



A Caregiver's Guide



# Caregiving is a journey. Let us help you find the right path.

### Introduction

Are you concerned about changes you are seeing in your loved one? Do you question whether you are making the right decisions as you navigate new care needs for them? The Joyful Journey Caregivers Guide is meant to be a quick reference for you to have in your "tool belt" as you travel along on your caregiving journey. What you are doing is very important, but you do not need to travel this sometimes painful, sometimes exhausting path alone. In fact, it is our belief that your and your loved one's health and happiness depend upon building a support system to help you along the way.

Our hope is that you will find inspiration, validation, and practical skills that will help you get pointed toward the support and resources you need. For example, Chapter 1 discusses six signs that indicate you and your loved one need extra support. If you have noticed memory issues in your loved one, you may want to jump straight to Chapter 6: Spotlight on Alzheimer's and Dementia. Read the guide as a whole or pick and choose to read what you need, when you need it.



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# Welcome

## The Joyful Journey Guide to Caregiving

If you're reading this, chances are you have an adult in your life who needs additional support during the day. Whether this is a new development or you've been caring for your loved one for years, this Ebook is one more resource to help you provide the best care possible.

#### Our "Friends"

At Joyful Journey, our mission is to provide socially engaging activities that enhance quality of life, well-being, and independence for adults experiencing changes in mobility or cognition. We strive to provide families an alternative option for compassionate care outside the home while offering respite and support for the primary caregiver. Through intentional, person-centered programs, our team is committed to providing meaningful days filled with purpose for each Friend who comes to visit our house\*.

Building authentic relationships with the people in our care is central to the Joyful Journey approach, which is why we call the folks we serve our "Friends." Additionally, the Joyful Journey house was built to intentionally look like a house on the outside and feel like a warm, inviting home on the inside. We want the people who come to us for services to feel like they are visiting good friends at their house!

We invite you and your loved one to our house to make new Friends!



## Recognizing the Signs

There may come a time when you realize your loved one needs additional care and support. Knowing when the time is right to seek out this support can be complicated. We've put together some of the basic signs to help inform your decision-making process.

### 1. Moving from independent to dependent

Your loved one has become increasingly more dependent on you to attend to daily necessities of life. You consider yourself their caregiver. This can be the right time to start introducing additional care providers and support. By building these new relationships early, your loved one will hopefully have an easier time adjusting to new people, new situations and more dependent living. There may be a number of transitions you encounter, some of which you can handle solo, but just remember--it's okay to ask for help.



### 2. Life-changing event

A life-changing event has occurred and your loved one's needs have changed. Consulting a healthcare professional, like a trusted physician, is a great place to get guidance when trying to anticipate next steps in care. Some life changing events can include:

- \* Diagnosis of a chronic illness
- \* No longer being able to drive
- \* An injury that reduces mobility
- \* Loss of a spouse or friend, resulting in isolation

### 3. Physical changes

Changes in your loved one's physical abilities can also indicate the need for more support outside of the home. Providing the appropriate amount of physical activity that meets our loved ones' needs as they age can be difficult. Activities they once loved can be too strenuous or dangerous, which leads them to withdraw from physical activity altogether. If your loved one is experiencing longer periods of inactivity, muscle tone and strength will begin to diminish. Changes in vision as we age can also impair balance and mobility. Some signs of physical changes include:

- \* Issues with balance and/or frequent falls
- \* Reduced or inconsistent strength
- \* Increased need for support during grooming or bathing
- \* Changes in diet or eating habits

### 4. Cognitive changes

With cognitive changes, as with physical changes, it can be difficult to tell if a problem is ongoing or if your loved one is just having a bad day. As we age, we can experience forgetfulness or take a moment to recall information or memories. This isn't always a sign of an underlying condition or that additional care is needed. If you have concerns about the following symptoms of cognitive decline, please contact your physician:

- \* Increased confusion
- \* Difficulty in word finding and language skills
- \* Missing daily medications or over-medicating
- \* Wandering from the home

### 5. Changes in emotional state

You may notice your loved one is becoming more easily agitated and angry or they may withdraw from social interactions. You might suspect they are feeling depressed or have lost their sense of purpose because they are spending more time alone or in their room. Some of this can be part of the natural aging process, but in some cases, it can be the sign of an underlying issue. It is always a good idea to consult a physician if you notice any of these changes, including a general change in your loved one's personality.

Last, but certainly not least—safety is essential. If any of the signs listed above result in a safety concern or injury, now is the time to seek out additional care and support!

### Chapter 1 Review

As your loved one ages, you may want to be on the lookout for changes that can signal a need for caregiving support.

