

Welcome!

On behalf of the Murray Alzheimer Research and Education Program (MAREP) and our partners, the Alzheimer Society of Canada, the Alzheimer Society of Ontario, and the Dementia Advocacy Support Network International, I would like to welcome you to *A Changing Melody*. This learning and sharing Forum, specifically designed for persons with dementia and their partners in care, is the first of its kind in Canada.

The idea for *A Changing Melody* came from a person with dementia who had developed a tool to help him cope better with his memory loss. He contacted MAREP looking for a venue where he might share his tool with others. We found very few opportunities available that brought persons with dementia and their partners in care together with others experiencing dementia to learn with and from one another. In discussion with our partners, we decided it was definitely time to provide such a forum and *A Changing Melody* was born.

This forum was conceived out of the need to develop meaningful partnerships between people with dementia, their families, and all others involved in dementia care – partnerships that value the diverse expertise, perspectives, and experiences of all involved in dementia care. It was guided by recent research that demonstrates that people with dementia can learn and adjust to their illness, contribute to their own care, and live meaningful lives if provided with adequate information, resources and support.

Rather than viewing people with dementia as incapable of learning, growing and contributing to their own care, therefore, we strongly support the presumption of competency, and that all persons with dementia have the right to autonomy, to speak for themselves, and to have their voices heard and respected. This event will provide an opportunity for persons with dementia and their partners in care to become more informed about dementia so they can become more active in their own care and become stronger advocates for themselves and others with dementia.

Finally, by providing persons with dementia with a significant voice at this forum, we work towards breaking down the silence of dementia and the stigma and fear associated with it. This is an important step in the building of strong mutual support systems and providing the highest quality of life for all those living with an illness causing dementia.

Enjoy the forum. Use this as an opportunity to meet others experiencing similar situations and share your ideas, stories, and coping strategies with others. And, when you leave the forum today, we hope that you feel better equipped to LIVE with an illness causing dementia and to ADVOCATE on behalf of persons with dementia and all those involved in dementia care.

Sherry L. Dupuis, Ph.D.
Associate Director, Research

A Changing Melody **Forum Planning Committee**

Murray Alzheimer Research and Education Program

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We would also like to thank Christine Jonas-Simpson, Cathy Conway, Suzie Gregg, and Gillian Flynn-Reuss for their help with the Forum.



We wish to express our appreciation to the following:

Sponsors

Pfizer Canada Inc.
Shopper's Home Health Care
The Homewood Foundation
The Kitchener and Waterloo Community Foundation
UW/SSHRC Research Grants Program

Exhibitors

Janssen-Ortho Inc.
Pfizer Canada Inc.

We would also like to thank Alzheimer Society of Canada and Alzheimer Society of Ontario for providing travel funds.



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See the additional pamphlets enclosed in your registration bag for more resources and information on dementia.

Forum Schedule

8:30 - 9:15 Light Continental Breakfast and Registration

9:15 - 9:30 **Welcoming**
Scott Millar, Dr. Michael Sharratt

9:30 - 10:30 **Opening Speaker: Dr. Les Sheldon**
Getting the Most Out of Today

10:30 - 11:00 Break

11:00 - 11:45 **Workshop A: Living with Dementia**
Linda Westbrook, Brenda Hounam

11:45 - 12:00 **One More Memory**
Sara Westbrook

12:00 - 1:00 Lunch

1:00 - 1:45 **Workshop B: Adapting and Enhancing Leisure Activities**
Marilyn Truscott

1:45 - 2:00 Break

2:00 - 2:45 **Workshop C: Advocacy and Dementia**
Marge Dempsey, Lynn Moore

2:45 - 3:00 Break

3:00 - 3:45 **Workshop D: Planning Ahead**
Judith Wahl

3:45 - 4:00 **Closing Remarks**
Dr. Sherry Dupuis (MAREP)

4:10 - 5:00 **Premier of “I’m Still Here”**
A research-based play on the experience of dementia

5:00 - 5:30 Open Discussion on “I’m Still Here”

Getting the Most Out of Today



Dr. Les Sheldon

Geriatric Psychiatry Program
St. Joseph's Hospital
Vancouver, B.C.

Getting the Most Out of Today

We are much further ahead today than we think we are. If we can broaden our perspective and be proactive instead of reactive, both quality and quantity of life can be improved. A passionate and knowledgeable geriatric psychiatrist will fill this presentation with optimism and hope. Dr. Les Sheldon will deliver information on what medications are presently available to persons with dementia, and how to use these to their maximum capacity.

Workshop A: Living with Dementia



Linda Westbrook and Brenda Hounam

Linda is a Grief Consultant and Former Caregiver in Elgin County. Brenda is a retired Industrial Accountant and a Provincial Speaker for the Alzheimer Society, and a person living with dementia in Paris, Ontario.

Caregiving“R’S” to Give and Receive

1. **Research** your loved one’s condition. Check into services available in your community.
2. **Reassure** your loved one that you will be there for them.
3. **Respect** the opinion of your loved one. They know their bodies best. Celebrate their independence.
4. **Receive** advice with a smile and sense of gratitude. Know that people want to make a difference.
5. **Realize** you are only one person. Accept help.
6. **Remember** to allow yourself and your loved one to grieve the loss of good health.
7. **Rise** above the small aggravations. See the bigger picture. Know that you and your loved one would rather be anywhere else but here.
8. **Rely** on your inner self. Listen to your body. Follow its instructions.
9. **Rearrange** your loved ones space to provide convenience, safety and comfort.
10. **Rejuvenate** through rest and relaxation. Continue to indulge yourself in your favorite activities.
11. **Restore** your energy by drinking plenty of water and eating nutritiously. When you take care of yourself you can care for another.
12. **Re-evaluate** your role continuously. If you are overwhelmed seek help from family/friends, professionals and support groups.

Workshop B: Adapting and Enhancing Leisure Activities



Marilyn Truscott

Retired Researcher

Volunteer, Alzheimer Society of Hamilton-Halton
Person who lives with Dementia, Hamilton, Ontario

Creative and Recreational Activities for People with Early Stage Alzheimer Disease and Related Disorders

By Marilyn Truscott
for *Alzheimer's Care Quarterly*, 2004

Advice for Happy Hobbying

1. Do small, achievable projects that are not too complex for you.
2. Don't do anything with too many steps, until you are practiced at it or unless you have help.
3. Don't worry about doing it perfectly or failing. Just try it, and focus on enjoying the motions, the colours, and the textures.
4. Consider your particular abilities – can you safely use scissors, paints, hot equipment, electrical equipment, etc.? Keep your own particular difficulties in mind when you choose your hobby. Get advice about this from professionals (your doctor, recreational, rehabilitation and occupational therapists).
5. Work only when you are rested. Don't do your hobbies when you are mentally fatigued.
6. Stop working at the first hint of tiredness. The idea is to have FUN, not to feel pressured, frustrated or tired. Do your hobby in little bits of time.
7. Get help from recreational, rehabilitation and occupational therapists. Get ideas of how to do your hobby or interest with your present abilities; get ideas on projects that are suitable AND SAFE for you as an individual.
8. Talk to hobby and craft store staff for ideas and for help, and for classes.
9. Search in your community for easy-to-do activities where things are provided for you and there is a lot of hands-on help. Try Seniors Centres, Community Centres. Ask your doctors and the rehabilitation experts where to go in your area.

Suggestions for Easy Activities

Remember – some of these activities will not be suitable for everyone because of some safety issues. GET PROFESSIONAL ADVICE AND HELP.

