUB assistance to reflect true cost of medical relocation

3. Compassionate Response

Compassion is fundamental to coping well with the psychosocial burdens of living with a life threatening illness. The following are examples of non-compassionate approaches to service delivery.

- There are chronic delays in the application process to ODSP. This results in individuals living well below the poverty line, being unable to secure affordable or accessible housing, often living in housing conditions that pose a risk to their health, and being unable to afford food that is within their diet restrictions.
- Ontario Works and ODSP have different pay periods. Ontario Works pays at the beginning of the month and ODSP pays at the end of the month. Clients are unable to manage the delay in income as they are already living in poverty.
- Individuals who are living in a medical shelter (First Nations) are ineligible for social assistance yet those who are residing in a transition home, home for abused women or Long Term Care qualify for the Personal Needs Allowance (PNA). It is concerning that there is this inequity when the needs for basic necessities are the same
- Patients/clients suddenly find their transportation or diet benefits cut off without explanation. These are very important benefits to our patient population, some of which do not speak French or English, are illiterate, or are unwell and find the whole process overwhelming.

Recommendations

1. Accountability

- Consider a case management model of care
- Availability of ODSP worker voice mail for clients
- Availability of contact person on each letter sent – this person should be accountable and familiar with the contents of the letter (ie suspended benefits, changes to benefits, requests for updates)
- Accessible communication system for community professionals

2. Transparency

- Consistency in the delivery of the discretionary funding program
- Education is needed about the eligibility parameters of discretionary assistance

3. Continuity

- It is unclear why ODSP pays at the end of the month. Whenever someone transitions from another source of income, they find themselves accumulating debt and struggling to avoid eviction because there is a delay in income deposits.

4. Compassion

- Consider funding for dentures
- Review eligibility criteria for PNA (personal needs allowance) for all clients living in shelters, LTC, or medical lodges
- Review of C-SUB (Start Up Benefit) this has not been increased for many years and does not reflect the true cost of medical relocation for life support treatment
- Review of diet supplement to reflect true cost of special diet requirements

It is our request that the letters we have sent to you are reviewed within the context of the living reality of renal patients. We are appealing for your compassionate review of the processes that are currently in place with ODSP. Clearly, by the experiences described within this letter, clients are experiencing undue hardship with the current ODSP practise. We ask that you forward copies of our appeal to whomever within the Ministry that can respond or provide solutions to these concerns. We will look forward to your response.

Sincerely,

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Attachments:

1. Copy of letter sent to OASW
2. Copies of letter by Ontario Canadian Association of Nephrology Social Worker

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Janet Bick – Director of Professional & Government Relations
Greater Ontario Branch, The Kidney Foundation of Canada