- Becoming more dependent on you
- Medical diagnosis or loss of mobility
- Balance & strength issues or falls
- 4 Confusion, wandering, persistent forgetfulness
- Jones Increased anger, agitation, or depression

Become Our Friend

### Chapter 2

## Building a Care Team

Whether you are new to caregiving or you've been someone's primary caregiver for a longer time, bringing in reinforcements and building your care team can be a lifesaver.

### Why do you need help?

As your loved one's health and abilities begin to change, your health may begin to change as well. If you are in the sandwich generation, you may need additional support to maintain your employment status while raising children. Caregiving for someone with declining abilities or chronic illness requires round the clock vigilance. The constant state of alertness combined with assisting someone throughout the day can leave you physically, mentally, and emotionally exhausted.

### Caregiver Fatigue

This state of exhaustion is often referred to as caregiver fatigue or caregiver burnout and it will eventually have a negative effect on your health and well-being if ignored.

### **Increasing Needs**

Another scenario is where your loved one begins to depend on you with increasing frequency. As their needs progress, there may be some aspects of their care that are outside of your skill set or that you are uncomfortable doing. You may even find moments in your loved one's care

routine where they refuse your help, even though they can not complete the task safely without you!

Adding support people to the care routine when you begin to notice these types of situations can be a great way to relieve stress and tension in the relationship. This is why we recommend starting to build what we call your care team.

### Who is on your team?

The term care team can refer to different people depending on the setting. For our purposes, it will refer to people in your family and community, as well as professional caregivers and facilities that will assist you and your loved one with care needs.

### You & Family

At the beginning of your caregiving journey, you may find family members or friends ready, willing and able to help with tasks like visiting or sitting with your loved one while you go grocery shopping. They may be able to take your loved one on outings or pitch in to assist with yard work or other household tasks. However, when family members are unable or unwilling to assist, looking further into your community for support will be necessary.

### Area Agency on Aging (AAA)

Contacting your local Area Agency on Aging , AAA, can be a great place to start. The AAA in your community can direct you toward resources for care support, transportation, food services and even financial assistance programs.

### Community & Faith-based Organizations

Local faith-based organizations may also offer a congregational care option. As your journey continues with your loved one, it is important to plan ahead and start looking for help in your community.

### Chapter 2 Review

It's ok to get help and take some time for yourself. In fact, it's often the best thing you can do, both for you and for your loved one. Caregiver fatigue is a real issue that can negatively impact your health and the quality of care you can offer your loved one.

- Get help from family, friends and neighbors if available
- 2 Check your local Area Agency on Aging
- Look into community and faith-based organizations in your area



### Chapter 3

## Overview of Professional Care Options

Choosing a professional care option that is right for your individual situation can seem daunting. There are a variety of options available, ranging from an independent in-home contractor to a residential senior community with skilled nursing on site. We suggest answering the following questions before you begin your care search:

### 1. What do you need?

- a. Some personal time for respite, hobbies or errands?
- b. Freedom and flexibility to maintain employment?
- c. Someone to help with your loved one's personal care and shower schedule?

### 2. What does your loved one need?

- a. Their own time to socialize and build relationships?
- b. More mental and physical activity during the day?
- c. A club that they belong to and look forward to attending?
- d. Assistance with mobility, personal care and other activities of daily living<sup>1</sup>?

<sup>1</sup> The activities of daily living (ADLs) is a term used to collectively describe fundamental skills required to independently care for oneself, such as eating, bathing, and mobility.



Each person and family have unique scheduling needs that can be met in a variety of ways. Figuring out the schedule that best fits your life is helpful as you look into care options. For example, do you want/need:

- a. A few hours, a few days a week
- b. Full day coverage Mon-Fri for employment or other reasons
- c. 24/7 care

We've assembled some informative materials to help you answer these questions. Keep them in mind as you learn more.

### Types of Care

There are two main things to consider when searching for care options for your loved one: type of care and location of care. We'd like to help define what type of care is given and where the care is provided.

### **Adult Day Services**

Adult Day Services are designed to provide social engagement and stimulating activities in a non-residential setting outside the home. They also afford caregivers respite from the demanding responsibilities of caregiving. In Indiana, there are three levels of Adult Day Services. Level 1 is social support with assistance for activities of daily living. Level 2 and 3 provide medical support and oversight that incorporates care by a registered nurse. The National Adult Day Services Association, NADSA 7, uses the following definition for these services: Adult Day Services are a system of professionally delivered, integrated, home and community-based, therapeutic, social and health-related services provided to individuals to sustain living within the community.



