

Spring 1995

Guardianship News

Published by the Community Coalition for the Implementation of Adult Guardianship Legislation

Banishing the Ghost of Incapability

by Richard McDonald

I am a self advocate. I really need to advocate for myself, because there are many times when I am not treated the same as most everyone else. I want to tell you about something that happened to me just recently.

This is an example of me not being treated like everyone else. But I am a self advocate, and I was able to help myself. Here is my story.

On January 9, 1995, I expected to get a cheque in the mail from Revenue Canada. This cheque is a Goods and Services Tax (GST) credit, and is for \$62.75. The cheque didn't arrive. I waited a few days, but it never came.

I went to visit people I know at Citizen Advocacy of Powell River, to see if they could tell me what to do. I learned then that I was not the only person in Powell River who didn't get the GST

cheque. I called my brother who is a school teacher in Hope. He had heard that this had happened to people there.

I went to the Social Services

Office in Powell River and asked for their help. Then, I went to a meeting of the Vancouver Island Self Advo-

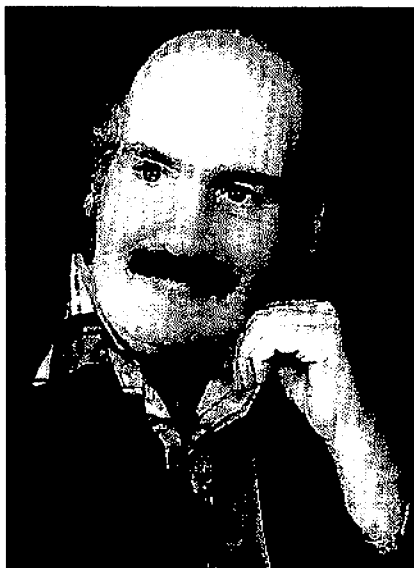
Continued Page 2



This issue is about Advocacy

Banishing the Ghost of Incapability

... continued from page 1



Richard McDonald is a self advocate living in Powell River.

cates Association. I am the second Vice President of this group of self advocates. I told people there about my GST cheque. Everyone was supporting me to find my cheque!

When I got back from Vancouver Island, Social Services told me that the Office of the Public Trustee had my cheque. I couldn't understand why. I called Gordon Wilson, my Member of the Legislature (MLA). He set up a meeting with some other self advocates from Powell River. He said that he would get right on it!

I called the Office of the Public Trustee. They told me that many years ago, when I lived in Woodlands

School, I had been certified as being incapable of making financial decisions. The *Patients Property Act* of B.C. says that certain people have the power to "certify" that a person is incapable of managing financial decisions. If you are certified as incapable, the Public Trustee in B.C. **automatically** takes control of your money. This is what happened to me.

Recently, Revenue Canada put all of their information into a new computer system. Their information included the papers that said that the Public Trustee should look after my money. That is why Revenue Canada sent my cheque to the Public Trustee.

The Office of the Public Trustee told me that they only make financial decisions for adults who **cannot** make these decisions. The Public Trustee will destroy the records of people who **are** capable of making financial decisions. I went to the Mental Health Centre and the doctor made a certificate of capacity. This certificate says I **can** make decisions.

When I left Woodlands School, I looked after my financial decisions. I have a job and my own apartment. I am a self advocate and I support other people to become self advocates. I do not need the Public Trustee to look after my money.

I got my GST cheque on January 27th! □

Some Questions Raised by Richard's Story

Richard was able to succeed using self-advocacy and the assistance of community supporters in proving his capability. However, his story raises a number of important questions:

- How many people have certificates of incapability that they don't know about?
- How can they change this situation if they want to?
- What does a "Certificate of Capability" mean?
- What role do the people who support us play in helping to make us "capable"? How is this role recognized?
- How can we ensure that people's needs for support and assistance are met before judging incapability?

The old guardianship laws did not provide answers to these questions. The new laws, in their spirit and words, offer opportunities to change old-fashioned ideas and procedures about what it means to be capable and to value the personal support that can help people to meet their needs.

