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**In Response to The Ministry of Health and Long-Term Care's**

***PATIENTS FIRST: A PROPOSAL to STRENGTHEN  
PATIENT-CENTRED HEALTH CARE in ONTARIO***

# **Our Call for Advance Care Planning**

**Submitted By:**

**Health Action Committee  
(City of Greater Sudbury)**

**February 23, 2016**

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## **Executive Summary**

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The Greater City of Sudbury's Health Action Committee is a group of sixteen citizens. We range in age from 54 to 79. We come from a variety of areas: business, education, health care, government, communications and labour. A number of us have extensive personal experience in caring for frail elderly family members. We have pooled our knowledge, skills, stories and experience, in order to offer a solution that is all about putting the patient first.

It has been said that medicine in Canada is focused on the disease, not the patient. We are encouraged, therefore, that the government's Action Plan suggests it is time to adjust and integrate the system to the patient's needs.

We have examined the needs of patients who are medically complex, may well be frail and beset with a number of serious co-morbidities. Some may be approaching the end of life. We recommend a specific health care initiative to better serve such patients. This approach also promises to generate significant financial savings that can be redirected to front-line care. Up to 25% of health care funding is spent in the last year of life, over \$10 billion in Ontario alone.

Our proposal is inspired by the story of Joan, a local woman with recurring cancer who wasn't given the information or the opportunity to choose her own path, and suffered a distressing end with unwanted, expensive medical interventions. Her story is not unique.

The medical literature has amply demonstrated that there is inadequate communication between health care providers and patients. There is little in the way of advance care planning. This type of approach for complex, frail patients can end really badly after aggressive treatment: resulting in the loss of the ability to live independently, the loss of cognitive function, and distress for patients and their family members.

The evidence points the way to *a coordinated, systematic model of advance care planning* that applies the lessons from Joan's story. This model uses trained facilitators to identify the patient's wishes. Conversations are focused on values, not on specific treatments. Such an approach improves care from the perspective of the patient and the family, and diminishes the likelihood of stress, anxiety, and depression in surviving relatives. This approach decreases unwanted investigations, interventions and treatments, decreases hospitalizations and admissions to critical care, and decreases overall costs.

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We believe that individuals want and deserve the opportunity to make decisions about their own care. The right to informed consent is law in Ontario.

The potential barriers to advance care planning include the lack of availability of trained staff with advanced communication skills that are allowed sufficient time by their institution, and have the comfort level, to lead such difficult conversations.

Pilot projects at Health Sciences North and St. Joseph Health Center's Complex Continuing Care are imminent. Our Health Action Committee recommends these initiatives be supported, expanded and accelerated by the province.

We urge Minister Hoskins to support our call for clear treatment plans that are developed collaboratively with patients and their families, focusing on the needs of the patient, not on the needs of the disease. Treatment plans that are developed before initiating the treatment. Treatment plans that will be subsequently shared across the system between healthcare providers. Support our call for the development of universal access to palliative care in Ontario.

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## **Our Call for Advance Care Planning**

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## Who Are We?

The Greater City of Sudbury's Health Action Committee (HAC) is a group of sixteen citizens who have long been concerned with the state of our local health care system. We have experienced our local system from a variety of perspectives and have much to offer to the province's efforts to improve access to "...consistent, accountable and integrated...care." Locally, we coalesced around Dr. Peter Zalan's invitation to pool our knowledge, skills, stories and experience, in order to offer a solution that will enhance patient-centred care. At the same time, it will save health dollars that can be re-directed to "the bedside."

We range in age from 54 to 79 and combine hundreds of years of involvement in our community as volunteers and professionals. We come from a variety of areas: business, education, health care, government, communications and labour. As spouses, mothers, fathers, sons, daughters, friends, neighbours and advocates, each of us has been profoundly touched by the successes and failures of our health care system. Our biographies are noted in Appendix 1.