### 3 Levels of Care: Adult Day Services

The Division of Aging in Indiana assists people in finding support based on three levels of care. Joyful Journey Adult Day Service offers Level 1 services. The three levels of care are defined as:

1

#### Basic adult day service (Level 1) includes:

- Monitoring and/or supervision of all activities of daily living (ADLs are defined as dressing, bathing, grooming, eating, walking, and toileting) with hands-on assistance provided as needed.
- 2 Comprehensive, therapeutic activities.
- 3 Health assessment and intermittent monitoring of health status.
- 4 Medication monitoring or administration.
- 5 Appropriate structure and supervision for those with mild cognitive impairment.



## **Enhanced** adult day service (Level 2) includes Basic (Level 1) service requirements **and additionally:**

- 1 Hands-on assistance with two or more ADLs or hands-on assistance with bathing or other personal care.
- 2 Health assessment with regular monitoring or intervention with health status.
- 3 Dispensing or supervising the dispensing of medications to participants.
- 4 Assessment and intervention for psychosocial needs, including counseling as needed for participants and caregivers.
- 5 Therapeutic structure, supervision, and intervention for those with mild to moderate cognitive impairments.

3

# Intensive adult day service (Level 3) includes Basic (Level 1) and Enhanced (Level 2) service requirements and additionally:

- 1 Hands-on assistance or supervision with all ADLs and personal care.
- 2 One or more direct health intervention(s) (required).
- 3 Rehabilitation and restorative services including physical therapy, speech therapy, occupational therapies (coordinated or available).
- 4 Therapeutic interventions to address dynamic psychosocial needs such as depression or family issues affecting care.
- 5 Therapeutic interventions for those with moderate to severe cognitive impairment.

2

### **Other Types of Care**

#### \* In-Home Care

There are a variety of in-home care options to choose from. For example, health aides can come to your home to provide companionship and supervision, bathing services and health monitoring. Some home health agencies will provide transportation to appointments and activities.

### \* Independent Living

Also known as senior living or retirement communities, these facilities provide homes within a designed neighborhood or complex, offering basic living amenities, recreational activities, security and transportation services.

### \* Assisted Living

Assisted living facilities provide adults personalized care in a residential setting. These are generally full service residences with meals, amenities, assistance with grooming and housekeeping, and medication management.

### \* Memory Care

Memory Care is a type of residential living facility that provides specialized care for people living with Alzheimer's and other forms of dementia. This type of community living environment will feature more security measures and staff assistance to aid residents with physical and emotional needs.



### **Some Helpful Examples**

To help illustrate the caregiving decision-making process, we have put together three different family stories that we hear often at Joyful Journey. We'll explore how each family chose their care support. (Please note these are fictional families.)

### Family 1: Stew and Betty

Stew and Betty have been retired for 10 years. Their children stay in contact with them, call often, and visit when they can, but they live several hours away. Betty and Stew still live in the family home they raised their children in, and it holds many memories. Betty was diagnosed with mild cognitive impairment three years ago after Stew noticed her having issues with her short term memory and sought out a neurologist to assess her brain health. Stew has been able to have several of Betty's friends help her stay active and social, but as her condition has continued to change and decline, he is beginning to realize he needs more help.

Stew needs more time to himself in his woodworking studio without interruptions. Betty misses playing piano for her church choir and attending her community outreach meetings. Betty has settled into a more sedentary lifestyle and has lost some of her mobility. Stew would like to find a care option that helps Betty socialize and stay active in a way that is both safe and fun. He has also noticed that when he helps Betty get in and out of the bath, they invariably get into arguments. Stew hopes that he and Betty will live in their home for a few more years before downsizing and possibly moving into a residential senior community. He realizes he will need more help to make that goal a reality.

After doing some research and talking to friends who have been through similar situations with their loved ones, Stew has decided on a combination of care options. He has found an in-home healthcare agency that comes to the house once a week to help Betty bathe, style her hair and play cards. Additionally, Betty goes to an Adult Day Center three days a week. At the day center, she is able to participate in a variety of activities. Her favorite activities include seated aerobics, art class, and singalong; she even plays the piano to accompany the sing-alongs. Although

Betty was hesitant to be out of the house at first, she has a new lease on life and looks forward to seeing her friends at the center. Stew has been able to complete several of his woodworking projects and reconnect with his golfing buddies.

### Family 2: Martha

Martha is a widow who is used to being independent and living by herself. In recent years her vision has declined and she is no longer able to drive. She has also begun to have balance issues resulting in several falls. The last fall she suffered landed her in the hospital and prompted an emergency family meeting. Martha's children pleaded with her to move into an assisted living facility, but she refused. Martha's daughter Sue thought they could try having Martha live with her while they figured out what their next step would be.