In order to make these opportunities work, self-advocates, community advocates and people who are affected by adult guardianship need to get involved. □

EDITORIAL**Building an Advocacy Network**

by **Christine Gordon, Co-ordinator of the Guardianship Coalition**

Advocacy is a cornerstone of personal support. Advocacy is at the heart of the new guardianship laws. It begins with the adult's own voice expressing personal beliefs, values and wishes and extends to the support that family, friends, community advocates and legal advocates can give to strengthening the adult's voice.

This issue of the newsletter is about advocacy. All of the stories are written by people who are speaking out about their own experience and reaching out to share their experience with others.

At the Advocacy and Adult Guardianship Conference that was held in October, 1994 it was agreed that if the new adult guardianship laws are to be effective, self advocates, community advocates and legal advocates must work together, linked by shared values and principles.

A statement of values and principles was endorsed at the Conference and a first edition of a Directory of Advocates has been published. This Directory will be updated regularly as more people learn about the new

laws and alternatives to public guardianship.

In the next few months the network will be activated to take plain language information about the Health Care Consent and Care Facility Admission Act out to people in all of the regions of the Province. Members of the Network will help to organize meetings in their communities to find out what will ensure that adults rights under this Act are protected.

Efforts are underway now through Community Legal Assistance's Legal Advocacy Project and the Community Coalition's Advocacy Task Force to plan for the Prescribed Advocacy Organization that will provide rights information and representation before the Health Care Decisions Review Boards that will be set up under the new Act.

Nobody knows better than people who speak out on their own behalf or on behalf of others how lonely and frustrating it can sometimes be. The network is an antidote to loneliness. As one participant at the Advocacy Conference put it: "I liked the stories of other advocates - the inspiration. I feel revitalized. It is a struggle worth sticking to."

I hope that the stories in this newsletter will inspire you to join the Advocacy Network. □

In This Issue:

Banishing the Ghost of Incapability	1
Caring for Murray	4
New Public Trustee	5
An Advocate's Report	6
Surviving Abuse	7
Legal Advocacy	8
Cowichan Valley Workshops	9
News from the Community Coalition	9
Remembering Norma Klopp	11

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contributors.*

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*Submissions for the next issue
are welcome.*

Caring for Murray: A Family's Struggle for Gentle Care

by *Berta Michel*

My husband, Murray, was diagnosed in 1985 with Alzheimer Disease. He was 55 years old. The neurologist said he was probably seven years into the disease at that time. The doctor told me, 'just go home and do the best you can.'

Murray had had a brain injury in 1978 from an accident at work. He had been in the hospital in a coma for 13 days. Some research shows that trauma to the brain can trigger early onset of Alzheimer. Murray was never able to hold down a steady job after that incident. There was no worker's compensation, and he never received any disability pension either.

From then on Murray was left locked in his room all day...

I noticed that he began to be forgetful, and that he would fall asleep easily and at inappropriate times. He gave away a lot of his money. I never suspected dementia, however, because he had a wonderful sense of humour that covered any embarrassment.

Murray began to wander away often. He could cover

14 kilometers a day. I was still working full time as a hairdresser, so I was very concerned about his safety. We were referred to Mental Health. I asked whether I could keep my husband at home, because we had a large house and property and if I was able to quit work, I could quite happily look after him. I thought that I could also look after other people with dementia at our home, and have a family care home. In that way I could afford to stay home.

Mental Health said an emphatic "NO". They told me I could only do this with my husband's full time income and his help. They just didn't get it that I wanted to be home caring for him and that I couldn't afford to do so. I continued to work and leave Murray home, but I was very worried about it.

Later I asked Mental Health if I could get some respite care for Murray and they said the soonest was eight months. I arranged for Murray's son in Alberta to have him visit for two weeks. I told Mental Health about this and they proceeded to arrange for Murray's GAIN cheque to be cut off. While Murray was away he wandered away at 3 a.m. and was found in his pyja-

mas by the RCMP. He remembered our phone number and they called me. It's wonderful that long-term memory is the last to be lost with Alzheimer!



