

October 3 – 4, 2003 Workshop Notes

On October 3 – 4, 2003, the second annual stroke workshop was held in Edmonton with 33 participants representing 8 of the 13 Alberta stroke support groups.

Friday October 3rd was devoted to an evening “meet and greet” reception to allow the participants an informal time get acquainted and to share ideas.

The theme this year was to focus on the invisible deficits of a stroke and on Saturday October 4th had the following agenda:

- Welcome and introductions
- SRAA update on status and activities
- What makes a successful support group? – ideas and discussion
- Group reports on their individual activities over the past year
- In house lunch with a keynote speaker, Dr. Margaret Brackstone, “*Long Term Challenges, and Strategies for Managing Communication, Emotional, Behavioral, and Cognitive issues*” (Notes attached as Appendix A)
- Break out groups to address the four issues of *Communication, Emotional, Behavioral, and Cognitive*
- A plenary session with break out group reports

SRAA Status and Activities

Frank Nieboer reported on the past year’s activities:

- There are 13 stroke support groups in Alberta however, some are still having initial growing pains
- New groups anticipated for the next 12 months include, Drayton Valley, Stettler, Strathmore, a young person’s group in Calgary

- Participating with the Canadian Stroke Network in the planning and development of a Canadian National Stroke Strategy which will encompass awareness and prevention, acute care, rehabilitation, community integration and supports, and re-entry
- Starting the initial planning and process to develop a National Stroke Support Group Network, having discussions with British Columbia and Manitoba with the view of having a founding convention sometime in 2004
- Initiating communications, partnerships, and coalitions with Brain Injury agencies by encouraging joint support groups in smaller communities, joining brain injury coalitions and networks in Calgary, and suggesting other stroke support groups to build relationships with their local brain injury support societies and service providers

Successful Groups-Some Ideas!

Besides the need for planning, organization and commitment, below are some of their suggestions for successful stroke support groups:

1. Have at least monthly meetings which have four components:
 - *Educational* - experts and practitioners can make the lives of stroke families easier with pertinent information
 - *Recognition* - recognize persons and acknowledge their victories, achievements etc.
 - *Social* – Members need time to visit and mingle
 - *Refreshments* – food is always an important component and is appreciated
2. Develop leadership – the current leaders have to develop the new leaders for the group by asking others to take on challenging tasks and increased responsibilities.
3. Emotional support – groups have a greater impact when they foster an environment of emotional support through a buddy system, welcoming committees and peer/visitor programs.
4. Information swapping – no one knows all there is to know about stroke and every stroke is different. Trading information and brainstorming solutions lessens the workload for new stroke families and gives the old hands a reason to keep coming to meetings.
5. Resource networking – the collective wisdom, knowledge and experience of a stroke group is an effective tool that provides many resources to its members and the community.
6. Outreach – get out into the community by having a speakers bureau, assist in patient/caregiver education classes, participate in public forums and health fairs, be a resource to your community

Keeping it SIMPLE

One way to check on a group's success is to check the following list for do's and don'ts:

Supportive – ask caring questions; listen attentively to the answers

Inspirational – reassure others that life gets better

Motivational – encourage action and acknowledge improvement

Practical – offer options, helpful tips and resource information

Laughter – do things with and in good humor

Educational – talk about what has worked for you and others; make suggestions; don't give advice.

Speaker Suggestions

One of the eternal questions for groups is, what speakers will we have this year? The following is just a partial list of speaker suggestions for a group:

- Accessibility, wheel chair and handicap access in the community issues
- Aids to Daily Living
- Alternative therapies, e.g. acupuncture, reflexology, etc
- Caregiver support, sources and ideas
- Depression, have a health care professional to talk about the signs of depression and the strategies for dealing with depression
- Gardening, inside and outside ideas
- Hobbies, have a hobby fair with your members displaying and talking about their hobbies
- Home Care, access and service availability
- Humorist, learning that laughter is the best medicine
- Income management on a limited budget
- Motivation, ask a local motivational speaker
- Nutritionist, diet and proper eating habits
- Occupational therapist
- Personal and home safety tips
- Personal histories of stroke survivors and caregiver
- Pets, the joy of owning and caring for a pet
- Pharmacist, compliance, side effects, etc
- Physio therapist
- Recreation therapist
- Relationships
- Resource fair, ask other agencies to present their services
- Self esteem, there are Self Esteem Societies who offer their expertise
- Sexuality
- Speech therapist
- Taxation, in January to assist in income tax preparation
- Transportation, issues and strategies
- Wills and estates, powers of attorney – have a legal expert in for advice

All of the above topics can be covered by asking for volunteer expert speakers in your community that you can access through hospitals, clinics, professional practices, social agencies, government agencies etc.

