

SUPPORTING CAREGIVERS

A GUIDE FOR PRIMARY CARE

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RATIONALE -- WHY CARE FOR CAREGIVERS

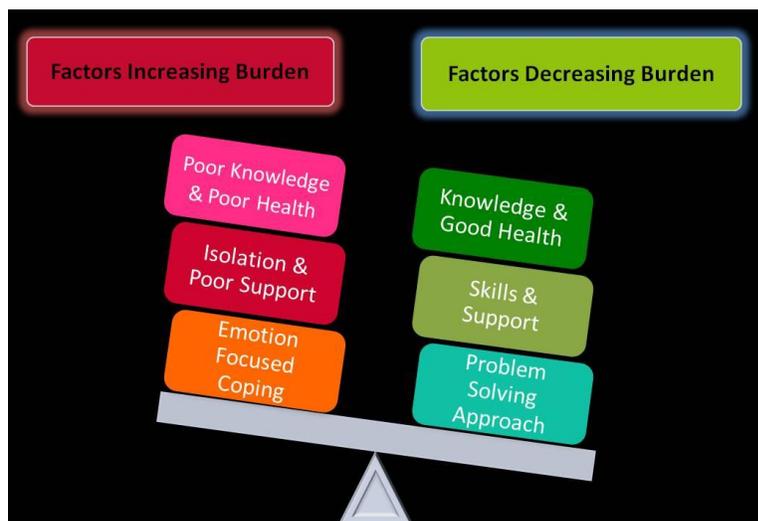
As clinicians, we tend to focus mostly on the needs of the person with dementia and may forget to address the needs of the caregiver who accompanies them. The caregiver is not only our partner in care and the main support for the patient whom he/she is caring for but they are in fact a population in need of care.

The key to manage dementia at home is a well supported, educated and skilled caregiver.

Quick facts about some risks of caregiving

Psychological	Physical
<ul style="list-style-type: none"> ➤ Higher rates of depression (14 – 47%) ➤ Up to 1 of 3 take psychotropic drugs ➤ More likely to suffer a relapse of pre-existing psychiatric illness ➤ More likely to over-use substances like alcohol ➤ Emotional costs: anxiety, grief, guilt, rage 	<ul style="list-style-type: none"> ➤ Higher prevalence of physical symptoms than non-caregiver peers ➤ Exacerbation of pre-existing illness (diabetes, hypertension) and more doctor visits ➤ Higher rates of prescription drug use ➤ Poorer subjective ratings of health

Model of Caregiver Burden – tip the balance towards decreased burden



WHAT CAN YOU DO?

1) **BE PROACTIVE** – ASK AND SCREEN FOR CAREGIVER BURDEN

Here are 3 quick screen questions you can ask a caregiver:

- ❖ What are your biggest challenges right now?
- ❖ How do you feel you are managing /coping with the demands on you?
- ❖ What more do you need in order to carry out your caregiving duties?

2) **SUPPORT**

Help caregivers focus on concrete elements within their control in each situation by using problem solving technique (PST):

PST is defined as the process by which a person identifies specific problems encountered in every day living and helps them develop effective, adaptive solutions. PST helps the caregiver to shift from an emotion focused coping to a problem solving approach.

By using these following quick steps of PST you can assist the caregiver in reaching a concrete and achievable solution:

1. **Creating a problem list** – write down the concerns and prioritize. Choose the one problem/challenge that is the highest priority for the caregiver and that is realistic for the time you have in your visit. Acknowledge emotions, but focus more on concrete challenges. For example rather than focusing on the emotional piece of feeling “lonely” or “Overwhelmed” focus on a specific challenge that is triggering this feeling such as “I don’t have time for myself” , or “I’m doing everything on my own” or “I don’t have time to see my friends”
2. **Clarify and define the problem** – focus the challenges of the caregiver him/herself rather than the ones of the patient with dementia. Ask, “Why is this a problem or a challenge for you?” You may need to repeat this step several times to get at the underlying issue.
3. **Establish objectives and achievable goals** – try to reach a concrete and focused goal such as “having time for myself twice a week in the afternoon”, “getting the bills paid”.
4. **Brainstorm and work out alternative solutions for the problem** – Generate as many ideas as possible. Remind the caregiver that at this stage the goal is to come up with as many options as possible without judging if they would work or not.
5. **Discuss pros and cons for each solution**
6. **Choose the preferred solution(s)**
7. **Discuss implementation of the solution(s)** – create a detailed plan of how, when and where each step of implementation should take place, and who else they may need to involve to be successful.
8. **Follow up** - on the next visit to evaluate the outcome.