Berta Michel

As soon as Murray got home, I had to convince Social Services that Murray should receive his GAIN cheque again. And Mental Health was insisting that he go into care. They made me sign a document that said I would have to do my utmost for Murray's care or they would be able to sue me! By July 1988 I was convinced that Murray might do well in care. He went into Cottonwoods, an extended care facility.

Not long afterwards, Murray got into an altercation with a woman on the

ward who was very persistent and aggressive. As Murray tried to bat her out of his way, an orderly came to try and separate them. He tripped over Murray and fell and hurt himself. Immediately Murray was labeled as 'dangerous', even though the orderly explained that he had not been injured by Murray.

From then on Murray was left locked in his room all day. He received his meals in this room. When I visited we were locked in. If we wanted to visit in the lounge, everyone else was moved out and we were locked into it. If we wanted to stroll around the garden, everyone else was removed, and we were locked outside. I spent many hours there every day to keep him company and to watch over his well being.

Murray was kept heavily and inappropriately medi-

cated. His medications were designed for people with schizophrenia, and he certainly was not schizophrenic. One day he leaned against the wall as if resting his head. As a nurse and I watched, he sank down to the floor. The nurse said he probably thought there was a chair there, but I knew it was the medications.

I videotaped Murray's life there and told the facility that I would use the tapes if they would not reduce Murray's medicine. A new psychiatrist attended and prescribed a lower dosage, but within a week the dosage was upped to the original level. I was so discouraged I asked to take him home, and they agreed.

The day I signed the papers to bring Murray home I felt as if a great weight had lifted from my shoulders. Murray was thrilled to be home and to be free to move

around. He walked around and around the house, and soon was back to his 14 km a day. I learned a lot of techniques about caring for a person with dementia without using restraints or unnecessary medication.

I was still worried about how to afford to care for Murray without working at my job. I was asked to care for a woman with dementia by a family who wanted a supportive environment for their mother. In June 1989, I received a licence to be a family care home. From that time on I could care for Murray comfortably. On February 2, 1993, Murray died peacefully at home; never having had to leave his home again. □

Berta Michel is a member of the Alzheimer Society of B.C. and the Community Coalition.

Introducing the New Public Trustee

On January 16, 1995 the Attorney General appointed Dot Ewen as the new Public Trustee, the successor to Myrna Hall who resigned in July, 1994.

Prior to becoming the Public Trustee, Dot Ewen was Executive Director for 9 years of the Neurological Centre, a community rehabilitation centre.

Throughout her career she has been involved with co-ordinating government and community initiatives to promote independent living for people with disabilities, as co-ordinator of the Tranquille Project, the Provincial Inservice Resource Teams and executive director of Laurel House Society. She has acted as a valuable resource person to many groups in the community of people with disabilities.

The Guardianship Coalition welcomes Dot Ewen and wishes her success in her new role as Public Trustee.

At the Planning Group Table: An Advocate's Report

by Gregg Schiller

In September, 1993 I became the Chair of the Advocacy Task Force of the Community Coalition. This task force was set up to protect the principles of advocacy that are set out in the new guardianship law.

The Advocacy Task Force's job is to inform self-advocates and community advocates about the issues and keep them up-to-date on all the implementation activities so that they can speak up for themselves. At our Advocacy Conference, in October 1994, we were also directed to create a cross-disability advocacy network throughout B.C. This network would support people who are vulnerable.

The Task Force saw the need to keep an eye on the implementation of all four Acts of the new Guardianship legislation. In particular, we felt we had to focus our attention on the *Health Care Consent/Care Facility Admissions Act* (HCC/CFA).

The Advocacy Task Force nominated Berta Michel, Ludo Van Pelt and me as

community representatives to the HCC/CFA Planning Group. Monthly meetings are held at the Public Trustee's Office.

Some of the important issues raised at the HCC/CFA Planning Group are:

1. the right of an adult to make health care decisions with the support they need;
2. the right of an adult to make choices about where they want to live and receive health care with the support they request;
3. ensuring that consent is given for the use of restraints (chemical, physical and social);
4. the right to appeal decisions by the health care provider at Review Boards;
5. how to assess whether an adult is considered competent to make decisions;
6. how to educate the public on the new laws.