## Sudbury's Health Care System: A History of Disappointment, A Future Full of Opportunity

*"Too often, health care services can be fragmented, uncoordinated and unevenly distributed across the province.... Too often our system is not delivering the right kind of care to patients who need it most."* (Patients First: Action Plan for Health Care)

Sudbury's recent health care story is one of particular frustration. Construction of our new hospital incurred significant budget over-runs. Construction that began in 1999 was suspended for years and the hospital's architectural plans downsized from the requirements that were projected a decade and a half before its completion in 2009. We lost capacity, impacting negatively our ability to provide the "right care, at the right time, in the right place." The challenges associated with a downsized hospital facility, poor integration of community services, an aging population, rising numbers of complex, frail patients and high re-admission rates have proved challenging for health care leaders, professionals and patients alike.

Each of us has stories, often harrowing, of how we, our families, friends, colleagues and neighbours have been detrimentally affected. Too often, the patient was not first.

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The drafters of this submission reflect the mood of our community. We choose not to dwell on the negative, but instead to use our stories to drive improvement. We are pleased, therefore, to answer the Minister's call, "...*seeking your input on our proposal, and your advice about how to integrate other improvements....*".

## **Introduction**

It has been said that medicine in Canada is focused on the disease, not the patient. We are encouraged that your Action Plan suggests it is time to adjust and integrate the system to the patient's needs. To that end, we have examined the needs of patients who are *medically complex, may well be frail and beset with a number of serious co-morbidities*, regardless of age. Some may be approaching the end of life. For some with a diagnosis such as dementia, death may still be a number of years away. We suggest a specific health care initiative that can better serve such patients. This approach also promises to generate the added benefit of significant financial savings that can be redirected to front-line, patient-centred care.

## **Stating the Case**

For several years Dr. Peter Zalan, a local intensive care physician and anesthesiologist has been planting the seeds of reform by speaking to local groups about the necessity for "difficult conversations". From his valuable perspective of caring for patients for more than 30 years, he has witnessed the non-stop increase in the power of medical interventions, many applied to patients at the end of life. New technology has enhanced the ability of medical professionals to prolong life, to attempt to cure, to never give up.

Even as the power of medicine has made so much more possible, discussion between health care professionals on the one hand, and frail, complex patients and their families/advocates on the other, is too often inadequate to make informed decisions about treatment plans. Too often families, friends and spiritual advisors are not invited to support patients in these situations. The medical literature has amply demonstrated that there is inadequate communication between health care providers and patients.

In an audit of communication practices in 12 hospitals in Canada published in 2015 in the British

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Medical Journal, the authors interviewed patients and family members shortly after hospital admission to determine their perspectives about whether healthcare professionals engaged them in key processes of communication. The authors found that there was very little effective communication between the patient/family and members of the healthcare team about goals of care.

A 2009 U.S. study published in *Critical Care Medicine*, of outcomes after prolonged\* mechanical ventilation, only 26% of families reported that physicians discussed what to expect for the patient's future survival, general health and caregiving needs. \*Prolonged means greater than 21 days.

Two thirds of terminal cancer patients in the 2008 Coping with Cancer Study reported having had no discussion with their doctor about goals for end of life care.

Aggressive treatments have too often led to poor outcomes: the loss of the ability to live independently, loss of cognitive function, distress for patients and their family members.

A 2014 Alberta study looked at how frail patients did after a stay in the Intensive Care Unit. Even though most people survived their operations and ICU stay, only 15% of all the frail patients who lived independently prior to illness were still living independently in follow up.

The current approach to treatment is the challenge. Too often, especially at the hospital, care is focused on attempting to cure the presenting problem, with the goal of returning the patient back to his/her pre-illness state of health. Many family doctors now are saying they only want to consider one complaint per visit. This approach reflects the **physician's** goal of care. While appropriate for the otherwise robust individual with an acute illness, this approach for complex, frail patients often ends badly when it fails to consider the **patient's** goals of care.

Evidence is emerging that, given the appropriate information, sufficient time and support for discussion, patients may choose different options for care. Our collective experience corroborates the medical literature and Dr. Zalan's observations. We believe that individuals want and deserve the opportunity to make decisions about their care. The right to informed consent is law in Ontario.