Sue and her husband work full time and are raising two children who are in high school. Sue refuses to let Martha stay home by herself because she is afraid Martha will fall again and seriously injure herself. After several heartfelt discussions, Martha has agreed to move in with Sue and her family. She has also agreed to attend the local Adult Day Center while Sue and her husband are at work. Sue has peace of mind knowing her mother has a safe, stimulating place to be during the day, and she's thankful she can continue to enjoy the job she loves. Martha has made several new friends at the center and rediscovered her interest in music and art. After three months in this new and more active lifestyle, Martha is feeling stronger and more confident!

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### Family 3: Ted and Sally

Ted and Sally live on a farm 10 miles outside of town. After Ted suffered a mild stroke, his doctor recommended that he attend a local adult day center to help keep him active after his physical therapy was completed. Ted did not take the doctor's recommendation because he didn't think it was necessary.

Several months later, while Sally was running a "quick errand", Ted got up to get something in the kitchen and fell in the process. Since then, he sticks to his recliner and watches TV or naps. Sally has noticed that Ted can no longer get out of his recliner without her help. Sally is now seeing her doctor because she is having back pain due to the extra stress on her body. She called the adult day center to see if they can offer support while she goes through physical therapy for her back. The center reassessed Ted and determined that he has declined past their level of service and is no longer eligible to attend. The only options available to Ted and Sally now are in-home health or a residential care facility. Sally wishes she would have followed the doctor's original recommendation and encouraged Ted to give the adult day center a try.





### What is the cost of care?

Cost of care can vary greatly depending on location, but you can expect the costs to increase incrementally as the care needs increase. Below is a cost comparison chart for different care options found in White County and Tippecanoe County, Indiana. Rates were compiled in 2021.

Organization	Care type	Accommodations	Costs per month (estimated)	Source	Hourly/Daily	Daily
Joyful Journey	Adult Day	Half Day	\$1,197		5 days/ week * 4.2 weeks	
Joyful Journey	Adult Day	Half Day/ Lunch	\$1,302		5 days/ week * 4.2 weeks	
Joyful Journey	Adult Day	Full Day	\$1,680		5 days/ week * 4.2 weeks	
Creasy Springs Health Campus	Independent Living	1 bed/ 1 bath	\$2,617	2		
Creasy Springs Health Campus	Assisted Living	24/7 Semi-private	\$3,337	7		
Creasy Springs Health Campus	Assisted Living	24/7 Private	\$4,345	7		
Creasy Springs Health Campus	Memory Care	24/7 Private	\$6,148	7		
The Springs of Lafayette	Assisted Living	24/7 Semi-private	\$2,671	7		
The Springs of Lafayette	Assisted Living	24/7 Private	\$4,474	7		
The Springs of Lafayette	Assisted Living	24/7 Private	\$5,444	7		
White Oak Health Campus	Assisted Living	24/7 Semi-private	\$3,445	7		
White Oak Health Campus	Assisted Living	24/7 Private	\$4,194	7		
White Oak Health Campus	Memory Care	24/7 Private	\$6,395	7		

Rates were compiled in 2021

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Organization	Care type	Accommodations	Costs per month (estimated)	Source	Hourly/Daily	Daily
Beehive Homes	Memory Care	24/7 Private	\$5,700	7		
Bickford of Lafayette	Memory Care		\$3,346	7		
Digby Place	Assisted Living		\$2,520	7		
Five Star Residences of Lafayette	Assisted Living		\$1,915	7		
Five Star Residences of Lafayette	Independent Living		\$2,810	7		
University Place	Independent Living		\$2,307	7		
University Place	Assisted Living		\$4,000	7		
University Place	Memory Care		\$6,200	2		
Friendship House	Subsidized Housing for seniors/ disabled	1 Bed/1 bath	\$2,350	7		
Independent Caregiver	In home Care	Half Day	\$1,411		\$12/hr * 4 hours	•
Independent Caregiver	In home Care	Full Day	\$2,822		\$12/hr * 8 hours	•
Independent Caregiver	In home Care	Half Day	\$3,528		\$30/hr * 4 hours	•
Independent Caregiver	In home Care	Full Day	\$7,056		\$30/hr * 8 hours	•
Independent Caregiver	In home Care	24/7	\$8,467		\$12/hr * 24 hours	•
Independent Caregiver	In home Care	24/7	\$21,168		\$30/hr * 24 hours	•
AVERAGE for Home Health Agencies	In home Care	Full Day	\$3,813	7	44 hours per week	

Rates were compiled in 2021

### 4. Financial Support Options

Depending on your or your loved one's financial situation, you may have additional payment options at your disposal, including: long-term care insurance, veteran's benefits, or eligibility for state financial aid like Medicaid Waiver programs.

Check with your local Agency on Aging to see if you and your loved one are eligible for local or state benefits. Area IV is the Agency on Aging for Tippecanoe County.