<p style="text-align: center;"><u>The Invisible Deficits of Stroke - Cognitive, Emotional, Behavioral, and Communication – Issues/Challenges, Barriers, Strategies, and Resources</u></p>

Break Out Group Reports

NOTE: these comments should be read in the context and in conjunction with Dr. Margaret Brackstone's Luncheon Presentation notes attached as Appendix A to this report

Cognitive

Issues and Challenges

- Knowledge – gaining and using new knowledge
- Perception and motor skills, dealing with denial
- Memory, especially short term memory
- Judgment, decision making
- Problem solving, identifying the issues and alternate solutions
- Sequencing, orderly thought processes
- Attention, keeping focused on the conversation, the problem, the issues
- Processing, not having enough time to process information and come to a timely conclusion
- Personal safety

Barriers

- Diminished self image, not willing to lower previous standards in work, in play, in house work, in hobbies
- Expectations of yourself and from others may not be met
- Excessive and sometimes all background noise interferes with thinking and processing information
- Need time to process information, need patience from all parties
- Understanding instructions, translating the written word to thought and action
- Speed and volume of receiving new information in a short time frame
- Having friends and family recognize and understand the issues, challenges, and barriers

Strategies

- Realize and recognize your limitations, may have to do other activities
- Adapt, adapt, adapt – often activities may have to be done in other manners, with other aids, using alternate strategies and actions
- Focus therapies, relaxation, meditation, tai-chi, guided imagery, massage
- Use outside feedback, e.g. videos, to accept limitations and focus on new coping strategies
- Break problems into smaller component steps to come to a solution
- Have an understanding of the brain damage of the stroke
- Allow time to assimilate new information through pre-reading and study of materials prior to meetings
- Anticipate problems and solutions prior to taking on a new activity
- Receive information in different formats, electronically, verbally, visually
- Be an advocate for yourself and/or identify an advocate from your family or friends
- Understand that education never stops, keep learning

Resources

- Obtain assistance with your paper work, bills, letters, tax forms, from trusted family and friends – financial assistance available through Brain Injury Coalition
- Access local stroke support groups and other community support agencies
- Access Home Care
- Use community mental health supports
- Get help from qualified family members
- Access the Self Esteem Society
- Enroll in Toastmasters
- Access community rehab centers

Emotional

Issues and Challenges

- The caregiver loses their identity as caregiving is a full time job
- Everything becomes a chore, nothing is easy
- Hard to find any quality ‘down’ time
- Hard for the caregiver to find even 5 minutes for themselves
- Easily irritated, survivors have a short fuse with family, directed anger at the family
- Children may provide over stimulation however are also a source of delight
- Caregiver misses the emotional support of the survivor, need to find other supports
- Isolation, there is a tendency to avoid others and social situations

- Life is so different, it is hard for others to understand the changes and challenges in daily living
- Anxiety and fear re how stroke related changes will continue to impact in the future
- Overprotection, caregiver may be smothering the survivor which ties down the caregiver, need to build trust that others can participate in caregiving

Barriers

- Everything is focused on the survivor's needs
- No one asks how the caregiver is doing
- Taking anger and irritability personally
- Lack of understanding by family and friends
- Lack of interest by others to really know what you both are going through
- Distance from family members to receive support and sometimes adjusting to a new community
- Lack of involvement by family members, they seem not to care, there is usually an uneven distribution of care and support

Strategies

- Admit that something is wrong and has to change
- Identify what help and support you need and ask/tell others what you need
- In large families, the main caregiver sometimes has to make explicit demands for supports
- Persevere, have determination, be stubborn
- Embrace life, love life, make future plans
- Get out of the house as much as possible, on your own and together
- Having specific goals to take trips, attend special events, can help motivate yourself to strive to improve
- Rely on the stroke survivor's previous skills/knowledge and experience to contribute in real ways in daily tasks and problems, e.g. car care, maintenance issues
- Have expectations of others and voice these
- Don't take credit for all the successes or the blame for all the failures
- Generate hope by helping others, giving something back e.g. other survivors and caregivers in their early stages of recovery
- Be what you are, do what you can
- Let the survivor know they are important and valued

Resources

- Humour, laugh together, shares stories and jokes
- Use your imagination and creativity to find new ways to meet ongoing needs
- Enjoy your memories