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## Joan's Story

We all have examples of when the system failed the patient, when his or her interest and input were neither the drivers, nor the co-pilots for their own care. Particularly telling and illustrative of the untapped opportunities for positive change, is “Joan’s” story. The name has been changed but the facts are authentic.

Just forty-something, Joan had already fended off death twice in her young life. She was only a teenager the first time she faced mortality and its accompanying existential and practical questions. Her struggles didn’t end with her early victory over cancer. In her thirties when the dreaded cancer came back for another go at her, she beat it again. But last year, when her doctor delivered the latest diagnosis, the evidence was overwhelming that this time she could not win the battle. She was terminal. Yet in the eyes of her well-intentioned health care professionals, who had been trained, as Dr. Zalan reminded us, “to prolong life, to attempt to cure, to never give up,” she was young, and their treatment plan was clear.

At this point in her life Joan lived alone, with little family support. Further, the earlier chemotherapy had induced cognitive dysfunction. Even as confused as she was about what was happening, very early on she divulged to friends that if she were destined to die anyway, she didn’t want to go through chemotherapy or other aggressive interventions again. She, better than most, *knew* what that journey entailed. She wanted a peaceful ending at the Vale Hospice.

Nevertheless, somehow, chemotherapy was initiated. Joan continued to feel she wasn’t being heard. Even when she expressed concern to her health care professionals about increasing pain and her struggles with the three flights of stairs to her apartment, she was brushed off with, “You can still do stairs.” It was only after she insisted on an MRI that the full extent of the progress of her cancer was acknowledged and she was put on the Hospice waiting list. The Hospice has proved a blessing for dying patients. For Joan, it proved too late to ever get access.

Her friends closed ranks and cared for her to the best of their abilities. They witnessed the frustrating lack of continuity in personal support workers. Some PSWs did not show, some had to be briefed on Joan’s condition and one even had to be sent away when Joan could not cope with the odour of smoke on her clothes. During two crises, well-meaning friends brought Joan to the Emergency Department where she predictably waited for hours before being assessed and sent

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home. Although she early on expressed the wish that she did not want to die in hospital, she spent her last two weeks of life on a hospital ward where the routine noise and bustle kept her agitated to the point of frequent panic attacks.

Hospital staff was not initially aware that Joan was palliative. The counselor, who had for years helped her adjust to post chemotherapy deficits, was never invited into her circle of care to ease her final days. Attention to her spiritual and emotional needs was left to friends who felt ill-equipped to give her what she needed.

As Joan faced death, she, like other patients we have known, expressed fear of dying alone and of pain that would not be controlled. Joan's friends established round-the-clock shifts to meet her first need, but the roster of rotating hospitalists didn't effectively manage her pain until her last hours.

Joan's friends want her story to matter.

## **Our Vision**

We can do better.

Recent academic evidence points the way to *a coordinated, systematic model of advance care planning* that applies the lessons from Joan's story. This model, published in the British Medical Journal in 2010, used trained facilitators to identify the patient's wishes about end-of-life care. Conversations focused on values, not specific treatments, are all about giving someone like Joan all the available information in a supportive environment so that she can be the one deciding her treatment plan. The research demonstrated that such an approach improves care from the perspective of the patient and the family, and diminishes the likelihood of stress, anxiety, and depression in surviving relatives. This approach decreased unwanted investigations, interventions and treatments, decreased hospitalizations and admissions to critical care, and decreased overall costs.

The development of advance care plans and goals of care should become a key component of the care of all individuals in our community who are medically complex, frail and have multiple chronic conditions. These plans should be updated as required. The plans should be readily

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available to all health care providers in the patient's circle of care. Once widely available, such a plan would be a powerful tool for integration, focusing as it does, on a planned, consistent patient experience across the system.

The implications of our proposal are profound for patients and the system. Our proposed change in approach would offer patients sufficient information, support and opportunity to make truly informed choices. It would honour the provincial commitment to informed consent. Furthermore, such an approach would generate substantial financial savings that could be re-directed to front-line care. Currently, Ministry data suggest that up to 25% of health care funding may be spent in the last year of life. This is in the order of \$10 billion dollars in Ontario. Judging from Joan's story, a significant portion of that money could be potentially saved. It would also offer patients the best possible quality of life in their final days.