You can also check with your employer to see if they offer a Dependent Care Account option in their benefits package. Dependent care benefits include dependent care tax credits, paid leave for the care of dependents, and flexible spending accounts for dependent care.

### Chapter 3 Review

There are a variety of professional care options available. Answer the following questions before you begin your care search:

- What do you need?
- What does your loved one need?
- 3 How much support is needed each week?

Learn more about the different types of care that are available with this helpful resource .

## Is Adult Day Right for You?

Now that you have learned a little bit more about care options and cost, we want to more fully examine the concept of adult day services. When you've made the determination that you need some extra caregiving support, an adult day service is a great supplement to your everyday routine.

Here are six compelling reasons to help you along in your decision:

### 1. Give yourself a Break

Caregiver fatigue is a very real health concern that can leave one physically, emotionally, and mentally exhausted. If you find yourself dayafter-day feeling depleted or overwhelmed, it is time to start looking for options that help support your mental and physical wellbeing.

Adult day services can help you keep your loved one in their home longer, while giving you the necessary time away from caregiving to attend to household, career, and everyday matters. Building your care team early will also help ease the transition for your loved one to trust the care of someone other than family.

It's natural to feel like you need to be there for your loved one at all hours. And it can feel selfish to take a break. However, it is important to note that you as the caregiver need time to connect with your friends and maintain the parts of your life that make you feel good! With this in mind, adult day services benefit the whole family. Win-win!

As we often tell our caregivers—you can't pour from an empty cup!

### 2. A Community of Friends

An adult day service gives your loved one, who may otherwise feel isolated at home, a community of friends. It's vital to have someone with whom to share experiences, enjoy leisure time, and share a sympathetic ear. Socializing and being part of a group makes us feel good, gives us confidence, and helps us find more self-acceptance. Additionally, humor and laughter are powerful tools to foster camaraderie and positive feelings.

In a very real sense, we're all on this joyful journey together!

### 3. Increased Engagement and Activity

Physical and mental engagement can have a very positive effect on overall health. An adult day center can provide a variety of ways for people with different needs to receive their optimal level of activity, both physically and mentally.

At Joyful Journey we learn each person's individual and unique history, then design activities accordingly—activities that are both fun and fundamental! For instance, chair aerobics and washer toss help activate gross motor strength and balance, while modified card games and word games help build resilience in the section of the brain connected to word and number recognition.

The foundation of our program model is our staffing ratio of one Program Assistant to a maximum of four Friends. This ratio is unparalleled in healthcare congregate settings, such as adult day centers and residential living facilities. Our knowledgeable and professional caregiving team makes activities easy and accessible to ensure your loved one is set up to feel successful during their day.

### 4. Sense of Purpose

Taking it a step further, a great quality of life requires a sense of purpose. This is more than a place to be—It's a reason to be.

A sense of purpose is most often fulfilled through attaining life

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goals and enjoying career accolades or being part of a service group in the community. As we experience life changes like retiring from our life's work or being unable to drive, we can lose our sense of purpose.

However, with a caring and creative adult-day team, purpose-filled activities are once again part of the fabric of your loved one's life. For instance, our Friends light up when we introduce a service project that will impact their community!

### 5. Fostering Creativity

Trying new things, engaging in the creative process for arts and crafts, gardening, and listening to music can help engage our mind, body and spirit. Completing a project fosters a sense of pride and personal growth. When done in a group, it creates lasting interpersonal connections and feelings of belonging.

Our Friends participate in a diverse range of arts and cultural experiences that encourage freedom of expression and personal choice through the creative process. When we introduce a new creative project to them, we break down seemingly complex ideas into simple steps to ensure Friends feel comfortable and successful throughout the project.

### Music and Memory® Certified

Music uniquely connects us with our memories and each other. We are Music and Memory<sup>®</sup> certified, allowing our team to create the perfect playlist for your loved one.

These music favorites – specifically the beloved songs from a person's formative years – tap deep memories not lost to dementia and can bring listeners back to life, enabling them to feel like themselves again, to converse, socialize, and stay present."

- Music and Memory.org

Although the Music and Memory approach is specifically designed to benefit people with dementia, all of our Friends have this amazing program available to them.

### 6. Quality and Affordability

When you compare the quality of care, activities and engagement level at an adult day to other options, there is no comparison. However, is it affordable?

Adult day is one of the most affordable options when it comes to professional caregiver support. On average, adult day services cost 40-60% less than home health and 50-75% less than long term care options. For further information, see the cost comparison chart in chapter 3.

