

EXPLORATION GUIDE



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ABOUT THIS GUIDE

Patterns in Time is a real family history of one family's experience with one person's Alzheimer's. Everything in it comes from a place of love and respect. *Patterns in Time* is meant to help readers make even better choices than the family depicted. (Think of it as *the opposite* of a How-To.) Everything is offered to improve the reader's ability to NOTICE, ACCEPT AND RESPOND to the unusual yet normal experiences that come with Alzheimer's.

A diagnosis of Alzheimer's is different from other medical diagnoses. The neurologist reports a diagnosis, then often leaves the person and their family to figure out next steps on their own. General Practitioners have few medications to prescribe or treatments to recommend, and no cures to offer.

This means that facing Alzheimer's requires a different approach than facing other medical diagnoses.

Alzheimer's impacts every member of a family, starting with the person diagnosed. It's effects, care requirements and duration change their life, the life of the person who is the caregiver in the home; their children (whether they live nearby or at a distance); family members added through friendship and even family members estranged by divorce.

Alzheimer's is a team sport. Diagnosed individuals and their team members who in the past have kept medical issues private, do well to consider a more open and transparent approach to communicating the Alzheimer's experience with the whole team.

Honest sharing makes it easier for each team member to play their position. Those involved in care decisions for the person with the diagnosis do so fully aware. Those looking to support the caregiver see today's care load and its requirements accurately. Those involved from afar are acknowledged as invested, involved and in need of support themselves. Everyone recognizes and supports one another in their unique journey.

Everyone's life depends on it.

ABOUT THE AUTHOR

Barbara Ivey writes The Perfect Thing blog, teaches workshops on Alzheimer's as a team sport, and is a former researcher at Microsoft. She received a B.A. in English from Concordia Bronxville, an M.L.I.S. from Dominican, and holds a certificate in Lean Healthcare from Belmont.

1. PURPLE PAGES – THE EXPERIENCE OF THE PERSON LIVING WITH ALZHEIMER'S

Alzheimer's disease is different in every person.

Look at the **PURPLE PAGES**.

The physical, cognitive and personal events that happened to Chris as her Alzheimer's progressed are marked with **PURPLE ICONS** on the timeline.

Review them.

1. Do any events in Chris' timeline surprise you? Which ones?
2. What is surprising about them?
3. What might the surprising events suggest about the experience of Alzheimer's?
4. How would you describe the progression of Chris' Alzheimer's?
5. Which years were less eventful?
6. Which years were more eventful?
7. What else comes up for you?

2. PURPLE PAGES – THE EXPERIENCE OF THE CAREGIVER

Look at the **PURPLE PAGES**.

The physical, cognitive and personal event that happened to Caregiver Buzzy are marked with **ORANGE ICONS** on the timeline.

Review them.

1. Do any of Caregiver Buzzy's events surprise you? Which ones?
2. What is surprising about them?
3. What might the surprising events suggest about the experience of Alzheimer's?
4. What else comes up for you?

People diagnosed with Alzheimer's eventually need someone to support them as they take care of their own daily needs. Over time, these needs increase. The person who supports them is referred to as a caregiver, care partner, primary caregiver or carer. At different points this person may be a spouse, an adult child, a friend, a family member, or healthcare provider.

HOUSEWORK

Look at the **ORANGE PAGE**.

Find the **GREEN SQUARE** labelled **HW**.

In the legend, **HW** stands for **HOUSEWORK**.

For 10 years after her first memory issues appeared, Chris was able to complete her usual housework tasks independently.

The first time **HW** appears on the chart it is in **GREEN SQUARE**.

This means that in July 2010, for the first time, Chris relied on her caregiver Buzzy to **PROMPT** her to help her complete the sequence of steps in her housework tasks.

5. What might it sound like to **PROMPT** someone to help them complete their usual housework tasks?
6. When did Buzzy go from **PROMPTING** Chris, to **DOING** the housework?

BATHING

On the **ORANGE PAGE** find the **GREEN SQUARE** labelled **BA**.

In the legend, the **BA** label stands for **BATHING**.

For 10 years after her first memory issues appeared, Chris was able to complete her bathing independently. The first time **BA** appears on the chart, it is in a **GREEN SQUARE**. This means that in July 2010, for the first time, Chris needed her caregiver Buzzy to **PROMPT** her to help her complete the sequence of steps involved in bathing.

7. What might it sound like to **PROMPT** someone to bathe?
8. When did Chris first need Caregiver Buzzy to **ASSIST** her in bathing?
9. When did Chris first need Caregiver Buzzy **TO BATHE HER**?
 - a. How old was Caregiver Buzzy when Chris first needed him to bathe her?