The HCC/CFA Planning Group has just completed

focus testing of proposed new policies and regulations. The testing concluded that much more information was needed from consumers. Our Advocacy Task Force will sponsor regional meetings with consumers based on the Coalition's Plain Language Guides.

The Plain Language Guides outline what the HCC/CFA Act says and then describe the issues that most need input from the people who will be affected. Two sensitive issues are the policies around the use of and monitoring of restraints in care facilities and the process for assessing capability to give informed consent.

Our experience on the Planning Group has taught us that representing the rights and needs of people who are most affected means being accountable and referring discussions back to people whenever possible. □

Gregg Schiller is an advocate at the B.C. Association for Community Living.

What is Plain Language?

- Plain Language explains things in every day language.
- It puts legal language into words we understand.
- It helps us understand our rights and gives us more power over our lives and choices.
- It helps us to communicate and to participate in making decisions about our lives.

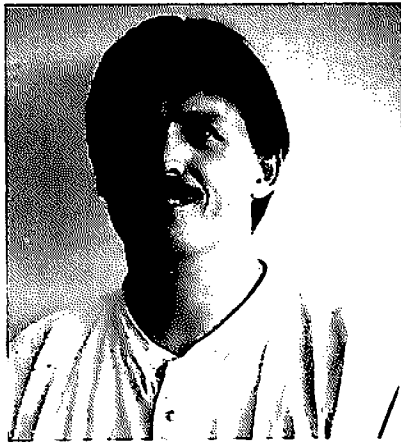
from the Plain Language Consultant's Group.

Surviving Abuse and Speaking Out

by Ludo Van Pelt

Do you ever feel that the bad way people treat you is all your own fault? That if you were a better person these terrible things wouldn't be happening? Have you ever needed help but been too afraid to ask for it?

Until 1990, I felt this way every day of my life. I lived for eight years in a residential rehabilitation program, and every day for eight years I was sexually abused.



Ludo Van Pelt

My hell began when I was eight years old. I had lived happily with my family in Nelson, B.C., going to the local elementary school. But by grade three, it was clear that I could not keep up with the school work. After being sent to Vancouver for testing, it was decided that I had a mental handicap and would need a "special school". In those days they did not have integrated schools. My parents

were advised to send me to Cedar Lodge Boys School in Mill Bay. I was a very sad and scared eight year old, in an institution with only three other young boys. Most of the boys were there because they had behaviour problems.

I did not know how to stand up for myself; I was not assertive and I allowed the boys to rule me. On the very first night I was there I was gang raped by the boys in my room. I was molested in the shower room; I was sexually assaulted in my bedroom. The boys told me never to complain or they would say that it was me who had asked for it. They told me that I must tell the staff that I liked it. Every night, when the boys were finished, I lay awake, unable to sleep. For awhile I tried to avoid having a shower so I wouldn't have to endure the abuse, but the staff insisted that I smelled so bad that I had to give in and have a shower.

I never told anyone about my experiences. I tried not to think about it. I was relieved when I turned 16 and left the institution. But I couldn't stop the painful memories. I couldn't stop the flashbacks that hit me when I least expected it. One day I was on a crowded bus, and I was pushed by people on all sides. I had a rush of horror and pain

flooded through me. I couldn't breathe, and I shoved my way to the exit. Another day, I got a ride with a man I didn't know. He began to fondle me, then shoved my head down to his crotch. I pulled away and opened the car door with the car still running, and hopped out. Moments like these kept coming up and I didn't know what to do.

When I married Patty, I told her about my hell. Patty's social worker told me there were counselling services available. I found out about SARA, the Sexual Abuse Recovery Association. I was able to get into one of their programs where I met men who, like me, had been abused. I learned some important things:

- 1 I am not alone; other men have had this experience and understand my feelings;
- 2 I can talk about these experiences without getting emotional;
- 3 I can manage the pain of the flashbacks, and can handle my feelings when this happens; and
- 4 I will not become a sexual offender myself. I was terrified that I would become an offender, and I learned that most men shared this fear.