**** See examples of cases and PST based discussions in Appendix A.**

3) **REFER** - Here is a list of resources for caregivers:

Caregiver's need	Resources	Contact information
Information	Alzheimer Society of Toronto – First Link program: Information, resources and education	T:416-322-6560; F: 416-322-6566 www.alzheimertoronto.org
	Canadian Mental Health Association – for Mental Health related information and resources	T: 416-789-7957 info@cmha-toronto.net
	CLEO – for financial and legal right information	T: 416-408-4420; F: 416-408-4424 cleo@cleo.on.ca ; www.cleo.on.ca
	Advocacy Centre for the Elderly (ACE) - for legal right information	T: 416-598-2656 F: 416-598-7924 www.advocacycentreelderly.org
	Ontario Senior's Secretariat – provides resources and information about legal and financial rights as well as other resources available in the community.	T: 1-888-910-1999 infoseniors@ontario.ca
Emotional Support	Alzheimer Society of Toronto – Counselling services (phone/face to face) and support groups (in person or online)	T:416322-6560; F: 416-322-6566 www.alzheimertoronto.org
	CARERS Program – Reitman Centre Mount Sinai Hospital – Individual and group therapy for caregivers	T: 416-586-4800 ext. 5192 F: 416-586-3231
	Caller Reassurance Program – support service and distress line for vulnerable seniors	Program – 416-439-0744 Distress line- 416- 408-4357
Skills and coping techniques	CARERS Program – Reitman Centre Mount Sinai Hospital – A Problem Solving Technique based program that supports and teaches coping skills to caregivers through group therapy and simulation practice. A concurrent group for the care recipient is also offered.	T: 416-586-4800 ext. 5192 F: 416-586-3231
Respite services: Day programs Night programs Short term stay Overnight stay Group activities Friendly visiting Home help Transportation Caregiving services PSW	Community Care Access Centre (CCAC) - provides: case management and coordination, Personal Support Workers (PSWs), Home Help, links to Long Term Care short stay facilities, links to all other services.	Toronto Central CCAC: T: 416-506-9888 F: 416-506-0374 Outside of Toronto call: 416-310-2222.; www.ccac-ont.ca/
	Community Navigation Access Program (CNAP) – links to agencies that provide: PSW, Caregiving services, group activities, short term stay, day and night programs, friendly visiting, transportation, home help, etc.	T: 1-877-540-6565 www.cnap.ca

4) **FOLLOW UP**– Schedule regular follow-ups with caregivers to assess their level of coping and their needs on a on-going basis.

APPENDIX A
CASE EXAMPLES OF PST BASED CAREGIVER DISCUSSION

7 steps of PST:

1. Clarify and define the problem.
2. Establish objectives and achievable goals.
3. Generate alternative solutions through collaboration and brainstorming.
4. Discuss pros and cons and create decision guidelines.
5. Choose the preferred solution(s).
6. Develop an action plan.
7. Evaluate the outcome.

Problem case example #1:

Joanne is a 72 year old woman whose husband, Bill, was diagnosed with Alzheimer 4 years ago. Joanne is finding it increasingly frustrating to care for Bill because of his frequent repetitive questions, and his desire to be with her at all times. They have one son, age 40, who lives about 30 minutes away, and who is supportive but not readily available because of family and work commitments. Joanne does not feel Bill would be safe if left alone, as he has left the stove on, and has tried to stand on furniture to change light bulbs. Her greatest identified challenge: "I just feel totally overwhelmed. It's too much."