### **Chapter 4 Review**

As you think about what type of care your loved one needs, you may want to consider adult day services to supplement your daily routine. The benefits can be immense, especially if you are flying solo in your caregiving journey. Adult Day Services can:

- Provide caregiver respite and support
- Be a great social outlet for your loved one
- 3 Encourage active minds and physical wellbeing
- 4 Give your loved one a sense of purpose and belonging
- Provide a creative outlet that enriches their life
- 6 Save your family money

For more resources and information on Adult Day Centers in Indiana, please contact the Indiana Association of Adult Day Services.

Learn more from our Joyful Blog!



### Chapter 5

## The Joyful Journey Difference

We'd like to share with you our approach to enhancing the quality of life of our Friends at Joyful Journey! We call it the "Domains of Wellness," as we believe that maintaining an optimal level of wellness is crucial to quality of life.

At Joyful Journey, there are 6 Domains of Wellness that guide our development of programs and activities to ensure each Friend's unique level of wellness is addressed.



#### **Social**



### Creative

Participating in a diverse range of arts

and cultural experiences that encourage freedom of expression and per-

sonal choice throughout the creative

process. Exploring creativity through

a variety of artistic mediums: music,

painting, drawing, sculpting, crafting,



### Intellectual

Encouraging continuing education

and exploration through activities

that provide historic and cultural

information, language and numeric

skill building and retention, and cre-

ative problem-solving.

Making Friends, feeling close to another person, and sharing experiences in ways that enhance feelings of belonging. Building healthy, nurturing and supportive relationships as well as fostering a genuine connection with others.



### **Physical**



#### **Emotional**



### **Engagement**

Addressing gross/fine motor skills, balance, range of motion, muscle tone and control for independence in Activities of Daily Living (ADL's). Also includes nutrition and positive dining experiences.

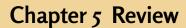
Reminiscing about personal histories and experiences to access emotions and memories. Promoting optimism, self-esteem/confidence, and self-acceptance. Using humor and laughter to discover camaraderie and enhance positive feelings.

Feeling purpose, pride and worth, achieving a goal, helping someone else accomplish their goal. Providing benefit and giving back to the community through a variety of activities. Sharing personal knowledge, skills, and interests with others.

### Philosophy of Care

As you can see from the domains of wellness graphic, central to each of the domains is our Philosophy of Care. This philosophy is the foundation through which our organization serves our community, guides each moment of Friend care, and informs our program choices:

- We accomplish things with our Friends based on their current abilities and interests because everyone needs a sense of purpose.
- We respond to our Friends, including to their changes in abilities, in a way that upholds their dignity and self-esteem.
- We appreciate that our Friends have important histories and thoughts to share. It is our responsibility to offer the right environment plus time and encouragement so their voices are heard the most.
- We understand that a Friend is doing the best he or she can. When something is not working, it is our responsibility to change our behavior and approach.
- We are aware of the environment and its impact on our Friends. We will make changes supporting our Friends as needed.
  - We know body language and visual cues, not our words, are the best communication tools. We strive to use fewer words and more visual cues.
  - We respect the privacy of our Friends and their families.



We'd like you to consider Joyful Journey as a trusted provider of adult day services for your loved one. We hope this chapter has demonstrated our compassionate and caring values that will make your loved one feel welcome and secure.

Learn more from our Joyful Blog!









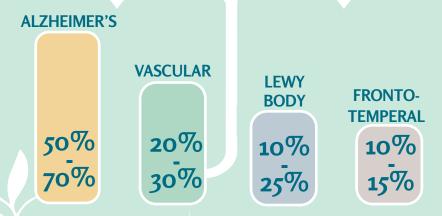
### Alzheimer's and Dementia -

## What Should I Know?

Dementia is a general term for a loss in memory and cognitive abilities. It can be brought on by a variety of diseases, but dementia itself is not a disease. Although minor issues with memory and cognition are common as we age, dementia describes difficulties that begin to interfere with one's life. Alzheimer's is the most commonly diagnosed cognitive disease, making up 60-80% of dementia cases.

### **Dementia**

An "umbrella" term used to describe a range of symptoms associated with cognitive impairment



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#### Alzheimer's

Alzheimer's is a degenerative brain disease without a known cause. Discovered in 1906, the condition was first described by Alois Alzheimer as "a peculiar disease" that is due to changes in the brain. The earliest stages of Alzheimer's include an inability to remember new things. Your loved one may have perfect long-term memory, but if they cannot remember details from yesterday or last week, it may be time to see a doctor.

As the disease progresses, you'll see other signs that indicate a slide into dementia, including:

- \* Memory loss
- \* Difficulty communicating, including word-finding issues
- \* Confusion
- \* Behavioral/mood changes
- \* Paranoia

We have mentioned changes in cognition due the natural aging process versus changes due to diagnosable disease, so here is a simple chart to help you decipher the difference.

