



**SRABC**

**STROKE RECOVERY ASSOCIATION  
OF BRITISH COLUMBIA**

# ‘Speaking Up and Getting What You Need Post-Stroke’

Stroke Recovery Education Days

**Fraser Region - White Rock**

June 8, 2013



“When you have exhausted all possibilities,  
remember this – you haven’t.”

*~ Thomas A. Edison*



# What is Self-Advocacy?

- Being able to ask for what you need while respecting the needs of others
- Standing up for your needs or those of a loved one
- To be clear, specific and firm way.
- Not being afraid to ask for help when you need it.



# Speaking Up is Important

- A stroke can take away your sense of control.
- Speaking up for yourself means that you take personal responsibility for your stroke recovery.
- You have a say in what you want and get what you need.
- You are empowered to directly impact your own quality of life.
- You can make your own choices



# Speaking Up Isn't Always Easy

- Sometimes we feel challenged because:
  - We feel unprepared in appointments or when researching information
  - We worry what others will think or that service will be affected
  - We may become aggressive or defensive
  - We may have unrealistic expectations
  - We might be unwilling to listen to other people, or to explore alternate solutions
  - English is our second language



# Be Prepared!

- Writing down your questions, thoughts and concerns.
- Keeping a diary or notebook handy.
- Put your most important questions first
- Being patient. Finding the right answer or person may take time.
- Finding the person who can give you the answer you need.
- Asking the person if they have time to speak with you before you start your conversation.



# Health Appointments

## HEALTH CARE APPOINTMENT FORM

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Name of health care provider: \_\_\_\_\_

Reason for Appointment: \_\_\_\_\_

Questions for health care provider: (fill out in advance)

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

Answers: (fill out at appointment)

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

Notes/Additional questions:

- Organize your questions and be concise.
- Don't be afraid to ask questions, but try to be specific.
- Keep records about things like sleeping, eating, symptoms, medication, habits, etc.
- The more detailed information you have, the easier it is for the professional to work out the best solution.



# Keeping a Daily Log

- Encourage stroke survivors and caregivers to keep a daily log...
- You don't need to write a book, just a few lines!
- Keep track of:
  - Date and Time
  - Health or Emotional Concern
  - What makes it worse? What makes it better?
  - How long does it last? How long did it last?





# Example of Health Journal

| Date and Time              | Health Event or Change in Physical or Emotional Health   | Length of event or change                    | Other Notes  |
|----------------------------|--|--|--|
| April 15, 2009<br>10:00 am | Mom seemed overwhelmed this morning with getting ready to go out for coffee<br>She said her knee was bothering her more than usual | Once we got out the door, Mom's mood changed | Schedule Dr's App't for May 15 at 1:10 pm; on Backpackit |
|                            |  |  |  |
|                            |  |  |  |