It sounds like you have a lot going on right now. What would you say is the thing that is most overwhelming?

I don't know. He just drives me crazy, he never lets me out of his sight. I have no time for myself. He has a fit if I say I want some time alone. I can't even go to the bathroom without his asking where I'm going!

I can understand why that might be difficult for you. What in particular makes this a problem for you? (Step 1: Clarify and define the problem.)

I need some time for myself.

What would you do if you had more time for yourself?

If I had more time I would be able to do things for myself that relieve stress, like go swimming or see friends, but I cannot leave him alone.

How much time to do those things do you think you would need to make a difference in the way you feel?

If I could know that I had 3 hours once or twice a week to exercise or meet friends, I would really look forward to that, but I don't have anyone to help, and he won't like having a stranger come to the house.

When is it the greatest problem?

I need a break most in the early afternoon. That's when I feel like I just can't escape.

What have you already tried to solve the problem?

I've asked my son, but he's not able to come over very often. I tried asking my neighbour, but she's quite unreliable.

Okay, so it seems the problem is that you would like to have 3 hours twice a week to swim or spend time with friends, but you have not been able to arrange care for your husband regularly to do that.

Yes.

Would you say your goal is to come up with a way to make sure your husband is cared for by someone else twice a week for 3 hours at a time? (Step 2: Establish objectives and achievable goals.)

Yes.

Let's brainstorm some possible solutions. (Step 3: Generate alternative solutions through collaboration and brainstorming.)

You could ask your son...

Right, but he's not available.

Let's put every possible idea on the page without thinking yet if it would work or not. The goal is to have as many as possible. After we finish you'll have a chance to say whether or not you think it will work.

Okay.

So, you could ask your son for help, or your neighbour. Who else could be involved?

Well, there's my cleaning lady. And my niece might help. Bill has some old friends who know about the situation too.

Have you contacted any agencies?

I have a CCAC case coordinator but I don't think I am entitled for any more assistance. I would be willing to pay privately if I had to, I just don't know where to begin.

What about adult day programs?

I haven't looked into those yet. I don't have the time!

....

Now that we've generated a few ideas, let's take a look at the options we've come up with and see which of them might work. Let's start with your son, what would be the positive side of asking him for help, what's the pro for involving him? (Step 4: Discuss pros and cons and create decision guidelines.)

Well, I know Bill would be comfortable with him, and I know John would be happy to be able to help in some way. But he doesn't have much time, and certainly not every week.

So that's a con of that idea. Any other cons?

No.

Do you think he would be willing to be with Bill while you make some other phone calls or try to find out about other services, such as adult day programs?

Yes, that might work.

Let's go on with the other items on our list.

...

So, now that we've gone through the possibilities, do you think you could use any of them, or a combination of them to help you with your goal? (Step 5: Choose the preferred solution(s).)

I want to involve my son and Bill's friend to help me to find an Adult Day Program (ADP) for Bill and ask my CCAC case coordinator about eligibility for a Personal Support Worker (PSW). I could contact a private service for help in the meantime.

Let's make this action plan as specific as possible. When are you going to call your son and what are you going to ask for? (Step 6: Develop an action plan.)

I'll call tonight after dinner and I'll ask if he could come over next week for a couple of hours after work so I can look on the internet for information about ADPs. I'll call Bill's friend Steve on Monday morning to see if he can stay with Bill while I contact the ADP.....

When you come back next time we can talk about how the plan went, and if there were any problems with the steps you've outlined. (Step 7: Evaluate the outcome.)

Case Example #2:

Sam is a 68 year old man caring for his brother, Eddie age 72. Eddie was diagnosed with frontotemporal dementia 4 years ago. He moved in with Sam and his wife Elizabeth 2 years ago. The arrangement is becoming increasingly difficult for Sam and Elizabeth as Eddie has begun making inappropriate sexual comments to Elizabeth, especially when she tries to encourage him to bathe. Eddie's personal hygiene has deteriorated such that he bathes only when wrestled by Sam into the bathroom, an ordeal he is willing to undertake every 10 days or so. Sam's greatest identified challenge: "He just won't cooperate!"