1. Stamp collecting – collect themes, time periods, put in ring binders to enjoy the pictures
2. Paint-by-number – all equipment is provided in the kit. Don't worry about the lines
3. Metal foil etching kits – make pictures by marking or pounding on foil. All equipment is provided in the kit.
4. Painting with fabric paints:
 - a. Use stencils or free-hand.
 - b. Paint on ready-made aprons, T-shirts, caps, bags, gloves, clothing, placemats, tablecloths, pillows, etc.
 - c. Paint on fabric pieces and fabric squares to make up into quilts, clothes, wall-hangings, pillows, placemats, tablecloths, table runners.
 - d. Paints come in paint-pot sets attached in a row; easy to keep organized; or in larger jars; or squeeze bottles.
 - e. You can make tie-dyes of all kinds, in plastic bags or in pails.
5. Drawing and painting with fabric crayons:
 - a. Different kinds are available: one kind you draw on paper and then iron your drawing face down on the fabric piece; the other is a pastel crayon and you draw directly onto the fabric, then iron it in with a paper between the iron and the fabric.
 - b. Make up into quilts, clothes, wall-hangings, pillows, placemats, tablecloths, table runners.
6. Painting with acrylic paints:
 - a. Paint on paper, masonite board, canvas.
 - b. Acrylic paints are washable; so easy to clean up and they don't smell.
 - c. Paints come in attached little pots (easiest to keep organized), or bottles, or tubes.
 - d. Things to do: make pictures, painted canvas rugs, memory book covers, paint wooden chairs, milk cans, pails, wastebaskets.

7. Painting with plastic paints:
 - a. Paints come in attached little pots (easy to keep organized).
 - b. Things to do: paint plastic containers, cups, tumblers, plastic outdoor furniture (finish with a coat of outdoor plastic preservative – ask at the paint store or hobby store. Do this in a well-ventilated place.)
 - c. Use stencils or do free-hand paintings.
8. Painting with glass paints:
 - a. Paints come in attached little pots (easy to keep organized).
 - b. Things to do: paint glass containers, vases, plates, cups, glasses.
 - c. Use stencils or do free-hand.
9. Drawing on paper:
 - a. Use charcoal, pencil, pen and ink, oil or chalk pastels, marker pens.
 - b. To preserve charcoal, pencil or pastel drawings, spray surface with special spray-on sealer (ask at craft store. Do this only in a well-ventilated place.)
10. Preserving flowers – make cards, pictures.
11. Leaf prints on paper and cloth – make cards, pictures.
12. Felt: glue, stitch to make pictures, animals, frames, tablecloths, pillows, etc.
13. Wool collages: cut lengths of wool and sew them or glue them onto a backing (cloth or burlap) to make a design.
14. Working with fabric : Raw-edge quilting:
 - a. Cut pieces of fabric and stitch them onto a backing, stitching $\frac{1}{4}$ to $\frac{1}{2}$ inch from the outside edge.
 - b. Use embroidery thread or pearl cotton.
 - c. After you have put your pieces together, wash the item and dry it well in the dryer to make the raw edges fluff up.
 - d. To make sure it will be very fluffy, before you stitch the pieces onto the backing, make short cuts into the edge of your pieces (cut perpendicular to the raw edge). Do your stitching inside these little cuts to keep the edges secured.
 - e. You can even make a raw edge crazy quilt: pin together odd-shaped pieces of varying fabrics and stitch them so that raw edges show.

15. Collages with glue:
 - a. Put pieces of cloth on a cloth backing or on paper and fix them in place using glue.
 - b. Add ribbon, beads, buttons, pieces of yarn.
 - c. Use pictures from magazines and catalogues, photos, wallpaper pieces, wrapping paper.
16. Wood crafts :
 - a. Wood burning.
 - b. Sanding, smoothing of driftwood and tree branches.
 - c. Use small pre-cut kits for bird-houses, etc. with glue and nails.
 - d. Wood carving – be careful with tools and use the softest wood.
17. Music – play tapes, instruments, compose music, sing along to taped music, join a choir for fun. Try bells, drums, chimes, dulcimer, marimba, recorder, harmonica, any simple instrument to make enjoyable noise and rhythm.
18. Fun with plants – grow plants, try unusual plants (e.g. fly-catchers, cacti); make a miniature indoor garden with tiny cacti – doesn't take much space or care, just sun.
19. Birds and bird-watching – keep a log of your birds, collect pictures.
20. Things with stones - - yard designs, garden paths, sculptures, decorate mirrors and picture frames, etc.
21. Making mosaics with pieces of pottery, china, small tiles, stones, beads, shells, marbles – and more. Be careful with broken pieces of pottery and tiles as their edges are VERY sharp. Make garden stepping stones, cover vases, garden plant pots big and small.
22. Things with floppy plastic – cut and glue or use pre-cut pieces. Make pictures, coasters, placemats.
23. Make jewelry – make beads from soft plastic that you bake or roll paper into beads; string pre-made beads. Roll and shape fine wire for jewelry.
24. Decorate lamp-shades – be careful not to use flammable materials.
25. Photography.
26. Video-photography.
27. Poetry writing – it does not have to rhyme!

28. Creative writing or creative taping – your short stories, memoirs, family stories, family history.
29. Write a “Journal of Joy” – 5 things a day that made you happy, were wonderful, or that you like about yourself.
30. Painting with sand: paint glue on a vase or plate, then drizzle coloured sand in a pattern onto the glue.
31. Stitchery – cross-stitch and needlepoint. Use simple patterns and large grid cloth.
32. Sculptures: with soft wood, soapstone, clay, plaster molds, plasticine, even bakeable bread dough and dough made of flour and salt (there are dough recipes just for this purpose).
33. Make collages of your favourite pictures (planes, cars, flowers, people, costumes, etc.) and glue them onto stiff paper. Cover with clear MacTac (adhesive-backed clear plastic paper). Cut into shapes for coasters, placemats, table-coverings.
34. Kits for making model airplanes, model cars, etc.
35. Painting pottery – there is green-ware to paint to suit every interest, from dishes, vases, ornaments, cars, animals, to chess sets. Find a pottery shop.
36. Decoupage – gluing decals and pictures on wood and varnishing and polishing several layers. Can be done on some other hard surfaces also.
37. Making aprons, vests, shorts from pre-printed cloth panels – stitch with a machine, hand-sew, or use blanket stitching.
38. Origami – Japanese paper-folding. Make animals, flowers, boxes, etc.
39. Make mobiles to hang from the ceiling – use your imagination.
40. Rug-hooking; rug-braiding; rug-knitting, etc.
41. Leaf pounding on paper and cloth – make cards and pictures, cloth objects.
42. Memory books, albums and scrap-books.
43. Stamping, using stamp-blocks and ink pads; Stenciling; Metal foil embossing:
 - a. Things to do: make cards, letter paper, memory album decoration, or just have fun.
 - b. You can colour or paint parts of the stamping, using marker pens or paints.
44. Make things into wind chimes.

45. Make water fountains – essentially a small water pump in a waterproof pail of water, covered with a grill and then put stones or other objects over the grill to have the water spout pour over the stones.
46. Soap making and candle making are possibilities but are dangerous due to the hot liquids. Do this with great care and with help.
47. Decorate mirrors, book covers, album covers, picture frames with beads, shells, stones, small mosaic tilings, other small objects.
48. String beads into curtains, wall-hanging.
49. Making simple pottery.
50. Painting plaster figurines using acrylic paints (ornaments, Christmas Village houses, animals, garden figures, etc.).
51. Paper tole, making pictures and cards. This requires extreme skill with scissors and good hand-eye coordination and therefore will not be possible for everyone to do.
52. Quilling – using thin pre-cut ribbons of paper and making designs on cards, pictures.