Making sense of Memory Loss			
SYMPTOMS OF ALZHEIMER'S	MEMORY LOSS FROM NORMAL AGING		
Forgetting whole experiences	Forgetting part of an experience		
Rarely able to remember later	Often able to remember later		
<b>Gradually unable</b> to follow written / spoken directions	<b>Usually able</b> to follow written / spoken directions		
<b>Gradually unable</b> to use notes as reminders	<b>Usually able</b> to use notes as reminders		
<b>Gradually unable</b> to care for oneself	<b>Usually able</b> to care for oneself		

To better understand the changes you see in your loved one, it can be helpful to learn more about the underlying brain changes that take place during the progression of a cognitive disease like Alzheimer's. There are both structural and chemical changes going on in the brain.

### Brain Begins to Shrink

Structurally, the brain begins to shrink as Alzheimer's progresses and will be a third of the size of a naturally aged brain by the late stages of the disease. The hippocampus section of the brain is usually affected first. This area of the brain controls memory and behavior.

### Language & Reasoning Issues

Changes in the cerebral cortex are responsible for losing the ability to find the correct word or to use language to communicate. One can lose the ability to reason and use logic as this portion of the brain begins to deteriorate. Behavioral changes may also be evident. Even though language can be greatly impaired, hearing generally is not. However, it may take longer for someone with dementia to process what is being said to them and then respond.

### **Vision Problems**

Your loved one may begin to experience major changes in their field of vision as chemical and structural changes take place within the optic nerve and occipital lobe. In this stage of the disease, someone might perceive less in their peripheral field of vision. As the disease progresses, they will experience more tunnel and binocular vision. This is why you may notice that they cannot see something that appears to be right in front of them. Your loved one may also interpret something in their visual field in an unusual way. For example, a dark rug may appear to someone with dementia as a hole in the ground, so they will stop and refuse to walk across it.

### My Loved One Has Dementia – What Can I Do?

**Talk to a doctor** – If you suspect your loved one is experiencing cognitive decline, talk to your doctor or a trusted healthcare professional. Ask about cognitive testing as well as resources and support within your community, including local support groups.

There are currently several pharmaceutical options and non-chemical options that can temporarily ease the symptoms of Alzheimer's. However, according to the Alzheimer's Association, "At this time there is no treatment to cure, delay or stop the progression of Alzheimer's disease."

**Be informed** – You're already doing the right thing by reading material like this! Caring for someone with dementia can be challenging. However, there are methods and approaches you can use with your loved one that will make life for both of you a little easier to navigate.

### Here are a few of our favorite caregiving tips:

- \* You may need to help initiate actions: One symptom of Alzheimer's includes loss of initiative. Your loved one may not be able to start actions that were once part of their everyday routine. For example, they may get out of bed in the morning but not change out of their pajamas. They are not being "lazy" or "difficult." They have lost the impulse and cognition to know what the next step is. To assist, you can try having their clothes laid out and ready for them to change into. You can also try cueing them verbally and/or with the clothing in hand.
- \* Include your loved one, but keep it simple: Give them a choice of two things. For example, instead of asking what they want for breakfast, ask if they would like eggs or cereal. Open-ended questions can be increasingly difficult for someone with dementia to answer. By giving them only two options, you set them up for a successful decision-making process.
- \* Your loved one can't, but you can: Your loved one's brain and thought processes are going through significant changes. Connections that were once made easily are now more difficult for them. For this reason, it is really up to the caregiver to adjust their approach

to get the desired outcome. The person experiencing cognitive decline is no longer in a position to reasonably compromise. For example, your loved one may eat a meal and then five minutes later say, "I'm hungry! Are we going to eat?" Their short term memory of eating is no longer available and the signal from their stomach that tells them they are full is no longer working. You can tell them they just ate, but they may not believe you because in their mind it never happened. One way to change your approach is to leave the dish with the remnants of the meal in front of them on the table to help provide a visual cue that they ate. Then clear the plate after they have moved on to a different activity or room in the house.

\* A great approach: One of the approaches our Team at Joyful Journey is trained to follow is the Positive Approach to Care© designed by dementia care professional Teepa Snow 7. You can find resources, videos and literature on this method online. Positive Approach to Care can give you some great insights and practical tips to aid you in your caregiving journey.

### Provide a safe, comfortable home environment

Overall, the caregiving basics should be geared toward comfort and ease. The goal is to create a simple and regular routine to help reduce sources of frustration in the home and in daily tasks. Here are a few ways to start the process in your home today:

- \* Simplify daily tasks like dressing and washing. For example, lay out an outfit for your loved one or set out their toothbrush and toothpaste.
- \* Consider leaving doors open to help your loved one find the room they are looking for, such as the door to the bathroom or bedroom.
- \* Eliminate clutter, but leave items that are familiar and comforting to your loved one. Items that connect to their past can be particularly helpful.
- \* Add supplemental lighting.
- \* Remove rugs that pose a safety hazard. For example, a plush rug can be a tripping hazard.