A 2009 study sought to monetize the differences in health care use in the final week of life for patients with advanced cancer who reported having end of life discussions with their physicians compared with those who did not. The study also examined the association between expenditures and patients' quality of life. Interestingly, the two groups did not differ in survival time but patients who reported end of life discussions had less physical distress in the last week of life than those who did not and the costs of care were 35.7% lower.

When this process is applied to creating a *plan for the future*, it is termed "advance care planning." When the process is applied to decision making for *current care*, it is establishing "goals of care".

## **The Process**

What goes into the process? It is all about asking, within an empathetic, supportive environment, a series of questions.

What are your fears about what is to come? What do you value? What brings quality to your life? What trade-offs are you willing to make for the possibility of added time? What is your understanding of your illness? What do you expect to happen? This is quite important because the majority of patients underestimate the severity of their illness and infirmity.

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In a 2012 issue of the New England Journal of Medicine, they asked nearly 1200 patients with metastatic lung cancer or colorectal cancer whether they expected their treatment to cure them. The authors found that the majority of patients with these conditions with a poor prognosis regardless of therapy felt that their treatment course was likely to “cure” them.

Who is to do the asking? Leading such conversations requires advanced communication skills. The average physician does not have the time, the training or the comfort level. Thus the requirement for trained facilitators. It is important that the patient be given the opportunity for support from family, advocates and/or spiritual advisors in these conversations which focus on the patient’s values, not on specific treatments.

The potential barriers to advance care planning include the lack of available trained staff with advanced communication skills who are allowed sufficient time by their institution, and who have the comfort level to lead such difficult conversations.

It is important that health care professionals understand and support advance care planning. Transportation constraints may impede the patient's ability to attend and fully participate in treatment planning.

### **Successful Examples**

Physicians in Halifax, Nova Scotia, developed a successful model of advance care planning: The Palliative and Therapeutic Harmonization (PATH) Clinic. <http://pathclinic.ca/>. A similar model was developed in Melbourne, Australia: Respecting Choices. <http://advancecareplanning.org.au>. Both groups identified the use of trained facilitators as crucial to their positive results. Both organizations published their positive outcomes.

The province of Ontario has its own instructive story using trained facilitators. Ontario’s rate of success in obtaining consent for organ retrieval had been historically low at 10%. Intensive care physicians used to be responsible for seeking consent. The province’s Trillium Gift of Life Network subsequently elected to train coordinators to take over the dialogue with families about organ donation and to seek consent. The success rate rose to 70%. The coordinators had the training, the skill, the empathy and the time to successfully perform a very important job.

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## **Local Interest**

Locally, Health Sciences North is in the process of developing a pilot project to have this “*Goals of Care Conversation*” with patients over the age of 85 admitted to a medical inpatient bed. Once the process is standardized, the intent is to expand it across the organization and then across the local community.

St. Joseph’s Complex Continuing Care Centre and its two associated Long Term Care (LTC) facilities have embarked on a similar project. The other local LTC facilities are being urged by their Family Councils to follow suit.

Both initiatives are very welcome. They need support, expansion and acceleration by the province.

## **Need for Universally Available Palliative Care**

Provision of information is an important first step in developing a patient-centred plan for end-of-life care. While research demonstrates that this approach results in fewer hospital admissions and thus significant financial savings, the primary goal is to provide the right care at the right time in the right place. If patients like Joan do choose to remain at home and avoid hospitalizations utilizing aggressive, expensive medical interventions, then they and their families need to be able to count on timely access to the necessary home care resources as conditions deteriorate. Joan didn’t want the two ER visits and the final hospital admission. She wanted to die at home surrounded by family and friends.

## **Conclusion**

We are a community collaboration brought together by a common passion for improving our health care system. We have all known too many Joans. Our encounters have laden us with valuable suggestions for serious and sustainable reform. From our perspective it is well past the time for simple reflection on Joan’s and other patients’ stories. It is time to act on what they have taught us.

We are encouraged to hear the commitment to real change and authentic patient-centred care.