Continued on page 8

Surviving Abuse and Speaking Out

... continued from page 7

When I started to get healing for my pain, some people, even in my own family, told me that what is past is past and that I about forget about it. But I know that you can't forget about it. If you do not talk about this pain, if you try to ignore it, you may always feel bad

about yourself.

Getting the counselling I needed has changed my life. Now I am able to talk about my experiences. Now I am able to support others who have had similar experiences. I am working with a group of self advocates at the B.C. Association for Community Living to write a booklet about abuse and what to do about it.

If you have had experiences like mine, I do hope that you will consider talking about it to someone you trust. I would be pleased to talk to you if you would like to contact me at the BCACL, #300 - 30 East 6th Ave., Vancouver V5T 4P4 or phone 875-1119. □

Ludo Van Pelt is a self advocate and a member of BCACL's Self Advocacy Caucus.

Legal Advocacy in the New Health Care Consent and Care Facility Act

by Brett Haughian

The enthusiasm surrounding a new law that gives us rights is always matched by the challenge of ensuring that the people who are affected by the law are able to exercise those rights. For the last seven months, Cecilia Kalaw and I have been funded by the Office of the Public Trustee to meet this challenge. We have been working on a project that deals with an adult's rights to receive legal advocacy services under the new *Health Care (Consent) and Care Facility (Admission) Act*.

Under this Act, an adult who is facing a health care or facility decision is entitled to receive the services of a legal information counsellor (LIC) and a legal advocate for the purposes of a review board hearing. It is essential that procedures and policies are developed which provide for an adult to receive proper notification, communication that is appropriate and a fair hearing.

The success of this service will depend on the degree to which it is responsive to the needs of adults who are affected by this legislation. Our project is committed to talking to in-

dividuals and groups about how to develop these procedures and policies. We welcome any ideas on the issue of legal advocacy, either directly to our project, or through the Community Coalition.

Please contact Brett or Cecilia at Community Legal Assistance, #800 - 1281 W. Georgia, 685-3425 (fax 685-7611) if you would like more information about the Legal Advocacy Project. □

Brett Haughian is a legal advocate with the Community Legal Assistance Society.

Learning How to Advocate: Cowichan Valley Workshops

by Laurie Williams &
John Auer

With limited government support for social programs and a growing need for these services by an increasing population of people with disabilities in the Cowichan Valley, a need for trained advocates was recognized by the Cowichan Valley Independent Living Resource Centre (CVILRC).

In response to this situation, the CVILRC held a one-day advocacy forum on February 10, 1995, followed by eight advocacy skills training workshops.

The purpose of the forum was to define the various forms of advocacy: self advocacy, individual advocacy, group advocacy, coalition building, and political lobbying.

The growing demand for advocacy support was a motivating factor in developing the volunteer advocacy

skills workshops. The issues most commonly addressed by the centre became the basis for the training.

The Independent Living philosophy focuses on the support of individuals in their endeavour to assume more control of their lives.

The March workshops included topics such as:

- Personal Empowerment/Independent Living Philosophy
- Communication Skills for Advocacy
- Casework Advocacy Skills
- GAIN and GAIN for Handicapped
- Negotiating with MSS
- CPP Information
- Tenancy Rights
- The School Act
- Children's Advocacy
- Mental Health Act Consumer Rights
- Communicating with Bureaucrats

Skilled advocates from the B.C. Coalition of People with Disabilities, Victoria's Together Against Poverty Society, Community Legal Assistance Society, and numerous resource people from the Cowichan Valley facilitated the training sessions.

The training was well received by the people attending the workshops. Many of the trainees expressed a desire to volunteer their newly acquired skills to assist the CVILRC. Some individuals also indicated they are interested in doing advocacy work at the local psychiatric unit and organizing a local poverty action committee. □

Laurie Williams and John Auer are advocates who live in the Cowichan Valley

News from the Community Coalition

by Christine Gordon

When the Community Coalition for the Implementation of Adult Guardianship was formed in January, 1994 its mission was a simple one - to promote alternatives to public guardianship. This mission is in keeping with the spirit and

the principles of the new adult guardianship laws that were passed in the B.C. legislature in July, 1993.