There are many more ideas for you at the craft stores, and all kinds of easy-to-do kits available.

HAVE FUN. ENJOY THE PROCESS. ENJOY THE RESULT.

Life Story Ideas for Scrapbooks, Photo Albums, Tape Recordings, Video-Tapes and Memory Books

By Marilyn Truscott
for *Alzheimer's Care Quarterly*, 2004

Here are some ideas for getting you started making up a life story album or scrapbook or family history or even working on your own short stories or memoirs.

If you can not write well, use a tape recorder or a video recorder and if you want, get someone to transcribe your spoken words into typed form to add to pictures or make a book.

These ideas are just a rough guideline to get you started. There are many other interesting topics you might want to pursue that are not listed here. Ask other people for their ideas.

1. My name – given name, pet names, what I like to be called.
2. Where I was born, details of my childhood.
3. My parents' names – when and where they were born, what they were and are like, stories about them.
4. My sisters and brothers - when and where they were born, what they were and are like, stories about them.
5. My wife/husband - when and where they were born, what they were and are like, stories about them.
6. My children, grandchildren - when and where they were born, what they were and are like, stories about them.
7. My friends and other family members – stories about them.
8. My schooling, where, when; stories about my school life, and life in college or university.
9. My wedding, when, where, who attended, clothing we wore, stories about the wedding.
10. Other special occasions – birthdays, anniversaries, graduations.
11. Special presents I received.

12. When and where I worked, what I did, people I worked with and stories about my working life.
13. What were my favourite memories of my working life, school days, etc.
14. The clubs and associations I belonged to and still belong to.
15. The sports I like to do and used to do
16. My favourite cars I owned, boats, etc.
17. The houses I lived in: when, where, what they were like, memories of the time living there.
18. My pets; stories about my pets.
19. What I like to do in my leisure time – hobbies, travel, etc.
20. My favourite foods, restaurants.
21. Museums, galleries, fairs, historical buildings, exhibitions, amusement parks, zoos, other places I've enjoyed touring – where and why.
22. Books, music, movies and other entertainment I like and/or used to like.
23. My favourite clothes – memories of some of my clothing.
24. Shopping excursions, antiquing, garage sales – stories of places I've been, things I've bought.
25. What I dislike – foods, activities, etc.
26. What makes me really joyful.
27. What my goals in life have been.
28. What I want to do in the next year, next five years, next ten years.

From an article by Marilyn Truscott, "Adapting Leisure and Creative Activities for People with Early Stage Dementias" in *Alzheimer's Care Quarterly*, 2004. Lippincott, Williams and Wilkins.

Article available from:

Lippincott Williams & Wilkins
PO Box 1620
Hagerstown MD 21741
1-301-223-2300

Workshop C: Advocacy and Dementia



Marge Dempsey and Lynn Moore

Marg is the Director of Family Support for the Alzheimer Society of Niagara Region in St. Catharines, Ontario.

Lynn is the Director of Public Policy and Government Relations at the Alzheimer Society of Ontario in Toronto.

Advocating for Dementia

A Changing Melody

November 2004

Why Advocate

- Squeaky wheel
- Many competing demands, most valid
- Louder voices

Why Self-Advocacy

- Credibility
- Powerful message
- Human face
- Self esteem and sense of control

What is Advocacy

Making the case for someone or some group of people or helping them to represent their own views, usually to defend their rights or to promote their interests

Alzheimer Scotland

Individual Advocacy

- Break down barriers that prevent person from having needs addressed
- One specific case
- Usually involves direct, defined conflict with another individual or agency
- Not case management or help with navigating system

Self-advocacy is usually individual advocacy

Systemic Advocacy

- Behalf of classes/groups of individuals or society as a whole to break down barriers in systems
- Can become individual advocacy after a systemic change has occurred

Usually provincial in scope, but vital role for people with dementia and the caregivers / family to support systemic advocacy

Voice in Policy-making

- Traditionally providers & government have consulted on policy
- Need to add voice of consumers of services
 - Systemic advocacy
- Uncertain how to best do this
 - Balance perspective between caregiver & person with dementia
 - Research underway

ASO's Project

- Small group of people directly affected by ADRD
- Goals to inform ASO's public policy work and to be trained spokespersons
- ASO will provide support and knowledge about system, issues and how to influence public policy
- Based on input from focus groups

Speaking for Someone Else

- Self-advocacy continues through out life
 - Substitute decision-maker
- SMD – represents the wishes of the person
- Important to choose SDM & talk about wishes

Tips for Advocacy

- Examine your beliefs and values to ensure what is most important to you will be honoured and addressed
- Seek out someone you trust as a coach/mentor to support self-advocacy
- Start at the beginning & face-to-face where possible
- Try to clearly & briefly state what it is you need & why
- Plan ahead with your coach/mentor how you will signal that you would like them to step in for you..
- When all else fails go to your MP/MPP and media as a Last Resort

Never Give Up!

Individuals need to self advocate for:

- Personal Choice/Autonomy
- Access to a proper assessment for diagnosis and available medications/cognitive enhancers
- Entitled resources to meet their financial needs
 - Workplace insurance benefits / LTD
 - Disability tax credits
 - CPP disability
 - ODP benefits
 - Mortgage Insurance
 - Ontario Works

Individuals need to self advocate for:

- Transportation
 - Driving
 - Disabled transit
- Legal/financial procedures
 - POA for property and personal care
 - Wills
 - Advanced directives
- Housing
 - Current and Future Needs
- Therapeutic supports
 - Occupational therapy
 - Speech Therapy
 - Etc.
- Life enriching activities
 - Personal
 - Social

KEEPING RECORDS

Keeping records is very important as you go along.

Remember to take as many notes as you can about:

- ✓ who you talked to
- ✓ when you talked to them
- ✓ what was said
- ✓ what action they said they would take
- ✓ when and how they will let you know that action has been taken
- ✓ what action you said you would take
- ✓ whether you need to call them back

You could:

- ✓ write in a notebook
- ✓ use a tape recorder
- ✓ ask someone to take notes for you

KEEPING RECORDS

It's important to keep copies of everything, such as:

- ✓ your notes
- ✓ letters people send you
- ✓ letters you send to people
- ✓ policies and procedures

In order to keep all this information together, you could use:

- ✓ an large envelope to keep all your papers together
- ✓ a file folder
- ✓ a three ring binder
- ✓ your own system

**REMEMBER TO PROTECT THE PRIVACY OF PERSONAL
INFORMATION**

CODE OF ETHICS FOR ADVOCATES

Advocates:

- encourage & support others to advocate for themselves
- educate themselves about advocacy resources – before they start to help others
- obtain consent before they speak or act on someone's behalf
- make sure their own values & belief systems do not interfere with the right of individuals to make their own decisions
- put the interests, preferences, & decisions of the individual above their own when acting on someone's behalf
- never make false or misleading promises about the advocacy process or their role, skills or qualifications

CODE OF ETHICS FOR ADVOCATES, cont'd

- advise individuals to be honest
- advise individuals about the consequences might be of a particular plan of action
- respect confidentiality & ensure that they receive consent to release information
- declare potential conflict of interest in their advocacy activities
- respect cultural social & individual diversity
- continue to learn & maintain their advocacy knowledge & advocacy skills
- withdraw in a professional manner when their services are not longer needed

* Alzheimer Society British Columbia, June 2002.