- Enjoy the arts, music, theatre, paintings, and museums
- Make time to do things you both like and also what you individually like to do
- Contact professionals for support and strategies e.g. therapists, psychologists
- Financial planners can assist in financial matters
- Call “time outs” to manage anger episodes, and review anger episodes when calm
- Count your blessings you do have
- Enjoy food including desserts
- Look after your personal appearance and grooming, get your hair done, have a manicure, have your shoes shined...make it an outing
- Attend seminars and identify community resources for assistance
- Maintain contacts, e.g. reminder phone calls for meetings
- Maintain an interest in current affairs, news, sports etc.
- Get a pet, take the dog for a walk
- Caregiver needs to seek out a best buddy, a confidant for nurturing and support
- Read other stroke survivor and caregiver stories, these are inspiring and provide helpful hints on coping with life’s challenges

Communications

Issues and Challenges

- Aphasia sufferers don’t want sympathy
- Misunderstanding by public of “heart attack” and “stroke” and their differences
- Lack of understanding of the impact of aphasia
- Use of the telephone
- Caregiver lack of knowledge and understanding
- Caregivers take over, finish sentences, ideas, thoughts
- Need for patience by others to allow communication to take place
- Having a quality of life in the community
- Deficits are often “invisible”

Barriers

- Public lacks awareness of where to go for help
- Awareness of issues by health care professionals
- Shorter stays in hospitals and access to therapy
- Limited speech therapy availability
- No resources for long term therapy, lack of funding
- Lack of recognition of the continuing benefits of ongoing therapy
- The fallacy of the “seamless” care model in health care

Strategies

- Use humour, laugh

- Participate in stroke awareness and aphasia forums, programs, and seminars
- Speak and share stories to other stroke groups
- Celebrate success, you are a walking “billboard”
- Read stories aloud to children
- Participate in schools programs, spell-a-thons
- Use English as a Second Language programs if English is not your mother tongue
- Keep a diary of your progress, this reinforces your gains for the survivor and the caregiver
- Encourage independence
- Use aphasia cards, buttons, posters, t-shirts, cookbooks
- Participate in hospital visitations
- Participate in aphasia awareness in newspaper articles

Resources

- Neighbourhood Chat in Edmonton and area
- National Aphasia Assoc.
- Libraries
- Join community support groups and speech groups
- Use speech language professionals
- Alberta College of Speech language Pathology, resources and speech therapist lists

Behavior

Issues and Challenges

- Acceptance and non-acceptance of the changed life styles
- Personality changes from the stroke
- Grieving
- Involved with emotional issues
- Agitation
- Lability
- Frustration and anger
- Self centred behavior
- Low self esteem
- Self Blame
- Impulsivity
- Fatigue
- Declining concentration

Barriers

- False assumptions people make about stroke survivors

- Lack of funding resources
- Lack of respite services for the caregiver
- Little communication about this issue
- Lack of personal motivation for self help
- Access to all of the therapy resources
- Lack of the appreciation that you have some skills
- Lack of energy to change and access resources
- Health care professionals not really knowing or understanding the person affected
- Other prevailing medical conditions

Strategies

- Learn patience, both the survivor and the caregiver
- Access financial support for education and care
- Receive post discharge information to community resources and assistance
- Provide gentle feedback to the survivor
- Have consistent family strategies in dealing with issues
- Family has to adjust and change
- Create a low stress environment
- Include the survivor in the family and the community
- Promote independence
- Plan and organize activities, create a routine
- Keep energized, maintain hope
- Focus on the possible not the impossible
- Share your ideas, feelings, and plans
- Get involved with community resources, give back, reach out

Resources

- Family and the survivor have to learn about stroke and stroke recovery issues/ideas/strategies from community resources and health care professionals
- Join a support group
- Research new ideas
- Use the internet for ideas
- Ask your pharmacist
- Use the knowledge and experience of other stroke families
- Access respite services where available, or use family and friends for breaks
- Practice early intervention

Appendix A

Dr. Margaret Brackstone's Luncheon Presentation Notes

Today's Focus

"Higher Level Problems"

"Less Visible"

"Somewhat Private"

"More Subtle"

"Not so Obvious"

"Issues for the Walking Wounded"

Cognition

Challenge	<u>Management</u>
<i>Unawareness of deficits</i>	Survivor and family become experts on the brain injury
↓ insight	Don't blame. Present reality.
↓ attentional processes	Reduced distractions.
↓ rate of mental processing	Provide extra time.
Delayed responding	Wait for it!
↓ mental flexibility	Build structure and routine. Cue transitions.
Reduced executive functioning: <ul style="list-style-type: none"> · Reduced initiation · Reduced self-awareness and monitoring · Reduced planning and goal setting · Reduced organization · Reduced strategic behaviour · Reduced understanding of cause and effect · Reduced problem solving · Reduced judgement 	<ul style="list-style-type: none"> · Needs reminders · Careful feedback · Do together · Build structure · Review together · Elaboration of cause effect · Anticipate and help generate options · Calm intervention and discussion