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We urge Minister Hoskins to support our call for clear treatment plans that are developed collaboratively with patients and their families, focusing on the needs of the patient, not on the needs of the disease. Treatment plans that are developed before initiating the treatment. Treatment plans that will be subsequently shared across the system between healthcare providers. Support our call for the development of universal access to palliative care in Ontario.

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# Appendix 1

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**Linda Cartier**

Linda was primary care giver to her mother who suffered from dementia for a number of years and she cared for a close friend at end of life. She is 63.

Linda is Secretary of the Finlandia Family Council, Grand Family Council of Sudbury and North Eastern Regional Family Councils Network. She is a small business owner born in Sudbury.

**Peter Clark**

75; no health care involvement

**Vivian Field**

Vivian is 79-years-old. Her late husband (who passed away about 10 years ago) was diagnosed with a rare degenerative neurological disease. As his advocate, she interfaced with many community services. It was very confusing and difficult and she believes those who did not have her background or connections would be lost as there was no “one door” entry point. Because of her background and connections she was able to care for him at home for a long time. Sadly he spent his last six months of life in a nursing home. The nursing home provided the basics but no programming.

She had her own acute care hospital experience about five months ago, and found that the physicians took good care of her, especially in the Emergency Department but the nursing care that she observed was far less than optimal and she luckily didn't require much. Her observation suggests that much could be done without spending money the system does not have.

She believes seniors deserve advance care planning that does not fragment their care and provides the dignity they deserve.

Vivian's professional background is in the mental health sector. She has always maintained an interest in community issues. She is a founding member of FRIENDLY TO SENIORS and is currently the secretary.

**Laima Grasis**

Laima is 61-years-old and advocated for her mother who spent the last years of her life in Finlandia Nursing Home. Laima is currently Chair of the Finlandia Family Council, and an executive member of the Grand Family Council of the City of Greater Sudbury, and the Northeast

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Family Councils Network. Laima spent many years as a volunteer providing palliative care through Warm Hearts. She is a career registered nurse, still working in long-term care.

### **Bob Hibbs**

65 year-old Bob looked after his mother as her health declined. They experienced the many challenges of care-taking and trying to figure out how the system worked the elements of support that were available. Where services were lacking, he and other family members provided what was needed.

He has a background in the private healthcare plans provided by the insurance industry.

### **Nancy Johnson**

A life-long resident of Sudbury, 61-year-old Nancy spent the last decade advocating for her family's parents in navigating all aspects of the health care system (primary care/ems/hospital/mental health/home care/LTC and all points between) as their health deteriorated. Her mother, a teacher, had a particularly harrowing journey and early on made Nancy promise to record her story and use it to fuel a better health care system for her grandchildren.

Nancy spent two decades in various investigation roles with the province before transitioning to serving the interests of health care workers in a provincial health care union. She is a member of the Finlandia Family Council, Co-Chair of the Grand Family Council of the City of Greater Sudbury and of the Northeast Region Family Councils Network, and past member of the Health Sciences North (HSN) CEO Patient Family Advisory Council.

### **Charles Ketter**

Charles is 76 and has had much contact with the local health care system over the years:

Care giver and substitute decision maker for 49 year old son with autism \* Wife suffered a crushed pelvis at age 12 – many medical interventions over the years. She was diagnosed with Progressive MS in 1990 – served as her care giver.

Wrote a factum for Superior Court to appeal a Ministry of Community and Social Services ruling that was subsequently set aside.

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2012 – Interviewed for Patient Family Advisory Committee at Health Sciences North. Involved subsequently with Process Improvement Planning for Emergency Department; Discharge Planning; Care Transitions; Expanded Care Transitions; Medical Advisory Committee; Involved in several Rapid Improvement Events leading to positive revenue-neutral changes.

2015 – Volunteered for Health Action Committee with a focus on advance care planning.