The new laws aim to make public guardianship a last resort by offering new opportunities to build alternatives through:

- representation agreements that will enable adults to choose one or more representatives to help them make decisions or to make decisions for them in health care, personal care, financial and legal matters;

continued on page 10

News from the Community Coalition

... continued from page 9

- providing people with assistance that will meet their needs, with assessment of incapability occurring only if their decision-making needs cannot be met;
- ensuring that advocacy is available to an adult when she or her family objects to a finding of incapability;
- creating a community-based response to abuse/neglect and self-neglect which offers support and assistance to adults who are at risk.

The Coalition represents the people most affected by guardianship - seniors, people with disabilities, and people with chronic illnesses. It is their voice that must be heard when the work of implementation is being done (making policies, writing regulations or designing programs that will make the new laws work). It is their experiences, desires and beliefs that must be the foundation of the community work that is essential to nurturing alternatives to public guardianship.

Here are some of the things that the Coalition's volunteers have been doing over the last year in order to realize what the Attorney General, Colin Gabelmann, has called "the community-

based intentions of the legislation."

The **Representation Agreements Task Force** facilitated 40 workshops on "Designing Representation Agreements from the Ground Up". This action research was compiled into a report that was shared at a Provincial Conference on Representation Agreements that was held in November, 1994.

Following up on the action plan that came from the Report and the Conference:

- a Committee is working on the legislative and policy recommendations that came from the workshops;
- a guidebook on Representation Agreements has been developed by the Network of Burnaby Seniors and is being field-tested by other seniors.
- a presenter's kit has been assembled to enable volunteer facilitators to help people in their local communities to learn about representation agreements and to support representatives.

The **Advocacy Task Force** is facilitating the development of a provincial advocacy network of self advocates, community advocates and legal advocates by:

- sponsoring a Provincial Conference in October, 1994;

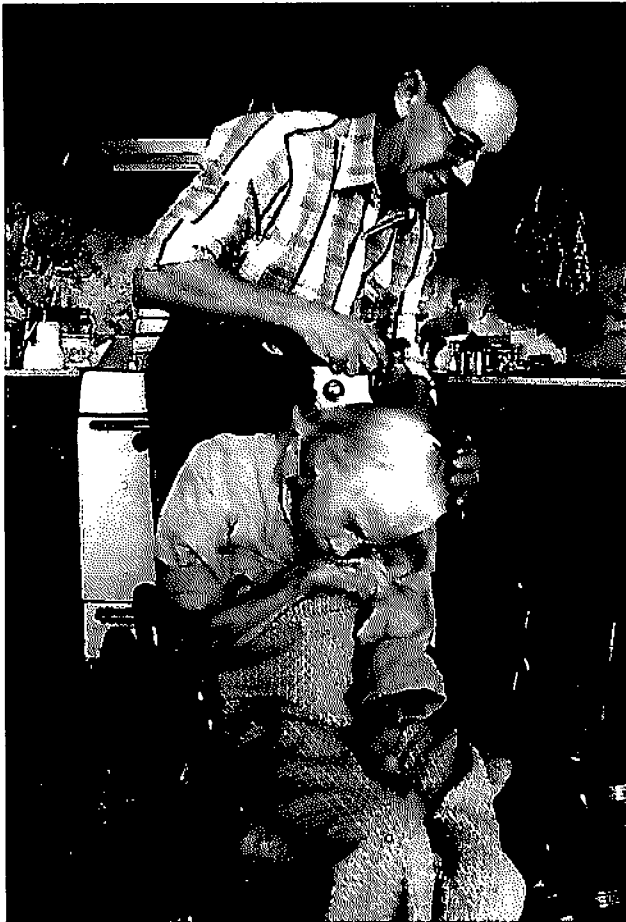
- publishing a directory of advocates;
- producing a plain language guide to the Health Care Consent and Care Facility Admission Act;
- planning an upcoming series of Provincial meetings that will allow consumers to use the plain language guide to discuss the policies for the Health Care Consent and Care Facility Admission law.