Code of Ethics for Advocates *

1. Advocates encourage and support others to advocate for themselves.
2. Advocates educate themselves about advocacy resources – before they start to help others.
3. Advocates obtain consent before they speak or act on someone's behalf.
4. Advocates make sure their own values and belief systems do not interfere with the right of individuals to make their own decisions.
5. Advocates put the interests, preferences, and decisions of the individual above their own when acting on someone's behalf.
6. Advocates never make false or misleading promises about the advocacy process or their role, skills or qualifications.
7. Advocates advise individuals to be honest.
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10. Advocates declare potential conflict of interest in their advocacy activities.
11. Advocates respect cultural social and individual diversity.
12. Advocates continue to learn and maintain their advocacy knowledge and advocacy skills.
13. Advocates withdraw in a professional manner when their services are not longer needed.

* Alzheimer Society British Columbia SELF-ADVOCACY WORKSHOP: BUILDING SKILLS TO HELP OURSELVES AND OTHERS, June 2002.

ADVOCACY AND KEEPING RECORDS*

Keeping records of your advocacy efforts is very important. Here are some tips...

It is important for individual advocates to keep records as they go along. Remember to take as many notes as you can about:

- who you talked to
- when you talked to them
- what was said
- what action they said they would take
- when and how they will let you know that the action has been taken
- what action you said you would take
- whether you need to call them back

You could:

- write in a notebook
- use a tape recorder (tell the other person(s) you are going to record the conversation)
- ask someone to take notes for you

You could end up collecting a lot of information. It's important to keep copies of everything, such as:

- your notes
- letters people send you
- letters you send to people
- policies and procedures

You will need a way to keep all this information together. You could use:

- an old envelope to keep all your papers together
- a file folder
- a three-ring binder
- your own system

Workshop D: Planning Ahead



Judith Wahl
Executive Director
Advocacy Centre for the Elderly
Toronto Ontario

Advance Care Planning and Health Care Consent

**Advocacy Centre for the Elderly
Judith A. Wahl**

Advocacy Centre for the Elderly

- Legal advice and representation
 - Public legal education programmes
- www.advocacycentreelderly.org**

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ACE 2003

Objectives

- Discuss the legal context of Consent and Advance Care Planning
- Discuss the difference between Advance Care Planning and Consent

ACE 2003

Legal Context of Decision-making

- Health Care Providers must get a consent or refusal of consent to a treatment
- In an emergency, Health Care providers do not need consent in order to treat
- In an emergency, Health care providers must follow any known wishes of the patient in respect to treatment

ACE 2003

Legal Context of Decision-making (2)

- A Patient, if mentally capable for treatment decision-making, is the decision-maker
- A Patient can also express WISHES about future health treatment (Advance Care Plan)
- An Advance Care Plan is NOT a consent

ACE 2003

Legal Context of Decision Making (3)

- If the Patient is not mentally capable, then his or her Substitute Decision Maker (SDM), is the decision-maker
- SDMs can only Consent or refuse Consent to treatments and cannot Advance Care Plan
- SDMs must follow the wishes (advance care plans) of a patient when making treatment decisions for the patient if known

ACE 2003

Capacity- Legal Definition

- Mental Capacity is a socio-legal construct and its meaning varies over time and across jurisdictions
- Assessment/Evaluation refers to a legal assessment not a clinical assessment
- Clinical assessments underlie diagnosis, treatment recommendations and identify or mobilize social supports
- Legal assessments remove from the person the right to make autonomous decisions in specified areas

ACE 2003

Capacity - Legal Definition

Capacity is a cognitive test - - not a functional test

Indicators are:

- Understand (factual knowledge and problem solving ability)
- Appreciate (realistic appraisal of outcomes and justification of choices)

ACE 2003

Who Assesses Capacity in Respect to Treatment?

- The health practitioner who proposes a treatment is required to form the opinion about the capacity of the patient to consent to treatment
- If a plan of treatment is proposed, one health practitioner on behalf of all the health practitioners involved in the plan may determine the patient's capacity for treatment

ACE 2003

Disclosure

- Must provide information in manner and way that particular patient can understand it
- Reasonable Person Standard - Information should be what a reasonable person would require to make a decision
- Health practitioner must also answer questions posed by patient in the course of getting the information

ACE 2003

Disclosure (Informed Consent)

Patient must receive information on the

- Nature of the treatment
- Expected Benefits of the Treatment
- Material Risks of the Treatment
- Material side effects
- Alternative Course of action
- Likely consequences of not having the treatment

ACE 2003

Disclosure - Culture

- Must get consent from patient but can accommodate culture within context of legal requirements
- Cultural differences and accommodations do not take precedent over legislated requirements

ACE 2003

Advance Care Planning

- Describes care and treatment that a person wants in the future when he or she is no longer mentally capable for decision making about treatment
- May focus on end of life care or also include wishes about care and treatment over course of life
- May provide information on patients values and beliefs to guide SDM's decision- making when the patient is mentally incapable

ACE 2003

Advance Care Planning

- Does not need to be in writing
- Wishes may be expressed at any time that a patient is mentally capable in respect to decisions about the subject of the wish
- Later wishes, however communicated, expressed while capable prevail over earlier wishes
- This is true even if the previous wishes were in writing and the later wishes are oral

ACE 2003

Problems of Advance Care Plans

- Wishes Change, particularly as health condition changes
- Not possible to anticipate given illness
- Vague language leading to misinterpretation
- Treatments change as Science advances so wishes would likely have been different if could anticipate advances

ACE 2003

Options for Advance Care Planning

- Wishes Expressed Orally
- Written Documents
 - (a) Power of Attorney for Personal Care
 - (b) Written Advance Directive
 - (c) Living Will
 - (d) Level of Care Form
- Wishes expressed by Other Means
 - (ie.Bliss Board)

ACE 2003

Wishes Expressed Orally

- Some people may not want to write down wishes but will want to express wishes orally.
- Oral wishes are as valid as written wishes
- Written wishes may be changed by later oral wishes
- Oral wishes may be recorded in chart or plan of care

ACE 2003

Written Wishes

- Can be in form of Power of Attorney for Personal Care (POAPC) or Advance Directive/Living Will
- POAPC is format in the Ontario Legislation
- POAPC names SDM (attorney) and may also include wishes about care , must be in writing, made when mentally capable, must be signed by person in presence of two witnesses

ACE 2003

Written Wishes

- Advance Directive/Living Will - only mentioned in the legislation as “Wishes”
- Not a specific format- Usually just a statement of wishes about health care and no appointment of SDM
- Only POAPC gives authority to name SDM

ACE 2003

Written Directives

- Person CANNOT be required to sign facility Advance Directive as condition of admission or to receive treatment or NOT receive treatment (ie No CPR)
- Only patient when capable can sign either POAPC or Advance Directive/Living Will
- SDM CANNOT advance care plan

ACE 2003

Who does Advance Care Plan “SPEAK” to?