Cognition

Challenge	<u><i>Management</i></u>
Memory problems	“Plan to remember”... Strategies, strategies!
Perceptual problems (e.g. neglect, apraxia, spatial relations problems, agnosia)	Teach compensatory strategies Arrange environment to assist
↓ sense of direction	Use aids++

Emotions

Challenge	<u><i>Management</i></u>
<i>Denial</i>	Gentle feedback
<p><i>Anger:</i></p> <ul style="list-style-type: none"> • A normal response to brain injury • Reduced control of anger expression common 	<ul style="list-style-type: none"> • Recognize as a problem • Set mutual goals • Work to enhance controls • Use strategies
<p><i>Grief:</i></p> <ul style="list-style-type: none"> • A natural response to significant losses of: <ul style="list-style-type: none"> • Identity • Control • Independence • Present and future goals/dreams • Income • Social network • Understanding 	<ul style="list-style-type: none"> • Engage vs detach • Find hope vs despair • Explore possibilities vs protesting losses <p>(from “Pathways through grief” Karen Martin & Dr. Sandra Elder 1996)</p>
<i>Depression</i>	Recognize it and treat it
<p><i>Anxiety</i></p> <ul style="list-style-type: none"> • Facing our fears 	Relaxation skills Reducing unknowns
<p><i>Lability:</i></p> <ul style="list-style-type: none"> • Loosened control of emotional expression 	<ul style="list-style-type: none"> • Differentiate from depression/despondency • Enhance self-control

Emotions

Challenge	<u><i>Management</i></u>
<i>Emotional flatness</i>	<ul style="list-style-type: none"> · Careful differentiation of this from depression · Give feedback and work cooperatively with this
<p><i>Frustration:</i></p> <ul style="list-style-type: none"> · Reduced frustration tolerance · Short-fuse · Easily irritable and impatient 	Environmental controls, and strategies (E.g. reduce provocation & plan for provocation)
<i>Helplessness, hopelessness, powerlessness</i>	Strive for realistic goals and related actions
<i>Burden of Care</i> Burden of responsibility	Find help. Don't do it all yourself.

Regarding emotions:

- Acknowledge them
- Own them
- Allow them
- Don't deny them
- Share them
- Identify what feeds your spirit

Behaviours

Irritability

Belligerence

Agitation

Misses Subtle Cues

Restlessness

Disinhibition

Reduced Initiation

Impulsivity

Reduced Self-Monitoring

Fatigue

Low Frustration Tolerance

Excessive Talking

What to do?

- Don't treat unreasonable behaviour as though it were reasonable
- Figure out what you will put with (because your spouse and kids already have)
- Require that the person you are living with meet you half way
- Identify one thing at a time that you agree to work on
- Set visible, doable goals
- Recognize high vs low energy (i.e. good vs bad) days
- Mutually set realistic goals

Intimacy & Sexuality

SO MUCH MORE THAN SEXUAL ACTIVITY

1) Communication Issues

- Aphasia
- Reluctance to voice concerns re
 - a) having sexual desires
 - b) being sexually active
 - c) things not going very well in ‘that’ department

2) Emotional State

Influence of:

- a) depression
- b) anger/irritability
- c) anxiety/fear

3) Changes in Motor Abilities & Sensation

May require:

- a) new positions
- b) exploration of what is now pleasurable

4) Medical Issues & Effects of Medication

- Reduced arousal & physical responses
- Negative effects of anti-hypertensives or anti-depressants (talk to your physician about these)

5) Role ‘Confusion’

- Caregiver tasks may dampen desire
 - New dependency issues
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6) Identity Issues

- Seems like a different person
- Personality changes
- Complex pattern of attraction disturbed
- Reduced sensitivity (misjudge receptivity)

7) Hygiene Issues

- Cleanliness
- Tidiness
- Freshness

8) Reduced ‘Refinement’

- Crude language
- Brusque manner (loss of tenderness)

- Reduced sense of privacy
- Less recall of idiosyncrasies of partner
- Sense of timing ‘off’

Survivor and caregiver may benefit from carefully assessing their own personal needs, exploring their experience of each other intimately, and discussing together, &/or with help, ways to enhance the experiences of both.