- b. What other care tasks was Caregiver Buzzy doing at that time?
 - c. What else was Caregiver Buzzy experiencing at that time?
10. What might you do the same as Caregiver Buzzy?
11. What might you do differently than Caregiver Buzzy?
12. Look at the tasks that Caregiver Buzzy - at age 79 - was doing for Chris.
- a. How might friends support caregivers like Buzzy?
 - b. How might adult children support caregivers like Buzzy?

3. PURPLE & BLUE PAGES – THE EXPERIENCE OF THE ADULT CHILD

Look at the **PURPLE PAGES**.

Some of the physical, cognitive and personal events that happened during Chris' Alzheimer's to adult daughter Barbara are indicated on the **PURPLE PAGES** by **LIGHT BLUE ICONS** on the timeline.

Review them.

1. For thirteen-and-one-half years, Buzzy chose to be the only caregiver for Chris.
 - a. Does this choice involve risks? What might they be?
 - b. What messages might a decision like this send to adult children?

Chris & Buzzy chose to live two-hours away from adult daughters Barbara and Diane. Medical appointments and Alzheimer's family education appointments happened on weekdays during office hours. Each time the daughters attended it required them to miss a day of work.

As Chris' support need increased, the number and frequency of appointments increased. Caregiver Buzzy's support needs increased as well.

2. What impact might the two-hour distance have had on their daughter's ability to provide hands-on support?
3. What impact might the two-hour distance have had on their daughter's professional lives?
4. What impact might the two-hour distance have had on their daughter's home lives?
5. What impact might the two-hour distance have had on their daughter access to caregiver education and support?

6. Why might Barbara's spine surgery have been included on the timeline?
7. How might her surgery have impacted the care she could provide to Caregiver Buzzy?
8. What might you do differently than Barbara?

Look at the **BLUE PAGES**.

Barbara and Diane learned that when Caregiver Buzzy **felt loved** he provided better care to their Mom Chris. As both daughters lived two-hours away, they tried many different ways to make Caregiver Buzzy feel loved from a distance. (Efforts that were positively received are depicted on the blue pages.)

9. What about Alzheimer's disease might make a Caregiver need extra love?
10. Why is providing extra love to a Caregiver a good role for family members who live at a distance?
11. Why might it be important for families to clarify decision-making roles during Alzheimer's?
12. How might families clarify who fills which role in making decisions regarding their loved-one-with-Alzheimer's?
13. What might be the benefit of clear decision-making roles?

COMMON ROLES IN DECISION-MAKING

- *Those who RECOMMEND various courses of action*
 - *Those who SIGN-OFF on a decision before it can MOVE FORWARD*
 - *Those who PROVIDE INPUT AND DATA on recommendations*
 - *The person who MAKES THE DECISION*
 - *Those who IMPLEMENT the decision*
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4. BLUE PAGES – CAREGIVER TO THE CAREGIVER

Look at the **BLUE PAGE**.

When Barbara observed the toll that caregiving was taking on her father, she chose to step into the role of Caregiver to the Caregiver.

1. What care might a caregiver need?
2. What might a “caregiver to the caregiver” do?
3. Why might caring for the caregiver be a priority for an adult child or close family member?
4. Does caring for the Caregiver count as Alzheimer’s Caregiving? Why or why not?
5. What is the difference between caring for a caregiver and helping a caregiver?
6. Can you know if a caregiver will accept help? How?

THE BEST WAYS TO CARE

Look at the **BLUE PAGE**. At the bottom are two recommendations for the best way to care for the loved-one-with-Alzheimer’s and the Caregiver.

7. How might caregiver education improve life for a loved-one-with-Alzheimer’s?
8. How might caregiver education improve life for a caregiver?
9. How might caregiver education improve life for the adult child?
10. How might an adult day program improve life for a loved-one-with-Alzheimer’s?
11. How might an adult day program improve life for a caregiver?
12. How might an adult day program improve life for the adult child?

5. DESIGN, LAYOUT AND KEY THEMES

1. What are the themes in *Patterns in Time*?
2. Does the layout and design of *Patterns in Time* support the explorations of the themes? How so?
3. What might the layout and design suggest about the experience of Alzheimer's?

Patterns in Time: One Family's Journey by Barbara Ivey. Fort Mill, SC: The Perfect Thing. 2017: pamphlet (ISBN: 978-0-9982641-1-0).

Available from <https://ThePerfectThing.info/shop>

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