- Wishes/Advance Care Plans are directions to future SDMs NOT to Health Practitioners except in an emergency
- Wishes, whether written, oral or expressed in any other manner are interpreted by SDMs as Health Providers always need to get consent from capable patients or SDM if patient is incapable

ACE 2003

Substitute Decision Makers (SDMs)

1. Guardian of Person
2. Attorney in POAPC
3. Representative appointed by Consent and Capacity Board
4. Spouse or Partner
5. Child or Parent or CAS (Person with Right of Custody)
6. Parent with right of access
7. Brother or Sister
8. Any other relative
9. Public Guardians or Trustee

SDMs

- List is Hierarchical
- All persons on same level have equal right to be SDM (ie all brothers and sisters equally rank)
- Person ALWAYS has SDM if incapable as OPGT is SDM if person has no one higher on hierarchy or if conflict between equal ranking SDMs

ACE 2003

Requirements for Person to be an SDM

Person highest in hierarchy may give or refuse consent only if he or she:

- a) is capable in respect to the treatment
- b) is at least 16 years old unless the parent of the incapable person
- c) is not prohibited by a court order or separation agreement from acting as SDM
- d) is available
- e) is willing to act as SDM

ACE 2003

How SDMs Make Substitute Decisions

It is the responsibility of the SDM to make treatment decisions for an incapable person by:

- a) following any wishes of the patient expressed when capable that are relevant to the decision; and
- b) if no wishes are known or are relevant to the particular decision, to act in the best interests of the patient

ACE 2003

Health Care Providers and Conflict with SDMs

If doubt SDM is fulfilling his/her role:

- Check if he/she understands the patients condition
- Check if he/she appreciates implications of the illness, treatments, risks, benefits for the patient
- Get a second opinion about your interpretation of illness and treatment options
- Consult Bioethicist
- Make Application to Consent and Capacity Board

ACE 2003

Applications to Consent and Capacity Board

1. Application by SDM or Health Practitioner for directions if patient had expressed wish and wish not clear etc.
2. Application by SDM or Health Practitioner to depart from wishes
3. Application by Health Practitioner to determine if SDM in compliance with HCCA s. 21 (wishes/best interests)
4. Application by Person to challenge finding of Incapacity to Make Treatment Decisions



Advocacy Centre for the Elderly – ACE

ACE Website: www.advocacycentreelderly.org

Materials and Links on ACE Website related to Powers of Attorney and Advance Care Planning

ACE Publications

- [Advance Care Planning and End of Life Decision-Making: More than just Documents](#)
- [Advance Care Planning in Ontario](#)
- [Consent and Capacity/Substitute Decision-Making - The Basics](#)
- [The Health Care Consent Act and the Substitute Decisions Act - Who Decides What When? 25 Common Misconceptions About the Substitute Decisions Act and Health Care Consent Act](#)
- [List of Substitute Decision Makers Who May Give or Refuse Consent in Respect to Health Care Matters if a Person is not Mentally Capable for Specific health Care Decisions - Health Care Consent Act S.20](#)
- [Options for Advance Care Planning](#)
- [Advocacy Centre for the Elderly 09/06/03 1 Who Assesses Capacity Under What Circumstances](#)

CLEO Publications

In co-operation with the community legal clinics in Ontario, Community Legal Education Ontario (CLEO) produces many helpful publications on a wide range of legal topics. The following publications, written by ACE and CLEO and produced by CLEO, are of interest to those wanting information about powers of attorney and related issues, and may be printed from the CLEO website:

- Continuing Power of Attorney for Property

Options for Advance Care Planning

There are several different ways a person may do advance care planning. The Health Care Consent Act (HCCA) makes it clear that a person may express “wishes” about future health care in a power of attorney for personal care, in any other written form, orally, or in any other manner (ie., through alternative means of communication such as a Bliss Board). (HCCA s.5) Later wishes expressed while capable prevail over earlier wishes. That would mean, for example, that even if wishes have been expressed in a written form, that later oral wishes may override those earlier written wishes.

1. WISHES EXPRESSED ORALLY

- some people may not want to write down any wishes but want to express these wishes orally
 - wishes about future health care may be expressed orally and are just as valid as wishes written in an advance directive form
 - must be mentally capable about matter expressing wishes for wishes to be enforceable
 - written wishes may be changed by wishes expressed orally if the person is mentally capable
 - oral wishes may be recorded in the person’s medical chart or plan of treatment
-
-

2. WRITTEN DOCUMENTS

(a) *Power of Attorney for Personal Care (POAPC)*

What is it?

- document in which a person (the grantor) names an SDM (an attorney)for personal care decisions may also include wishes about personal care (advance directive portion);
- may also include description of personal values and beliefs to guide SDM in decision making;
- personal care includes decisions about health care, nutrition, hygiene,

Who can make POAPC?

- only the person may make a POAPC for self. SDMs cannot create POAPCs for an incapable person

Who can be appointed attorney?

- “attorney” does not need to be a lawyer; persons who provide health care to grantor for compensation or residential, social, training or support services to grantor for compensation cannot act as attorneys unless he/she is spouse, partner, relative of grantor;

- Can name more than one person as SDM (attorney) – if more than one named, they must act “jointly” and make decisions together unless document states that may act “jointly or severally”. If joint and several, they may act together or separately

Capacity

- person must be mentally capable to execute POAPC and must have attained 16 years of age; to express wishes about future care, must be mentally capable for the matters on which he/she expresses wishes;
- Capacity to do a POAPC is specifically defined in the legislation as the “ability to understand whether the proposed attorney has a genuine concern for the person’s welfare and appreciates that the person may need to have the proposed attorney make decisions for this person”

Form of POAPC

- No particular form needs to be used to create a POAPC as long as it meets formal Requirements. Formal requirements for a POAPC:
 - (a) must be in writing
 - (b) must be signed by the person in the presence of two witnesses
 - (c) two witnesses must sign the POAPC as witnesses
- * Even if document called an advance directive, if it meets these formal requirements and names a SDM, then the document may be a POAPC

When POAPC in Effect

- POAPC comes into effect when the grantor is not mentally capable for personal care decisions
- Attorney determines when grantor is not capable for personal care decisions not covered by HCCA, unless document states otherwise
- Grantor may require that capacity to make personal care decisions be determined by a particular person or class of persons (ie physicians, nurses, social workers etc) before POAPC comes into effect
- Person or class of persons chosen to determine capacity need not be health professionals – may be anyone the person selects
- For treatment decisions, Health professional offering treatment determines capacity ; if person found incapable for treatment and that person has POAPC, POAPC is activated by this finding of incapacity
- Wishes expressed in POAPC must be honoured by SDM; must also be honoured by health practitioner in an emergency if known

When POAPC Ends - POAPC ends or is terminated:

- (a) when the attorney dies, becomes incapable for personal care or resigns unless the document provides for a substitute attorney or there are more than one attorney named originally and that attorney can still act;
- (b) when the court appoints a Guardian of the Person for the person
- (c) when the person signs a second POAPC unless the person states in the document that he or she wants multiple powers of attorney
- (d) when the POAPC is revoked by the person

Portability

- power of attorney law is different from province to province
- if a person has a power of attorney that was prepared in another jurisdiction (another province or country), it may not be valid to appoint an SDM in Ontario
- it MAY be valid if at the time it was prepared and signed, it complied with the law in the place it was executed AND the grantor who signed the power of attorney was either DOMICILED or HABITUALLY RESIDENT in that place. The terms "domiciled" and "habitually resident" have specific legal meaning.
- it is advisable to get a legal opinion on the validity of a foreign or out-of-province power of attorney before assuming it is valid
- wishes expressed in an out-of-province POA, even if the POA is not recognized in Ontario as "valid", must still be considered by the SDM highest ranking for the person from the list in the Ontario Health Care Consent Act
- it is recommended that the person, if capable, create a new Ontario POAPC to avoid any confusion

(b) Advance Directives and Living Wills

What are ADs and Living Wills?