**Dorothy (Dot) Klein RN DPHN BScN**

72 years ago Dot was born and raised in Sudbury. She cared for 2 uncles, 1 aunt and both of her parents during their last month's/years of life. The most recent (2012) was her 85-year-old aunt with a diagnosis of ALS. She lived in a Senior's Retirement Residence in Sudbury. She was on the waiting list for LTC for 3 months prior to her death. She had inadequate physical or emotional care in the community. She died in the Emergency Department (ED) at Health Sciences North with her AM medications and breakfast lodged in her lungs. Dot was with her in ED. Her aunt was single and had no children. As Power of Attorney, Dot had explained and discussed Do Not Resuscitate (DNR) in the days leading up to her death. This had not been done by her Doctor(s), CCAC, Bayshore Nursing staff or any other health care worker involved in her care. She was a woman of faith and needed the DNR explained in a way sensitive to her faith beliefs. This was not available through community resources and was considered a "family responsibility." Despite Dot's professional knowledge and experience it was still very challenging and lonely for her. She experienced personal grief as well as personal frustration with the health care system that failed to provide the support she, her aunt and the rest of the family required. All her brothers, sisters, nieces and nephews were seniors and needed emotional support with their grief. Dot has been an advocate for 2 decades for her adult son who was permanently disabled from a head injury playing high school football (frontal lobe brain injury). He lives independently in Sudbury with Dot's support. She is joint Substitute Decision Maker for his health decisions should it be required. It has been her families experience that Person and Family-Centred Care is not consistently practiced in our community hospital or the community health care services.

Dot graduated from the Toronto Nightingale School of Nursing (1965), then University of Western Ontario (1967). She is a member of the Registered Nurses Association of Ontario (38 years) and active at the local and the provincial level. She is in several RNAO Special Nursing Interest

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Groups including Gerontology and maintains a current registration with the College of Nurses of Ontario. Her nursing career has involved hospital, community (VON, We Care, Bayshore), teaching (LU, Cambrian College, Sudbury Catholic School Board and CarePartners), nursing supervisor in several LTC homes in Sudbury, manager of a resource and assessment centre for physically disabled adults living in NE Ontario. She is an honorary member of the Ontario Gerontology Association having been Provincial President and Past President. She was recently appointed to the Stand On Your Feet NE Regional Coalition Steering Committee representing Parkside Older Adult Centre.(a not - for - profit activities Centre for Seniors - staffed and managed by Seniors) She is leading a team of Older Adults (members of Parkside Centre) to implement Seniors' Fitness programs relevant for seniors living in Sudbury. SOYF is the NE Ontario Falls Preventative Program for Seniors and part of the provincial government initiative to improve the health of Older Adults living in Ontario. She was a founding member of the Sudbury Palliative Care Association and the Sudbury Older Adult Coalition that prepared the "ground work" for the establishment of Parkside Older Adult Centre.

### **Hugh Kruzel**

As Chair of the local chapter of CARP (A New Vision of aging for Canada) Hugh Kruzel has contributed to many discussions on the mechanics of health care delivery and policy, on topics from death with dignity, housing and aging, to healthy communities and transportation. While in the world of academia he researched and wrote on demographics and the (then) potential impacts of the greying of Canada on the social fabric, employment, taxation, education and the shape of the urban environment. Hugh is 54.

### **John Lindsay**

John's mother-in-law suffered from dementia, requiring long term care. He has no professional background in health but has been involved in several advocacy areas particularly LTC. John has been a resident of Sudbury since 1966 with various careers as teacher, broadcaster, federal public servant, school board trustee and chair, and business owner. He is Chair, Friendly to Seniors - Sudbury, an older adult advocacy organization involved in healthy community assessment and awareness. He is Vice Chair, Sudbury Chapter Canadian Association of Retired Persons (CARP). John is age 78.

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## **Lionel Rudd**

Lionel is 74. He was hospitalized in 1997 with cancer, then again in 2011 for 5 ½ months with “septic shock”. While recovering he was able to observe the finer points and intricacies of his care and the workings of Health Sciences North. Later he had two knee replacements which was another edifying experience. In 2014 he ended up in St John’s, Newfoundland Hospital Emergency with what was either food poisoning or a diabetic “incident”. He experienced “Home Care” as a result of his hospital stays.

Lionel taught occupational Health and Safety to Technology students at Cambrian College and Engineering students and Radiation Therapy Students at Laurentian University. This included audiometry to nursing students too.