The Abuse/Neglect Task Force has sponsored:

- a practical guide to enabling consumers to become involved in community responses to abuse, neglect and self-neglect;
- action research with consumers in four communities which describes what helps to keep people safe.

Other Coalition members have used a Workbook on Court Process to facilitate discussions about how the Court Process should work to meet the needs of adults and their families.

Now the Coalition is encouraging the creation of regional and local volunteer committees to promote alternatives to public guardianship using the resources, networks and experience that has been developed over the last year. □



Tom and Norma Klopp - Vancouver Sun photo, 1993

Remembering Norma Klopp

by Christine Gordon

In the summer of 1993, the new package of guardianship laws was about to be put before the Legislature in Victoria. Those of us who had been working from the community's perspective to create these laws were anxious about how this legislation would be presented to the wider public - we very much wanted the citizens of the province to see these new laws as an opportunity to honour individual choices and to value the role of family and friends in helping a person to remain a unique individual to the very end of her life.

We thought that we should try to interest

the media in presenting this perspective and we set about the usual round of press releases and cold calls. I must say that we weren't having a great deal of success in stirring the passions of the media--it wasn't a barn burner of a story. But then we persuaded a reporter to go out and visit Tom and Norma Klopp. She did and when she returned she and her editor decided not only did they have a story--they had a front page story.

What was it, I asked the reporter, that persuaded you? As part of her reply about the warm reception she had received in the Klopp's home she said "you know, while I was visiting, Norma lifted her head and said to her husband, 'Tom, put some cookies out for our visitor.' It hit me then what all of you had been talking about." And so, the *Vancouver Sun* had the best front page in recent memory, thanks to Norma Klopp's grace as a hostess.

The members of our guardianship coalition had many opportunities to meet and know Norma because Tom rarely came to a meeting without her. She was quiet for the most part, but she usually smiled and sometimes joked about the length of our meetings. She and Tom danced together at one of our parties despite the fact, as Tom whispered to me, it wasn't really their kind of music.

When Tom occasionally arrived alone, a meeting didn't seem quite the same. As long as we could see Norma, we knew what we were about. Because, even though we met her at the end of her life when she could no longer express herself as easily as she would have liked, we knew that this was Norma Klopp, the woman with a wry sense of humour, the dancer, the mother, the gracious hostess, the woman who convinced the *Vancouver Sun* that honouring the unique gifts of every individual, no matter how frail, was front page news. □

Tom and Norma Klopp are long-time members of the Guardianship Coalition. Norma died on February 21, 1995.

Purposes of the Community Coalition:

1. To provide a way for people who are immediately and critically affected by guardianship laws to speak with one voice.
2. To promote the community's work of keeping people safe and honouring their choices.
3. To build on community strengths when putting the adult guardianship laws into effect.
4. To promote community alternatives to public guardianship.

Information Available Through the Coalition Office:

- The Representative Agreements Task Group Report (October, 1994)
- Designing Representation Agreements from the Ground Up: A Presenter's Kit
- Guidebook to the Representation Agreement (2nd edition forthcoming)
- Building an Advocacy Network: Report on the Advocacy Conference (December, 1994)
- The Provincial Advocacy Directory (January, 1995)
- A Practical Guide to Discussions with Consumers about Abuse/Neglect and Self-Neglect (April, 1995)
- Plain Language Guide to Health Care (Consent) and Care Facility (Admission) (April, 1995)

Would You Like To Join Us?

The Guardianship Coalition is made up of:

- **Provincial Organizations** - like Seniors Resources and Research, BCACL, the Alzheimer Society, BCCPD, the West Coast Mental Health Network, the Council of Senior Citizens Organizations;
- **Local Groups** - like the Network of Burnaby Seniors, Family Link, ACE, Self-Advocates on the Move, Kamloops Seniors Liaison Council;
- and more than 300 individuals.

Would you like more information about how to get involved? - write, phone or fax us at:

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