- documents in which a person may express his or her wishes about future care
- terms “advance directive” (AD) and “living will” are not specifically defined in the Health Care Consent Act or Substitute Decisions Act or any other piece of Ontario legislation
- commonly differentiated from POAPCs as being documents in which the person does NOT name a substitute but only expresses wishes about care. Many documents “labeled” as “advance directives or living wills” are in fact POAPCs as the documents DO name an SDM, are signed and witnessed and meet the formal standards of POAPCs
- if the AD meets these requirements the document should be treated as a POAPC despite the name
- if AD or living will names an SDM but does **not** meet the formal standards of a POAPC, then that named SDM is NOT the substitute

Who can Make an AD?

- Only a person may prepare an AD/living will on behalf of him/herself when capable; SDM cannot sign an AD or living will for an incapable person; SDMs can only give or refuse consent to treatments or make personal care decisions for an incapable person

Capacity

- person who makes AD must be capable for matters about which he/she expresses wishes

Form of AD

- not prescribed in legislation therefore no particular form
- May be “medical” in format, communicating wishes about specific treatments or procedures: if such forms are used then person should receive information about these treatments and procedures and understand the risks/benefits/alternatives before signing AD; medical ADs most useful when person has a defined condition or knows details of illness and can express an “informed” wish about future treatments and care
- May be more oriented to recording values, beliefs, interests instead of specific treatment wishes in order to guide future SDM in making decisions for person; this type of AD useful as many decisions that need to be made for an incapable person cannot be anticipated because health/illness changes over time

When AD in Effect

- In effect when person incapable for treatment/health care
- Wishes expressed in an AD or living will must be honoured by the proper SDM
- Wishes must be honoured by a Health Practitioner in an emergency situation if he or she is aware of these wishes and has no reason to believe that these wishes have changed

When AD ends

- can revoke/change AD by oral statements, by communicating his or her wishes by alternative means, or by making a new statement of wishes in writing
- no requirement to execute a “revocation”; good idea for person to tear up the old AD and prepare a new written one if he or she wants to in order to make his or her wishes clear but not a necessary step to change his or her wishes

(c) Levels of Care Forms (LoC)

What is a Level of Care form?

- a form of Advance Directive; statement about levels of care may be included as part of a more detailed AD or part of a POAPC
- usually sets out a number of “levels of care” from no intervention through to extensive treatment and intervention, from no hospitalization (a wish to remain at the long-term care facility no matter what are the specific health needs of the resident) through to a request for transfer from the long-term care facility to a hospital for treatment if care needs exceed that which can be delivered in present setting
- problem with a Levels of Care form is that the levels outlined are arbitrary
- person signing the form should be advised that his/her choices for future care are not limited to the three or four levels outlined
- form is a good starting point for discussions about possible options and the range of options for care but should not be used as a complete definition of the person’s choices for future care

Who can sign a LoC form?

- expression of wishes for future care therefore only capable person can sign one not person’s SDM
- sometimes used improperly as consent forms- LoC forms lack specificity necessary for a consent

Capacity

- person who makes a LoC form must be capable for matters about which he/she expresses wishes

Form of LoC form

- not in legislation therefore no particular form or signing requirements

When in Effect

- In effect when incapable for treatment/health care
- Wishes expressed in a LoC form must be honoured by the proper SDM
- Wishes must be honoured by a Health Practitioner in an emergency situation if he or she is aware of these wishes and has no reason to believe that these wishes have changed
- because of lack of specificity may be problematic to interpret

List of SDM who may Give or Refuse Consent in respect to Health Care Matters—HCCA s.20

INTRODUCTION

Attorneys named in Powers of Attorney for Personal care are only one kind of SDM. A Person ALWAYS has an SDM for health care even if he/she has never executed a Power of Attorney for Personal Care. The following is the list of SDMS for health care (treatment, admission to long-term care, and personal assistance services in long-term care) in Priority

1. Guardian of person with authority for treatment

This person would be someone who has applied to court to become the GUARDIAN of the PERSON for the incapable person.

This is NOT the Guardian for Property of an incapable person and is NOT the Statutory Guardian of the incapable person. The same person may be appointed by the Court to be Guardian of the Person and Guardian for Property or this same person may be the Statutory Guardian for the Person but unless a person is the GUARDIAN OF THE PERSON they do not fall into this category of decisionmaker.

This person should produce a court order (a document) confirming his or her authority as Guardian of the Person and the scope of that authority (Appointed by process described in Section 55-61 of the *Substitute Decisions Act*).

2. Attorney in attorney for personal care with authority for treatment - This person is the ATTORNEY as named in a POWER OF ATTORNEY for PERSONAL CARE only. This person should be able to produce a Power of Attorney for Personal Care (a document) that has been properly signed and witnessed and that is otherwise valid as proof of his or her authority and scope of authority.

This is NOT a person who is named as the incapable person's attorney for Property in a Continuing Power of Attorney for Property.

This person (the Attorney for Personal Care) ONLY gets authority to act as a substitute decision maker for health treatment, admission to a long-term care facility or personal assistance services in a long-term care facility if the person who is the grantor of the Power of Attorney for Personal Care has become mentally incapable for treatment, admission, or personal assistance services as the case may be, and requires such a decision to be made on his or her behalf.

3. Representative appointed by Consent and Capacity Board

- This person is someone who has been appointed by the Consent and Capacity Board to make the decision currently required by the incapable person for treatment, admission to a long-term care facility, or personal assistance services in a long-term care facility. The Board may also authorize the Representative to make a wider range of decisions for the incapable person related to treatment, admission to a long-term care facility, or personal assistance services.

This application may be made by a person (for example he or she may be a friend or family member of the incapable person) who is at least 16 and who is mentally capable with respect to the required decision.

The Board will only consider this appointment if a relevant finding of incapacity has been made and the incapable person does not object. This application may also be made by the person who has been found incapable for a particular health purpose (treatment, admission, personal assistance services). SEE Consent and Capacity Board information Sheets - "Application to have a Representative Appointed" and "Applying to the Board to be Appointed a Representative" available on the CCB website. See also sections 33, 51, and 66 of the *Health Care Consent Act*.

4. **Spouse or partner.**

Two persons are "spouses" if they are "Members of the Opposite Sex and,

- a) are married to each other; or
- b) living in a conjugal relationship outside marriage and,
 - i) have cohabited for at least one year, or
 - ii) are together the parents of a child, or
 - iii) have together entered into a cohabitation agreement under s.53 of the *Family Law Act*." (see section 20(7) of the *Health Care Consent Act*)"

They are not spouses if they are living separate and apart within the meaning of the *Divorce Act* (Canada).

As of NOVEMBER 1, 2004 this definition will change slightly by striking out the words "they are members of the Opposite Sex" in the portion before (a) and by striking out the words "are married" at the beginning of (a) and substituting "they are married" and by striking out "are living" at the beginning of (b) and substituting "they are living".

"Partner" means:

- a) a person of the same sex with whom the person is living with in a conjugal relationship outside marriage, if the two persons
 - i) have cohabited for at least one year, or
 - ii) are together the parents of a child, or
 - iii) have together entered into a cohabitation agreement under s.53 of the *Family Law Act* or
- b) either of two persons who have lived together for at least one year and have a close personal relationship that is of primary importance in both person's lives. See *Health Care Consent Act* S.20(9).

