

READERS' GUIDE / SUPPORT GROUP LEADERS' GUIDE / BOOK GROUP GUIDE

POINTS TO PONDER OR DISCUSS ALONE OR WITH OTHERS

Pick, skip, do all, do some, do it all at once, do it over weeks/months/years.

Just like caregiving, there is no one way or right away.

DEDICATION

1. What type of caregiver do you see yourself as?
2. Do you think sooner or later caregiving touches us all?
3. Do we have a choice in the type of caregiver to be?

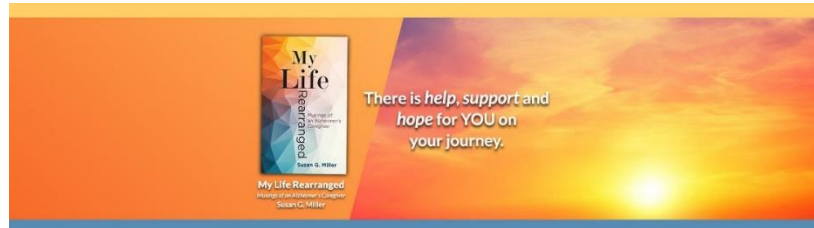
PRE-BEGINNING & BEGINNING STAGES

1. What signs did Susan miss in the beginning?
2. What signs did you miss and how long was it before diagnosis?
3. Why does this occur?
4. What was your first reaction when you received the diagnosis?
5. When you look back in retrospect, does it all make sense?
6. What was your defining moment?
7. What did you feel at that moment?
8. What decisions to you need to make at this point?
9. Where is your family in this process and how do you feel about it?
10. Susan had a dark side. Do you feel you have one, too?
11. What should one do about having a dark side?
12. What special things are you doing while you have this time?
13. Susan felt like she was being shadowed all the time, and all she did was straighten things up, resulting in feeling annoyed a lot.
Do you ever feel this way? What do you do when you feel this way?
14. What roles do you play now, that you hadn't before?
15. Do you think Susan exaggerated or was overly dramatic?
16. How do you cope?
17. Susan felt like she resided in two worlds? Do you feel that way?
18. What are your biggest issues at this stage?
19. As stage one winds up, it seems like Susan has found acceptance. Do you agree? Have you?
20. Are you able to commit to the present? If not, why?
21. Have you found a source of friendship to sustain you and have you started to think about building a path to tomorrow? What is the status of old friendships?
22. As you move closer to middle stage, have you taken time to congratulate yourself for how far you have come?
23. Do you agree that the public has a stereotypical view of an Alzheimer patient?
24. Have you joined a support group?



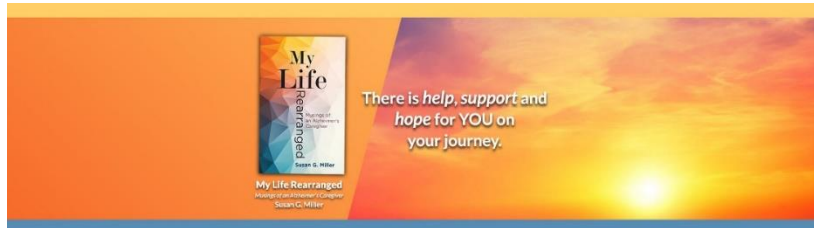
MIDDLE STAGE

1. What signs or indicators were there that you knew you were about to enter middle stage?
2. Why do you think Susan waited so long to go to support group? Have you joined one?
If not, why?
3. Do you agree with Susan's neurologist, that many big decisions have to be made?
4. What do you think those decisions are for you for middle stage and where are you in the process?
5. How did you feel about the transition of your role of companion to caregiver?
6. What are your defining moments for this stage?
7. Have you been able to begin the process of letting go? If so, how are you doing this?
8. What do you think of the concept of "the good enough" caregiver?
9. Susan hit her husband. Do you ever think you could be pushed that far?
10. What is the biggest difference between beginning stage and middle stage?
11. What new losses are you facing?
12. Are parts of your life just disappearing? What can you do about this?
13. Taking away a driving privileges is one of the hardest but necessary tasks a caregiver must do. Where are you on this subject?
14. Have you had meltdowns? How did they make you feel?
15. Do you use fantasy as a coping skill?
16. Have you considered a part-time caregiver? If not in the budget, is there someone who could help you out so you could have a few hours to yourself?
17. What constitutes your professional healthcare team?
18. Have you considered a therapist?
19. Are you learning about the disease, so you can cope better?
20. What did you think about Susan's refusal to have her husband get a colonoscopy?
Do you agree or disagree? Have you thought about what procedures you will or will not do, moving forward?
21. Do you feel you can trust your judgement more these days, and can be your own expert?
22. How are your relationships with family and friends going?
23. Do you think people romanticize this disease and make saints out of caregivers?
If so, why and what can be done?
24. At this juncture, how has caregiving changed you?



FINAL STAGE

1. At this point, are you having problems remembering your life Before Alzheimer's?
2. How are you doing with the transition from caregiver to custodian?
3. Has compassion fatigue set in and, if so, what are you doing about it?
4. Watching someone disappear before your eyes, is very difficult.
What are you doing to alleviate some of that pain?
5. Have you made up your mind about home care versus assisted living memory care or skilled nursing? Have you visited places and are you on a list?
6. If waiting is what caregivers do, how are you waiting?
7. Are you experiencing conflicting emotions?
8. Do you feel like a mother again?
9. What do you do when the one you care for has hallucinations?
10. If you are going to place your loved one, at some point, in assisted living memory care of skilled nursing, what will be the final straw?
11. What do you think of Mary Oliver's poem, The Journey? Does it speak to you?
12. Why was Susan having 2nd thoughts? Do you think this is common? Might it apply to you?
13. What do you think about the elderly woman who told Susan that placing her husband in assisted living or a nursing home, will be harder than burying him?
14. Does a secret voice taunt you? If so, what do you do about it?
15. Why do you think the days before placement are so difficult?
16. If you are married, how would you feel about your spouse connecting with someone of the opposite sex?
17. If you placed your loved one, how are you adjusting to free time? Are
18. Do you think Susan was correct in transferring her husband across the country?
19. Have you considered Hospice?
20. Susan had 2nd thoughts about treating her husband at the end. How do you feel about what she did? Would you do the same? Have you thought about what you would do in various situations so you are prepared?
21. Have you started to put in place your new life?
22. Why was Susan and her family so shocked by the final breath?
Do you think this could happen to you?
23. Are you prepared for all the tasks aftermath brings?
24. Do you think you will feel like your life is over when your loved one passes?



FINDING TOMORROW AND NEW BEGINNINGS

1. Have you tentatively been thinking about your new life?
2. Have you given yourself time to mourn?
3. How do you feel about finding tomorrow?
5. Down the road have you thought about dating or having a companion?
6. What are your thoughts about marriage?
7. What do you think about Susan's decision to save herself when her companion became increasingly more like her late husband?
8. How could Susan have missed the signs the second time around?
9. Do you think a "good enough life" is something you would be happy with?
10. What have you learned?
11. Has it changed you?
12. What would you tell others?
13. Do you have any regrets? If so, what do you plan to do about them?
14. How did you make it through caregiving?
15. What was the most valuable lesson you learned?
16. What is the next chapter in your story?
17. Have you considered joining in, in the fight for a cure?
18. Do you think there will be a cure someday?
19. Are you relieved it is over, but also sad?
20. What does your Tomorrow look like?

For more resources regarding Alzheimers and caregiving:

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