



## **Survey: User-Centered Needs Assessment of A Caregiver's Guide - A Handbook About End-Of-Life Care**

**Dr. Jennifer Dobbles**

Date: September 8, 2020

## User Centred Needs Assessment of *A Caregiver's Guide- A Handbook About End-Of-Life Care.*



September 8, 2020

Dear Family Member or Caregiver,

If you are receiving this letter, you have cared for a loved one at the end of their life and have used *A Caregiver's Guide - A Handbook about End-of-Life Care*. I am hoping you may be interested in helping us improve *A Caregiver's Guide* to help others.

My name is Dr. Jennifer Dobbelsteyn and I am a researcher and an Officer of the Order of Saint Lazarus of Jerusalem, the organization that partnered with the Canadian Hospice and Palliative Care Association to write and publish this handbook. I have been asked by Dr. Robert Boyko, Hospitaller for The Order of Saint Lazarus, to conduct a needs assessment to identify any gaps in the handbook and make recommendations to fill these gaps.

I am writing this letter to you to ask for your assistance to improve this valuable resource for other family members and end users. What would I be asking of you? I am asking for your input based on your firsthand experience using *A Caregiver's Guide*. How could you provide your input? There are various ways you could provide your input:

1. Complete a survey of questions and add additional comments
2. Or discuss your responses to questions on a telephone interview with a Registered Nurse
3. Or participate in a Zoom call interview with a Registered Nurse.

We intend to collect data for this assessment in September and October 2020. The time commitment would be no more than 30-60 minutes.

If you would like more information or another contact, please get in touch with Dr. Robert Boyko at [hospitaller@stlazarus.ca](mailto:hospitaller@stlazarus.ca) or Grand Prior, Jane Anema at [grandprior@stlazarus.ca](mailto:grandprior@stlazarus.ca).

Please complete the attached survey and send to me by email at [caregiversguidesurvey@stlazarus.ca](mailto:caregiversguidesurvey@stlazarus.ca) or call me at (506) 471-1710 to express your willingness to participate in this assessment process via interview to provide your input. Confidentiality will be insured for all participants. Feedback will be provided to you at the end of the process.

Thank you for your interest and I look forward to hearing from you.

Sincerely,

Dr. Jennifer L. Dobbelsteyn, RN, PhD

Thank you for completing this survey on *A Caregiver's Guide- A Handbook on End-Of-Life Care*. Please choose the best response with a check mark - either agree, neutral or disagree. Additionally, there are spaces at the end of each chapter questions to add your specific feedback. The results of this survey will serve as a needs assessment and will inform improvements to *A Caregiver's Guide*.

I am a family member -----

I am a friend-----

I am a hospice caregiver-----

The province I live in is -----

Date of completion-----

<b>Questions Chapter 1: “When a Progressive Life-Threatening Illness is Diagnosed”</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>
1. Receiving a life-threatening diagnosis is life-changing and the information presented in Chapter 1 helped me know what to expect and how to help our loved one.			
2. <i>A Caregiver's Guide</i> taught me how to care for myself and be aware of caregiver burnout.			
3. I learned about the value of using support networks such as a doctor, nurse, pharmacist, and spiritual advisor.			

<p><b>4.</b> Hints on communicating with my loved one and others were helpful and I learned about the ‘gift of presence’.</p>			
<p><b>5.</b> Sufficient information was provided in Chapter 1 regarding meeting spiritual needs of our loved one at the end of life.</p>			
<p>Add any additional comments here on Chapter 1 content - what was most helpful or what was lacking and needs more information.</p>	<p>Most Helpful----- ----- ----- ----- ----- ----- -----</p>	<p>Lacking----- ----- ----- ----- ----- ----- -----</p>	<p>Other----- ----- ----- ----- ----- ----- -----</p>
<p><b>Questions Chapter 2: “Giving Physical Care”</b></p>	<p><b>Agree</b></p>	<p><b>Neutral</b></p>	<p><b>Disagree</b></p>
<p><b>6.</b> I learned how to prevent infections when caring for our loved one by handwashing and using things such as gloves when required.</p>			
<p><b>7.</b> Bathing a loved one can be a new experience and I found the information on bathing, mouth and hair care to be helpful in offering comfort as well as cleanliness.</p>			