Acknowledge your loved one's emotions when things become difficult, and try to take a moment to refocus and find calm before proceeding. Daily tasks are going to take longer; plan for this both in your schedule and in your heart.

Help your loved one stay active – Studies show that moderate to vigorous exercise not only provides a stronger physique, but it also strengthens the memory and learning centers of the brain. Something as simple as a daily walk can do wonders for overall health and state-of-mind.

Cognitive changes can become more apparent as your loved one settles into a less active routine post-retirement. However, there's an increasing body of research that shows pursuing a hobby, learning something new and remaining social can build cognitive resilience. It is important for both the caregiver and person in need of care to engage in an active lifestyle.

The Alzheimer's Association also provides a variety of resources to assist you on your care journey.

### **Chapter 6 Review**

Alzheimer's is a very complicated disease. As your loved one begins to change, it can be difficult to know what to do. Seeking as much assistance and information as you can is essential for securing the best solutions for you and your loved one.

As you embark on your journey of learning and caregiving, please browse our resource page at the end of this book for helpful information. Also, see our inspirational blog that showcases how we can all age with grace!

Learn more from our Joyful Blog!



## Joyful Journey Adult Day Service

### - About Us



We hope this has been a useful resource for you! As caregivers ourselves, we know what it's like to need an extra hand every now and then. Our adult day service helps folks just like you get the support they need to provide the best quality care possible for those in their care.

Founded in 2013 by Cathy and Gerard Benner, caregivers themselves, Joyful Journey is a not-for-profit adult day center that serves Greater Lafayette, Indiana, and surrounding counties.

Our mission is to provide socially engaging activities that enhance quality of life, well-being, and independence for adults experiencing changes in mobility or cognition, while offering respite and support to their caregivers.

The organization was established so that families would have another option when it comes to compassionate care for their loved one ('FRIEND'). Joyful Journey is committed to providing meaningful days filled with purpose for each Friend who comes to visit.



### Additional Joyful Services

Joyful Journey offers a delicious and nutritious three-course lunch, as well as morning and afternoon snacks. Our expert caregivers can provide restroom assistance and medication monitoring, as needed. They are also certified in first aid, CPR, AED, and other advanced care practices to provide a safe and supportive environment.

### Call Us - (765) 607-6156

To ensure Joyful Journey will be a good fit for your loved one, you are invited to tour the house and ask questions regarding support and activities. For more information about Joyful Journey's mission and activities, visit or



## Helpful Resources

We'd love to assist you further. We know how much every bit of knowledge can help along your journey!

### **Local Resources**

Area IV Agency on Aging - Information & Referral Service

(765) 447-7683

(800) 382-7556

www.areaivagency.org

**Indiana Association of Adult Day Services** 

(317) 446-6974

http://www.iaads.net/

Indiana Alzheimer's Association

IN Alzheimer's Association 24/7

Helpline: 1-800-272-3900

http://www.alz.org/indiana/

**Caregiver Companion** 

(765) 423-1879

https://caregivercompanion.org/

Purdue Speech Language Science Dept.

(765) 494-2343

### **National Resources**

National Adult Day Services Association – Family Checklist for Adult Day Programs

Open Checklist (PDF)

Family Caregiver Alliance

www.caregiver.org





### Online/DVD Educational Resources

Here are some resources for those caring for someone with dementia such as Alzheimer's Disease.

Teepa Snow Workshops, Webinars or YouTube videos

Example: <a href="https://www.youtube.com/">https://www.youtube.com/</a>

watch?v=pqmqC-702Yg

Alzheimer's Reading Room

https://www.facebook.com/alzheimersreadingroom/

National Institutes of Health-Caring for a Person with Alzheimer's Disease

https://www.nia.nih.gov/health/alzheimers-caregiving-caring-yourself

### Books \*

Alzheimer's Early Stages, Daniel Kuhn, MSW

Creating Moments of Joy for the Person with Alzheimer's by Jolene Brackey

The Alzheimer's Plan, P. Murali Doraiswamy MD, Lisa P. Gwyther MSW

The 36-Hour Day: A Family Guide to Caring for People with Alzheimer's Disease, Nancy L. Mace and Peter V. Rabins

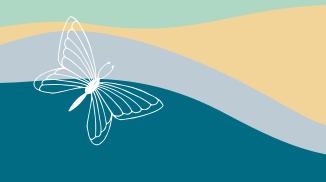
\*Joyful Journey has a small lending library. Please contact us if you'd like to browse our shelves.







(765) 607-6156 www.joyfuljourneywl.org





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