You are describing a frustrating situation. What would you say is the thing that is causing the most conflict right now?

Bathing. Eddie just won't listen to reason, even when we explain to him that it has been too long since he last showered. We don't want to hurt his feelings so we tell him it isn't healthy for him. He doesn't care. He even tried to hit me once when I tried to take him into the shower!

What about him not wanting to bathe is the biggest concern for you? (Step 1: Clarify and define the problem.)

Well, I don't think it is healthy for him.

But what is the problem for you with this?

Well, it is just so sad. He used to be so dignified, and it shows how far he's declined. And it makes me so angry that he is fighting me when all I want to do is help!

So there are two issues: first, it makes you feel upset, and second how and how often to get him clean. Let's try to tackle the second one because that is a more concrete problem.

Maybe a shower is the solution, but maybe not. How would you finish this sentence, "My problem is..."

I can't get him clean enough. He smells.

When is it a problem?

Right now I force him, really wrestle him, into the shower when we can't stand it anymore. It would be so much better if we could get him to shower every 3 or 4 days. He always used to shower in the morning, so that's when we do it.

Who is involved?

Just me. We did try to have Elizabeth talk to him, because he responds much better to her in general, but he started making all these sexual comments to her and she felt really uncomfortable.

Where does it happen?

He has his bedroom and bathroom in the basement. Usually I wake him up in the morning and tell him he has to go into the bathroom to shower. That's when he starts shouting and I have to

physically pull him out of bed. But he's really groggy when I wake him up and he seems really confused by the whole thing. That makes it worse too, I hadn't thought of that before.

What have you already tried to solve the problem?

We've tried to reason with him and explain why he needs to shower. And obviously, the physical method I'm using now.

Okay, so I think I have a good sense of the problem now. You and your brother fight when you wake him up in the morning to have a shower. There are three pieces to this problem: the fighting, the waking him up in the morning, and the shower. What do you think would be a reasonable goal? (Step 2: Establish objectives and achievable goals.)

Let's see. My goal is to change what I'm doing so my brother and I don't fight when it is time for him to have a shower in the morning?

Let's brainstorm some possible solutions, keeping in mind those three pieces, the fighting, the waking him up, and the shower itself. (Step 3: Generate alternative solutions through collaboration and brainstorming.)

When you put it like that, I guess I don't have to do it in the morning when he's groggy. We could try it at night before bed, when he's usually calmer.

Good idea. Anything else? Does it have to be a shower?

No, I guess not. Maybe he'd prefer a bath.

Do you think he could clean himself at the sink, like a sponge bath?

Maybe. We wouldn't have to do it all at once that way either.

...

Now that we've generated a few ideas, let's take a look at the options we've come up with and see which of them might work. Let's start with raising the issue at night, what would be the pro for that change? (Step 4: Discuss pros and cons and create decision guidelines.)

He's calmer. But I'm much more tired at the end of the day.

So that's a con of that idea. Any other cons?

No.

Let's go on with the other items on our list.

...

So, now that we've gone through the possibilities, do you think you could use any of them, or a combination of them to help you with your goal? (Step 5: Choose the preferred solution(s).)

I will put "bath days" on the calendar so Eddie knows ahead of time. I will raise the issue of cleaning with Eddie after dinner, and I will help him run a warm bath. I will not use the word "shower". I will try to stay calm and make the bathroom as pleasant as possible, and make sure he is warm. I will not worry about getting Eddie clean for the days in between bath days, and help him wash at the sink if necessary.

Let's make this action plan as specific as possible. When are you going to set the bath days? (Step 6: Develop an action plan.)

I'll do that this afternoon. I'll set tomorrow as the first bath day...

When you come back next time we can talk about how the plan went, and if there were any problems with the steps you've outlined. (Step 7: Evaluate the outcome.)

APPENDIX B

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