The (b) section can include same sex partners as well as friends who have lived together for at least one year (a non-sexual relationship) and "have a close personal relationship that is of primary importance" in both their lives.

At November 1, 2004, this definition of Partner will change by striking out (a) and just leaving (b). This is happening because the same sex relationships will be recognized as "spouses" rather than "partners".

5. **Child or parent** or Children's Aid Authority or other person lawfully entitled to give or refuse consent to treatment in place of parent - not include parent with right of access only - if CAS or person in place of parent, does not include parent.
 6. **Parent with right of access only.**
 7. **Brother or sister**
 8. **Any other relative.**
People are relatives if related by blood, marriage or adoption.
see section 20(10)HCCA
- * **If no person meets requirement as SDM, then the PGT is the incapable persons decision-maker. Documents that purport to override this default to the PGT as last resort substitute decision-maker are not appropriate and not legally enforceable.**
- * If there is a conflict between persons in same category and they cannot agree and claim to be SDM above others PGT shall act as the decision-maker. The PGT does not choose between the battling decision makers but “shall make the decision in their stead” (see section 20(6) of the *Health Care Consent Act*)

REQUIREMENTS FOR SDM - HCCA s.20

The SDM in the list may give or refuse consent for treatment, admission to a long-term care facility, or personal assistance services in a long-term care facility **only** if he or she is:

- i) Capable with respect to treatment,
- ii) 16 unless he or she is the parent of incapable person,
- iii) No court order or separation agreement prohibiting access to incapable person or giving or refusing consent on his or her behalf,
- iv) Is available, and
- v) Willing to assume responsibility of giving or refusing consent.

RANKING

A Person lower on list may give consent only if no person higher that meets requirements. (see section 20(3) HCCA)

EXCEPTION

Family member present or contacted may consent or refuse consent if he or she believes:

- a) no person higher or in same paragraph exists,

or

- b) if person higher exists, person is not guardian of person, POAPC, Board appointed representative with authority to consent and would not object to him or her making the decision. (see section 20(4) HCCA)

DEFINITION OF AVAILABLE

HCCA s.20 (11) - a person is available if it is possible, within a time that is reasonable in the circumstances, to communicate with the person and obtain a consent or refusal.

PRINCIPLES FOR GIVING OR REFUSING CONSENT AS SDM - HCCA s.21

- * Wishes
- * Best Interests

WISHES - HCCA s.5

- * While capable a person may express wishes in respect to treatment, admission to care facilities, personal assistance services.
- * Manner of expression of wishes - in POAPC, in form prescribed by regulations, in any other written form, orally, in any other manner.
- * Later wishes expressed while capable prevail over earlier wishes.

DEFINITION OF BEST INTERESTS HCCA s.21(2)

SDM to consider:

- a) values and beliefs that the SDM knows that the incapable person held when capable and believes that he or she would still act on
- b) other wishes of the incapable person with respect to treatment, admission, personal assistance services that are not required to be followed (i.e. those wishes expressed AFTER the person became incapable)
- c) whether treatment likely to:
 - i) improve the persons condition or well being
 - ii) prevent condition or well being from deteriorating
 - iii) reduce the extent or rate of deterioration of the persons condition or well being
- d) whether condition or well being is likely to improve or remain the same or deteriorate without the treatment
- e) if benefit outweighs risk of harm
- f) whether a less restrictive or less intrusive treatment would be as beneficial as the treatment proposed.

The Story Behind *One More Memory*

Brenda Hounam, a mother of two, has Alzheimer Disease. When Brenda went to St. Thomas, Ontario in January 2004 to speak about how this disease had affected her, little did she know how much her life would change. She spoke openly of her sadness at the thought of being unable to recognize her own son and daughter and especially of the pain and suffering this would cause them. A music lover, Brenda thought a song would be the best way to remind her children of her love for them. By a stroke of fate she met Sara Westbrook, a singer and songwriter from St. Thomas. Sara contacted fellow songwriters Andrew Ang and Matthew Tishler, and with Brenda's blessing, the trio wrote *One More Memory*. Written from the perspective of a person with Alzheimer Disease, *One More Memory* continues to touch hearts, helping loved ones cope with this disease's unpredictable symptoms.

One More Memory was recorded with the generous assistance of producer and mix engineer Troy Bynoe, guitarist Justin Abedin, drummer Wilson Laurencin, the JUNO® award-winning Toronto Mass Choir, and one of North America's premier recording studios, Metalworks.



*Troy, Andrew, Sara, and Matthew (bottom)
with Brenda (in red) and the Toronto Mass Choir.*

Source: www.onemorememory.com

I'm Still Here:

A Research Based Drama on Living with Dementia

Playwright: Vrenia Ivonoffski

Principal Researchers: Christine Jonas-Simpson RN, PhD and Gail Mitchell RN, PhD

The play, *I Am Still Here*, has been informed by research conducted with persons living with dementia during the early and later parts of the journey as well as with daughters whose mothers were diagnosed with Alzheimer Disease. The researchers and artists have been working together for more than a year to try to bring deeply moving experiences shared during research to life through dramatic performance. The intent of the play is to help diminish any unnecessary suffering that can come with living with dementia due to misunderstandings and stigma.

The play has been generously supported by the Collaborative Research Program: Rehabilitation and Long term care, Mr. Kenneth G. Murray and the Murray Alzheimer Research & Education Program in the Faculty of Applied Health Sciences at the University of Waterloo, as well as the Sunnybrook and Women's Research Institute. Principal researchers, Christine Jonas-Simpson, Director of Nursing Research at Sunnybrook and Women's Health Sciences Centre and Gail Mitchell, Assistant Professor at York University, School of Nursing, are grateful to persons with dementia and the daughters who shared their stories making this play possible. Also we would like to express our heartfelt gratitude to Vrenia Ivonoffski, playwright, and the actors of *ACT II STUDIO* for their impeccable talents and sensitivity to portraying the meaning of living with dementia from the perspective of persons living with dementia.

Vrenia Ivonoffski is the Artistic Director of *ACT II STUDIO*, a theatre school and creative drama centre for adults 50 and over at Ryerson University. It is part of the Seniors Education Programs of the G. Raymond Chang School of Continuing Education. *ACT II STUDIO* is committed to social action theatre as an agent of change. It has been translating social science issues and health related research into dramatic form for over 10 years. In addition to touring across Canada and into the U.S., *ACT II STUDIO's* plays have been performed by other groups in Canada, Singapore, and Australia.

Other Resources



DASNI (Dementia Advocacy and Support Network International)

DASN International is a not-for-profit corporation established to:

- *Promote respect and dignity for persons with dementia*
- *Provide a forum for the exchange of information,*
- *Encourage support mechanisms such as local groups, counseling groups and Internet linkages, and*
- *Advocate for services for people with dementia*

Since 2000, DASNI has been an international group of people with dementia. DASNI has members around the world. Approximately one-third of members have dementia themselves, and the DASNI Board always has a majority of board members being persons with dementia.

DASNI activities currently include an Internet-based support group for people with dementia (PwiDs) with diseases such as Alzheimer's Disease, Vascular Dementia, Dementia with Lewy Bodies, Frontotemporal and Picks Dementia. DASNI has an email community and twice-daily Internet chats which help ease the isolation of dementia and educate participants about living with dementia.

