



102 Things You Wish You Knew Before You Started Caregiving

Did you know that

1. Taking the role of family caregiver for someone with dementia you begin a long life-altering journey?
2. From diagnosis to death for a person with dementia can be as long as 20 years?
3. That 63% of the family caregivers actually die BEFORE the person with dementia does, due to the stress?
4. That most family care doctors /Primary care physicians do not know anything about dementia and will not refer you to a specialist.
5. That a day may come when you may actually be envious of the friends that have parents that have already died, because they can have a life.
6. That there are many different types of dementia, and your family member may not have the right diagnosis?
7. That there are some medications for dementia that once started, if stopped and restarted, will no longer be effective?
8. That you cannot count on coverage or help for anything from Medicare or Medicaid?
9. The right doctor can prevent or diffuse problems or even eliminate a crisis situation?
10. How to find the right doctor?
11. How important it is to remember that there is a life after care giving. That life needs nourishment and attention everyday, now. Do not neglect it.
12. Never be embarrassed by your parents actions or words. Realize early on that it is the disease, not the person acting or talking. Just make those around you of that.
13. For every problem there is a solution. You just need to give yourself an opportunity to allow the solution to present itself..



14. Life as a care giver is filled with going to medical appointments, going to the pharmacy to pick up medications, shopping, cooking, cleaning, paying bills, on the phone to coordinate care or find resources. Then there is the meeting of the physical, mental and emotional needs of another human being 24 hours a day. This leaves the caregiver feeling as if they are on a constant treadmill of care giving. All this and they have not met their own basic needs let alone wants and desires.

15. There are systems you can put in place to care for a parent, as a long distance caregiver?

16. How important support groups are to arm you with knowledge and confidence to be as proactive as possible. That most caregivers become socially isolated.

17. Things may not always appear, as they seem. Some with dementia become very good at covering up their cognitive deficits to others. You may not be believed by other family members, that your parent has dementia.

18. How important it is to catching changes early can make a difference with early treatment.

19. How important it is to have your parent with dementia do as much possible for as long as possible for themselves. When they loose the ability to do something, it will not come back.

20. All the alternatives that are available to you?

21. That dementia will bring out the worst in family dynamics. You must be aware ad sensitive to how you communicate within the family unit.

22. That there is a fine line between “allowing your parent” to be independent and not “allowing” them to get into a potentially dangerous situation.

23. Family and friends will disappoint you. Everyone has limits and boundaries. You must learn to set your own. Acknowledge and let go, some things are not worth getting upset about.



24. Many times a family caregiver needs to ask for help. Be specific about what it is you want and need and when it needs to be done. Do not hesitate to ask, do not feel guilty, or angry that you have to ask- just do it because it needs to be done.

25. That guilt is a wasted emotion and negates all the good you do. Work on getting rid of it. It strips away joy and other pleasure in your life.

26. Family care givers go through a grieving process everyday as they see they are slowly losing the person they are caring for everyday. Realize this is normal. At the end, you may feel relief and sadness. Sometimes, emptiness at starting all over again can be a common theme.

27. That one day, you may realize that there is something worse than facing death?

28. How important it is to be prepared for future care needs and do research into facilities long before you need them?

29. Finding a dementia care facility is not easy. A facility may say it does dementia care, but, if your parent acts out, is aggressive, is sexual, verbally abusive, a wanderer, you may find the facility hesitant. You will find that most dementia care facilities staff is not trained in how to handle behavior problems that dementia patients so often exhibit. (they really should not call themselves dementia units, but they do)

30. That if you have a parent that is sexually active with another individual in a community or facility- neither party is privy to the other person's HIV or hepatitis status

31. How important getting to know the staff and administration in the facility where your parent lives is important.

32. Do you know what legal, medical and financial papers are important to have in place?



33. Know if quality of life or quantity of life is of concern to your family member? Will your family member want to continue to have preventative care testing and be treated should something be discovered?
34. Do you know how to deal with a difficult parent?
35. Do you know how to deal with difficult siblings?
36. Do you know when to introduce end of life care?
37. Do you know where your family member wants to spend their last week, or months?
38. That there are days when you must accept that you are only human, have limits and needs like everyone else. You cannot make everyone happy or meet every ones needs. The sooner you realize this, the healthier you will be as a caregiver.
39. How to have enough energy to meet the demands for everyone in your family?
40. That there are tests you can do at home to check your stress level
41. That there are tests you can do at home to test your memory and your family member's memory for decline
42. Wished you were able to separate your parent for the disease
43. Knew how to handle all the physical needs
44. Realized how not to argue with someone with dementia, even in the very early stages.
45. Dementia may be hereditary, and as we get older we worry that we will become what is happening to our family member.
46. You will have regrets, guilt, wished you had spent more time with your family, your friends, your family member with dementia, had an opportunity to make amends, express gratitude or forgiveness. Do not hesitate to take opportunities now. Do not wait. Remember, guilt is a wasted emotion.