# Finding What You Need





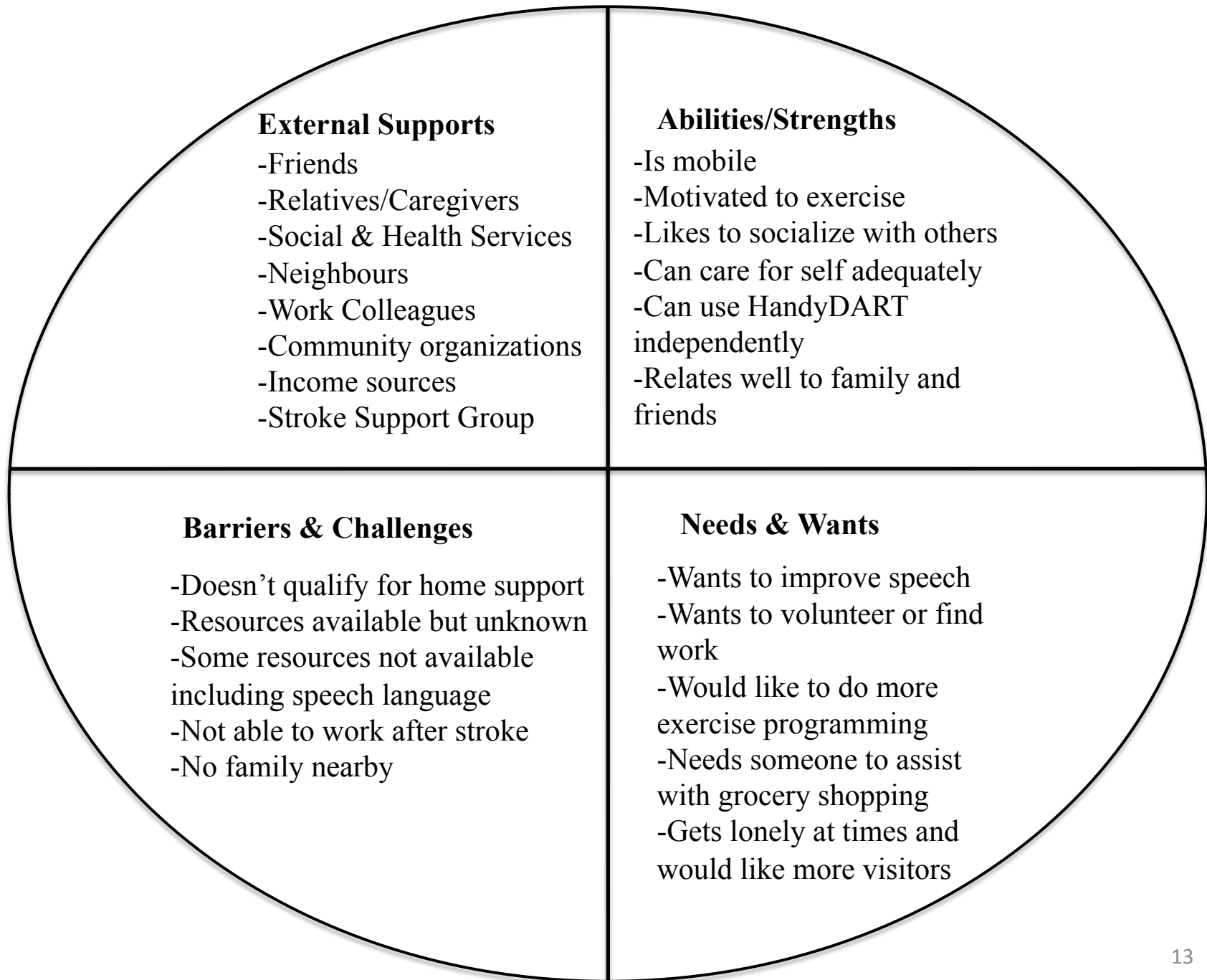
# What Do I Need?

- Sometimes we don't know what we need...
- **START BY:**
  - Thinking about what you want to be different
  - Listing strengths and abilities for both the stroke survivor and caregiver.
  - Listing needs and wants you want met.
  - Researching and finding resources and programs in the community that meet those needs and wants.



# Take stock...

- **Physical** - e.g. mobility, toileting, activity tolerance and fatigue.
- **Communication abilities** e.g. expressing needs, participating in conversation and understanding directions.
- **Visual and Perceptual** e.g. can you find your way, use public transit, understanding signs, crossing the road.
- **Behaviour** e.g. emotional difficulties, depression, aggression.
- **Social** e.g. feeling comfortable around others, involvement in group activity, friendliness.
- **Financial** e.g. being able to handle money, ability to pay for programs and services using cash and electronic devices.





# Getting What You Need

- Now that you know what you need or want, you can start researching what exists in your community.
- Talk to your doctor, therapist, family, friends, neighbours, other stroke survivors or people you know that have an interest in stroke.
- Sometimes there is more than we think, other times there is less.



# Finding What You Need

- It is helpful to keep all of our information in one place such as binder with plastic sleeves for brochures, bus schedules, etc.
- Questions to ask about community programs to see if they are right for you:
  - How long has the program been running?
  - Who teaches/leads the program?
  - Length of sessions and frequency?
  - Cost?
  - What requirements are necessary to take part?
  - Are the days and times convenient?
  - Accessible by public transit and/or HandyDART?



# SRABC Resources

- Visit us online at [www.strokerecoverybc.ca](http://www.strokerecoverybc.ca).
- Download **The Guides to Recovering from a Stroke**:
- <http://strokerecoverybc.ca/recovering-from-a-stroke/guidelines-to-recovering-from-a-stroke>
  - Scroll down this page to ‘Brochure Download’ and click on the brochure you want to read or print. If you would like copies of these Guides please send an email to [office@strokerecoverybc.ca](mailto:office@strokerecoverybc.ca) or call us at 604 688 3603.
- Sign up for The **Life After Stroke newsletter**
- Follow us on Facebook and Twitter





# THANK YOU!

- Thank you for your participation in our webinar.
- We will send you an evaluation via email and would be most appreciative of any feedback you can provide.
- Questions? Feel free to get in touch with us by:
  - Email: [office@strokerecoverybc.ca](mailto:office@strokerecoverybc.ca)
  - Toll-free: 1-888-313-3377