DASNI enjoys a 501(c)(3) nonprofit status in the United States.

The stigma of a diagnosis of dementia is very real, very cruel, and very widespread. There is also widespread ignorance about dementia, the impact of new medications, and the support available to PwiDs and their care-partners. By sharing their hopes and concerns and participating in dementia-related activities, DASNI empowers people with dementia to actively participate in their own care and treatment. We encourage a more accepting, more hopeful view of living with dementia, and encourage improving the quality of one's own life through advocating for others.

DASNI members have made plenary presentations, led groups and hosted a booth at Alzheimer's Disease International conferences in Christchurch, New Zealand (2001), Barcelona, Spain (2002) and Santo Domingo, Dominican Republic (2003). Participation is planned for Alzheimer's Disease International (2004) in Kyoto, Japan. Similar local and national presentations have been made throughout Canada, Australia, New Zealand, Europe, the United Kingdom and the United States.

DASNI members have published books, made TV and radio appearances and written many articles on the subject of diagnosis and living with dementia. Please contact our web site to find an author, arrange a talk or interview a DASNI member.

For factual information and local referrals, please contact your local Alzheimer's Association or Society.

DASNI WEB SITE:

<http://www.dasninternational.org>

EMAIL COMMUNITY:

<http://health.groups.yahoo.com/group/DASN/>

DAILY CHATS:

www.alzinfo.org

Your Local Dementia Network

Below is a listing of dementia networks in Central Ontario. The creation of new networks or the maintenance of existing dementia networks across Ontario enables the coordination and promotion of services for person, families and caregivers living with dementia. The goal of dementia networks is to improve the system of care (including service delivery, education, research and planning) for persons with dementia, their families and caregivers.

Central East

✿ Durham Region

Ms. Anne-Marie Yaraskavitch
863 White Ash Dr.
Whitby, ON L1N 7L8
Tel: (905) 666-3860
E-mail: dayaraskavitch@rogers.com

✿ Peterborough, Haliburton, Northumberland, Victoria

Ms. Cheryl-Ann Hassan
Alzheimer Society of Victoria County
P.O Box 730
Lindsay, ON K9V 4W9
Tel: (705) 878-0126
Fax: (705) 878-0127
E-mail: alzvic@on.aibn.com
Web: www.hkpr-dementia-network.net

✿ Simcoe County

Ms. Debbie Islam
Alzheimer Society of Greater Simcoe County
12 Fairview Rd.
Unit 103, P.O. Box #1414
Barrie, ON L4M 5R4
Tel: (705) 722-1066
Fax: (705) 722-9392
E-mail: alzgsc@csolve.net

Ms. Annemarie Welch
Orillia Soldiers Memorial Hospital
170 Colborne St.
Orillia, ON L3V 2Z3
Tel: (705) 325-2201 ext. 3504
Fax: (705) 327-9172
E-mail: amwelch@osmh.on.ca

✿ York Region

Ms. Penny Hubbert
Regional Municipality of York, LTC &
Seniors Branch York
Regional Health Services
194 Eagle St.
Newmarket, ON L3Y 1J6
Tel: (905) 895-3628 ext. 217
Fax: (905) 895-9583
E-mail: penny.hubbert@region.york.on.ca

Central South

✿ Brant

Ms. Laurie Biehler
Alzheimer Society of Brant
442 Grey St., Unit A
Brantford, ON N3T 6J6
Tel: (519) 752-3636
Fax: (519) 752-8671
E-mail: lbiehler@stjosham.on.ca

✿ Haldimand-Norfolk

Ms. Kit Julian
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Online Resources for People with Alzheimer Disease and Related Dementias

DASN International (Dementia Advocacy and Support Network International)

A worldwide organization by and for those diagnosed with dementia, working together to improve quality of life. <http://www.dasninternational.org>

✿ <http://groups.yahoo.com/group/DASN>

A dementia patient and supporters non-profit organization working to improve the lives of all people with dementia of any kind. This online community is the "workplace" of DASN International, with a message board, an e-mail list and a chat room.

✿ http://www.dasninternational.org/regular/reg_joinchat.html

(Daily real-time chat at 3 p.m. EST and 9 p.m. EST)

Join the DASN e-mail community. It is open to persons with dementia and others willing to work toward DASN goals.

Forums and Chat Lines for People with Dementia

✿ **Alzheimer Society of Canada Message Board**

<http://www.alzheimer.ca/english/forums/intro.htm>

✿ **Alzheimer's Association Message Board**

<http://search.alz.org/mb/system/login.html>

Caregiver Resources

✿ **Caregiving.com** (<http://www.caregiving.com/>)

An online support service for caregivers of an aging relative, friend or neighbour.

✿ **ElderCare Online** (<http://www.ec-online.net/>)

ElderCare Online is a beacon for people caring for aging loved ones. Whether you are caring for a spouse, parent, relative or neighbor, this site provides an online community where supportive peers and professionals help you improve quality of life for yourself and your elder. Includes chats for caregivers.

✿ **Empowering Caregivers** (<http://www.care-givers.com/>)

Empowering Caregivers offers comprehensive emotional and spiritual support for all caregivers through experts, articles, newsletter, journal exercises, spotlights, healing circle, resources, inspiration, humor and much more. It is about choices, healing and opening to love.

✿ **How to Care** (<http://www.howtocare.com/>)

A Canadian site to help caregivers manage the realities of caring for an aging parent, a chronically ill spouse or friend, and themselves.

✿ **The Victorian Order of Nurses (VON Canada)** (<http://www.von.ca/>)

A national health care organization and a federally registered charity that has been caring for the lives and well-being of Canadians in their homes and local communities since 1897.

Murray Alzheimer Research and Education Program (MAREP)

The Kenneth G. Murray Alzheimer Research and Education Program (MAREP) is an innovative program, which integrates educational and research activities in an effort to improve dementia care practices in Canada.

More specifically, the goals of MAREP are:

- to enhance the ability of care providers, both formal and informal, to respond to the needs of persons with Alzheimer disease and related dementias;
- to provide skills, resources and information to persons diagnosed with dementia to help them contribute to their own care; and
- and ultimately to improve the quality of life of persons with dementia and their families.

History

MAREP was launched in May 1993 at the University of Waterloo under the auspices of the Centre for Applied Health Research in the Faculty of Applied Health Sciences. The development of MAREP is largely due to the commitment and passion of its founder, Mr. Ken Murray, whose wife, Helen, died of Alzheimer disease.

In 1996, MAREP established "innovation centers" - long-term care facilities where on-going applied research and educational activities take place. MAREP's activities are funded through donations from individuals, groups and organizations.

MAREP Activities

MAREP is involved in a number of on-going activities and new initiatives:

- conducting psycho-social research in the community and in long-term care settings;
- developing and implementing education modules and materials;
- providing staff professional development;
- developing and disseminating information tools and resources;
- organizing conferences and forums for those involved in dementia care; and
- maintaining Alzheimer's Research Exchange – a web-based network promoting exchange and collaboration between all persons involved in dementia care (www.alzheimersresearchexchange.ca).

Critical Partnerships

MAREP has developed partnerships with the Ontario Ministry of Health and Long-Term Care, Ontario Senior's Secretariat, the Alzheimer Society of Canada, the Alzheimer Society of Ontario, the Dementia Advocacy Support Network International, long-term care facilities, researchers, and other agencies to identify priorities in education and research that would provide useful practical information and contribute to a broadening of our scientific knowledge base related to dementia care.