47. Wished you were better prepared to handle angry outbursts.
48. Knew how to handle all the physical needs of your family member
49. The first steps every care giver should take?
50. How to handle the difficult behaviors?
51. What sun downing is and how to deal with it?
52. That bathing, dressing, eating can become a battle?
53. That toileting can be a problem?
54. How to make the home environment safe?
55. That 6 out of 10 individuals with dementia wander. Meaning they could leave home and get lost
56. Do you know the difference between pacing and wandering?
57. Are you aware of the medications, what they are for and when they are to take them?
58. Are you aware of all the important medical information of your parent?
59. Do you have a mandatory evacuation plan in place during a government declared mandatory evacuation?
60. Do you have weather safety programs in place in case of emergency?
61. How are the communications between you and your parent? Driving, finances, need for future care
62. Are you aware how other medical conditions may trigger behavioral problems in persons suffering from dementia? Do you know what those conditions are?
63. Your reaction, your response, can have an impact on the behavior of your parent with dementia?
64. The environment- TV, lighting, a mirror, can have an impact on the behavior of a person with dementia?
65. Do you know how to respond when a person with dementia becomes physically aggressive, violent, or sexually acts out?



66. That this disease not only affects the entire family, but can break the family without preparation and support.
67. Caring for a person with dementia can be financially devastating. There is little to no medical insurance coverage for the care that is required.
68. That a once kind and sweet person can transform into a surprisingly mean and nasty individual in a few seconds with dementia?
69. That most medical professionals do not necessarily understand dementia. Networking with other family caregivers is key to support and properly treating and caring for someone with dementia.
70. That it is normal to worry that you may end up just like your parent?
71. That the transition from one stage of dementia to another is not always a slow progression.
72. Keeping a parent mentally, physically and socially stimulated is more important than medication?
73. When to increase the level of care or change the short term goals for your parent?
74. How and why family meetings are important?
75. A person with dementia loses their short term memory. They are living in the moment. You must help them create a moment of happiness- for when it is gone, so is the memory.
76. That you should prepare for caring for some one with dementia as if you were preparing for a triathlon. You need patience, endurance, and a sense of humor to make it to the finish line.
77. Do you know all the resources available to you?
78. Do you know the benefits of music at the different levels of dementia?
79. Do you know the benefits of pets with some one with dementia?



80. Do you know all the things you should consider before you move your parent in with you or before you move in with your parent?

81. Do you know how to respond to your parent if they are expressing delusions or seeing hallucinations?

82. Do you know the difference between a delusion and a hallucination?

83. Do you know how dementia may affect the grandchildren in your family?

84. Do you need some ideas for special projects a grandchild may be able to work on with a grandparent with dementia?

85. Did you know that a care giver gratitude journal and focusing on positive thinking can provide the care giver with a greater sense of well being, more energy, enthusiasm, and sense of optimism.

86. Do you know stress relief techniques to keep your health at its optimal level?

87. Do you know how to prepare for life after care giving?

88. When caring for a person with dementia, it is important to focus on what a person CAN do, not what they can no longer do. Laugh, smile, hug, walk etc

89. Do you know that it is normal to feel angry at a situation and take it out on your parent and those around you. Your parent cannot help that they have dementia and how they are behaving.

90. How beneficial it is to live in the reality of the person with dementia and not try to re orient to the present.

91. Can you determine how your parent with dementia is feeling?

92. How to advocate for your parent in the doctors office, hospital, nursing home, assisted living or ER?

93. Are you aware of the benefits available to you through the VA?



94. Do you know what to do when a person with dementia shows no interest in eating?

95. What to do when a person with dementia puts everything into their mouth?

96. Do you know how to identify that a person with dementia is in pain?

97. Did you know a person with dementia forgets to eat and drink?

98. Do you know what to do when a person with dementia loves to cook – and frequently forgets to turn off the stove?

99. Did you know that the person with dementia may be able to cover up their memory loss and judgment, especially if they have developed more social skills. Some are better at it than others.

100. Did you know that laughter is the best medicine – do not be afraid to laugh and find joy in things everyday. Your parent will benefit from the positive energy.

101. Did you know that you should never move anyone into an AL or NH on a Fri because the weekends are understaffed?

102. Did you know that your long term care policy may not have a cost of living rider and care provided may be only during certain times in certain settings?