He is a Certified Engineering Technologist (C.E.T.) Graduated in 1979. Worked in mine environment personal monitoring in 1970 and was the first Health and Safety Representative for Mine Mill Local 598 in 1975. He specialized in items from radiation monitoring to heat/cold stress, gases, noise, aerosols and dusts etc. He started his college courses in 1970 – part time while working in the minerals industry.

Further background:

Lionel served on the Health Sciences North Presidential Patient/Family Advisory Council for three years.

OTHER: He came to Canada in 1965 and worked mostly in the minerals industry. Prior to that in the UK he trained police dogs in the military, served in the British police among other things.

## **Irene Sacchetto**

Irene is 71, and looked after her mother who wasn’t officially diagnosed with dementia, but close enough. She had many issues, the most difficult for Irene as caregiver, was her Colon Cancer, which was not identified until a very late stage. Irene was her only caregiver. Her Mom thought everyone was stealing from her. Also, that someone was poisoning her.

## **Roma Smith**

Roma is 68 years old. Her mother was a resident of the Elizabeth Centre (2012-2015). She

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passed away at the Elizabeth Centre in Sept. 2015. During her stay there Roma joined the Family Council of the Elizabeth Centre. She continues to serve on the Elizabeth Centre family council and is now working as Co-Chair of the Grand Family Council of the City of Greater Sudbury and the Northeastern Region Family Councils Network. All of these councils have one common purpose: to improve the lives of those living in long-term care.

Roma has never worked in the health care system but has witnessed the dreadful decline in patient care here in Sudbury. She worked as a teacher in the elementary and secondary systems for most of her career. She specialized in working with students with special needs. It was after she retired that Roma found her call in volunteer work.

**Liisa Toner-Lindsay** BScN RN NCM NC, age 70.

Liisa, age 70, assisted and cared for and was advocate for her widowed mother who lived in her residence until she passed at age 90 of a massive myocardial infarction.

Liisa is a cardiac nurse, nurse case manager, nurse consultant. Her ongoing education includes Teaching, advisor, counsellor, researcher, theorist, author, group leader, advocate, key note speaker. Health care: prevention to rehab, human dynamics birth to death.

She continues as past and present member of multiple organizations, sciences and the arts. She is the founder of many. She continues as active participant in community issues at three levels of government. She is a member of the Canadian Association of Retired Persons (CARP), Health care: continue College of Nurses (CNO), local executive Registered Nurses Association of Ontario (RNAO), Canadian Nurses Association (CNA), Gerontological Nursing Association of Ontario (GNAO), Canadian Gerontological Nursing Association (CGNA), Health Action Committee (HAC). Ad hoc groups health issues: end of life, palliative care, euthanasia, ecology, ethical economics.

**Iris Unsworth**

Iris is 76-years-old. Her experience with aged family/people began as a child when her grandmother lived with them on a permanent basis. She passed at 89 in their home when Iris was 12.

As an adult, she watched her mother deteriorate for 10 years before passing at age 95. During that time, she had a fall breaking two ribs and was hospitalized in Guelph. Iris was pleased that

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they had an "advocate" for her well-being and advised that she not return to live alone. For a short time she went to live with Iris' brother until she was transferred to a nursing home. Iris spent the last three days and nights with her mother until her death.

Presently, Iris is involved as she watches a friend in her 70's go through our HSN system. It was obvious to any outsider that cleanliness was not a priority at the hospital. Her friend is now in rehabilitation. However, there is no consistency in her rehab and has now lost the desire to recover and is refusing rehab. Iris feels this is happening because there is no "advocate" to assist her decisions.

**Dr. Peter Zalan**

Dr. Zalan's system observations were enhanced by patients he has treated, as well as family insights gained when his brother was tasked with advocating for his mother who lived with a debilitating stroke for the last four years of her life, and for their aunt, who lived to age 100. Peter is President of the Medical Staff at Health Sciences North (HSN) and Past Chief of Critical Care. He is a member of Health Sciences North's Ethics Committee. He is a past Co-Chair of the Sudbury Community ALC Committee. He is 69.