8. When my loved one could not move and position themselves, I helped them with this and found the information provided on this topic helpful and complete.			
9. Techniques for toileting taught us about maintaining dignity while meeting toileting needs.			
10. Food and fluid needs change over the course of our loved one's illness and I learned to how to continue to discuss this topic with our loved one and the health care team as required.			
Add any additional comments here on Chapter 2 content - what was most helpful or what was lacking and needs more information.	Most helpful----- ----- ----- ----- ----- ----- ----- -----	Lacking----- ----- ----- ----- ----- ----- ----- -----	Other----- ----- ----- ----- ----- ----- ----- -----
<b>Questions Chapter 3: "Care of Physical Problems"</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>
11. The 0-10 pain rating scale was a useful tool to assess pain on an ongoing basis.			

<b>12.</b> I learned about other ways (non-medicinal) to manage pain.			
<b>13.</b> Opioids are often prescribed to manage constant pain and keep people more comfortable. I learned about opioid toxicity and managing complications.			
<b>14.</b> Skin problems such as itchiness can be expected with terminal illnesses and we found the suggestions on how to sooth itchy skin very effective.			
<b>15.</b> Chapter 3 of <i>A Caregiver's Guide</i> provides detailed information on mouth problems such as thrush. The information provided gave us new understanding of these common conditions and how to manage them.			
<b>16.</b> By using <i>A Caregiver's Guide</i> , I now know how to manage bowel and bladder problems.			
<b>17.</b> When a loved one experiences shortness			

of breath, it can be very frightening. I learned to remain calm, create a calm quiet environment and ask for help if needed.			
<b>18.</b> Confusion may be noted in people with a progressive illness. I learned it is best to be a quiet presence and stay with the person.			
<b>19.</b> Sometimes at end-of-life, people have trouble sleeping. I learned how to manage sleep issues.			
Add any additional comments here on Chapter 3 content - what was most helpful or what was lacking and needs more information.	Most helpful----- ----- ----- ----- ----- ----- ----- -----	Lacking----- ----- ----- ----- ----- ----- ----- -----	Other----- ----- ----- ----- ----- ----- ----- -----
<b>Questions Chapter 4: “As Life Ends”</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>
<b>20.</b> Chapter 4 provides information on what to know and what to do as life ends. A key decision to make is where a person prefers to be when they die. I learned it is best to discuss this and reach a mutual decision between the person			

who is dying, the family, and the care team.			
<b>21.</b> As the dying process begins, a person can withdraw and this is to be expected. I learned quiet music can be comforting at this time.			
<b>22.</b> Through <i>A Caregiver's Guide</i> , I learned how to recognize the signs that death was near and to talk to my loved one even though they seemed to be asleep, to reassure them I was right there with them.			
<b>23.</b> Grieving a loved one is a coping process and <i>A Caregiver's Guide</i> helped me understand grief and its multifaceted effects: physically, emotionally, mentally, spiritually, and socially.			
<b>24.</b> Chapter 5 provides several resources for further reading. This chapter was a comprehensive list of resources.			
Add any additional comments here on	Most helpful----- -----	Lacking----- -----	Other----- -----

Chapter 4 and 5 - what was most helpful or what was lacking and needs more information.	----- ----- ----- -----	----- ----- ----- -----	----- ----- ----- -----
<b>General questions on chapter structure</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>
<b>25.</b> Chapters in <i>A Caregiver's Guide</i> are structured with topics such as 'What you need to know' and 'How you can offer comfort and care'. This format met my needs and was clear as well as comprehensive.			
<b>26.</b> <i>A Caregiver's Guide</i> presents information on end- of-life care in a book format. This format was a satisfactory one to our family.			
<b>27.</b> I would prefer a handout format on topics as needed.			
<b>28.</b> I would prefer an online format.			
<b>I would suggest the following format:---</b> ----- ----- ----- -----			

<b>29.</b> A separate chapter on spiritual care would be beneficial.			
<b>30.</b> I feel I obtained enough information on emotional support as a caregiver.			
<b>31.</b> Are there any other topics you would like covered as a caregiver?	Topics----- ----- ----- -----	Topics----- ----- ----- -----	Topics----- ----- ----- -----
<b>32.</b> Additional comments can be added here regarding the design of chapters, book format, or adding/deleting chapters.	Comments----- ----- ----- ----- ----- ----- -----	Comments----- ----- ----- ----- ----- ----- -----	Comments----- ----- ----- ----- ----- ----- -----