Learning how to Get the Help you Need – a webinar for caregivers on how to navigate the health and social care system

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MS Navigator
MS Society of Canada
Sailing through Uncertain Sea: Navigating “The System”

Robert TerSteege, CIRS
Information & Referral Associate Parkinson Canada
CarePARTNER vs. CareGIVER vs. Carer

- Our loved one may not be in need of a lot of care-giving
CarePARTNER vs. CareGIVER vs. Carer

- Our loved one may not be in need of a lot care-giving
- What can your partner do for *you*?
  - Refocus that this is a Partnership
CarePARTNER  vs. CareGIVER vs. Carer

- Our loved one may not be in need of a lot care-giving
- What can your partner do for you?
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- Where are you along this journey together?
CarePARTNER vs. CareGIVER vs. Carer

• Our loved one may not be in need of a lot of care-giving
• What can your partner do for you?
  o Refocus that this is a Partnership
• Where are you along this journey together?
• Understand that you can not do everything for your partner
Care PARTNER vs. CareGIVER vs. Carer

• Our loved one may not be in need of a lot of care-giving
• What can your partner do for you?
  ▪ Refocus that this is a Partnership
• Where are you along this journey together?
• Understand that you can not do everything for your partner
• You can do anything…but not everything…
  ▪ What kind of supports do you need?
• Always
• Seek
• Knowledge
Parts of “The System”?

- Legal
- Financial
- Government
- Social Services
- Healthcare
Parts of “The System”?

- Legal
- Financial
- Government
- Social Services
- Healthcare
Parts of “The System”? 

- Legal 
- Financial 
- Health Care 
- Social Services 
- Government
Consider diagnosis…

You → Different specialist → Specialized specialist

GP → Specialist

Referral → Wait → You → GP
Beginning to take charge
Beginning to take charge

- Identify stressors
  - What is really stressing you?
Beginning to take charge

• Identify stressors
  ◦ What is really stressing you?

• Prioritize: Is this really important?
  ◦ Who is this important to?
Beginning to take charge

- Identify stressors
  - What is really stressing you?
- Prioritize: Is this really important?
  - Who is this important to?
- Plan ahead
  - What’s coming up?
  - What do you need help with?
  - Who can help you with it?
  - What resources are available?
Identifying issues

What am I worried about?

What is the problem?
What am I worried about?

What is the problem?

Is this a health issue?

Is this a financial issue?

Is this a legal issue?

Is this a social service issue?
Identifying issues

What am I worried about?

What is the problem?

Is this a health issue?
- GP
  - Specialist
  - Pharmacist
  - ER

Is this a financial issue?
- Accountant
  - Bank
  - Financial advisor

Is this a legal issue?
- Provincial Human Rights
- Lawyer
- Legal Clinic e.g. ACE

Is this a social service issue?
- Non-profit
  - Community leaders
- MPP
- 211
Resources

For-profit

Non-profit

Government

Community

Loved Ones

You
National, Provincial, Regional, Community

- Medicare
  - No single national plan
  - Province to province
National, Provincial, Regional, Community

- Medicare
  - No single national plan
  - Province to province

- Financial Support
  - CPP–Disability Benefits, EI–Sickness Benefits
  - Provincial Disability Support Programs
National, Provincial, Regional, Community

- Medicare
  - No single national plan
  - Province to province
- Financial Support
  - CPP–Disability Benefits, EI–Sickness Benefits
  - Provincial Disability Support Programs
- Social services
  - Provincial programs – in-home support
  - Local programs
    - Sliding scale programs
    - Day programs
Line in the sand

- What are your limits?
Line in the sand

• What are your limits?
• Plan Ahead
  o Medical
  o Legal
  o Financial
  o Physical
  o Emotional
Practical tips & tools

<table>
<thead>
<tr>
<th>Key Issue</th>
<th>Health Issue</th>
<th>Financial Issue</th>
<th>Legal Issue</th>
<th>Social Service Issue</th>
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<tr>
<td>This is a</td>
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<td>Name of Program/Service:</td>
<td>(Only one program/service per page)</td>
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<td>Date</td>
<td>Who did I speak to</td>
<td>What did we talk about?</td>
<td>Next steps?</td>
<td>Completed</td>
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Communication Journal
Practical tips & tools

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<th>Key Issue</th>
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**Communication Journal**

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<td>Date</td>
<td>Who did I speak to</td>
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<tr>
<td>Jan 5</td>
<td>Jon Smith</td>
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<td>Jan 18</td>
<td>Mimi Zang</td>
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“Honey Do” List! for those ‘if there’s anything I can do’ moments

<table>
<thead>
<tr>
<th>Things I need help with</th>
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<tr>
<td>Sit with my loved one, so I can go for groceries; get to place of worship</td>
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<td>Mow the lawn or shovel the driveway</td>
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<td>Drive to big specialist’s appointment</td>
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<td>Come over for dinner....but bring the dinner!</td>
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<td>Light housekeeping</td>
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<td>Take my loved one for a walk, so I can have some “me” time</td>
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<td>Call XYZ agency, as I don’t know what they want</td>
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<td>Help filling out paperwork</td>
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“No miss” days

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How to Determine Key Issue

Brainstorm
- Long list of all issues

Identify
- Main Issues
- Sub issues (to be worked on after main issue is resolved)

Complete “Reality” Check
- What issues are most likely to be resolved?
- What issues are least likely to be resolved

Complete Resource Check
- Issues with reasonable community support
- Issues with less community support

Identify
- Key Issue!
Individual Advocacy

Valerie Borggard, RSW
MS Knowledge Network Navigator MS Society of Canada
Self-Advocacy Planning Flowchart: 3 Stages:

**Stage 1**
Identification & Strategy Action Plan Development

**Stage 2**
Strategy Action Plan Implementation and Record Keeping

**Stage 3**
Evaluation & Next Steps
Step 1: Identify issue
- What is the concern(s)?
- Medical, legal, financial, housing, equipment needs, employment relationships, transportation, etc.

Step 2: Set specific goal
- Tangible & Measureable

Step 3: Develop strategy action plan

Step 4: Determine criteria for success
- How will you know when you have achieved the goal?

Stage 1: Identification & Strategy Action Plan Development

Write down steps you will take to resolve the concern.
- Who, when, why, method and follow-up
- Gather information/Research process
- Put into motion the steps included in the strategy action plan
- Review processes, criteria, requirements
- Research potential asks
- Gather information & documentation
- Complete and send correspondence as needed
- Communicate with the people identified
- Adjust time lines as needed
Evaluate the process

- Take time compare the outcome with the criteria identified in STAGE I
- Criteria is met. Check it off!
- Criteria is NOT met or it is felt that it needs more work review the goal, strategy and action from Stage 1
- Revise as needed and continue with Stage 2 Implementation

Identify potential sources of assistance

- At times everyone needs assistance and support advocating.
- People with disabilities can get this support from partner organizations or other community groups

Stage 3 Evaluation & Next Steps
Questions?

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Valerie.borggard@mssociety.ca
1-866-922-6065

*Please contact us for handouts!*