Navigating Dementia

What to Expect When You are Expecting… Brain Changes!

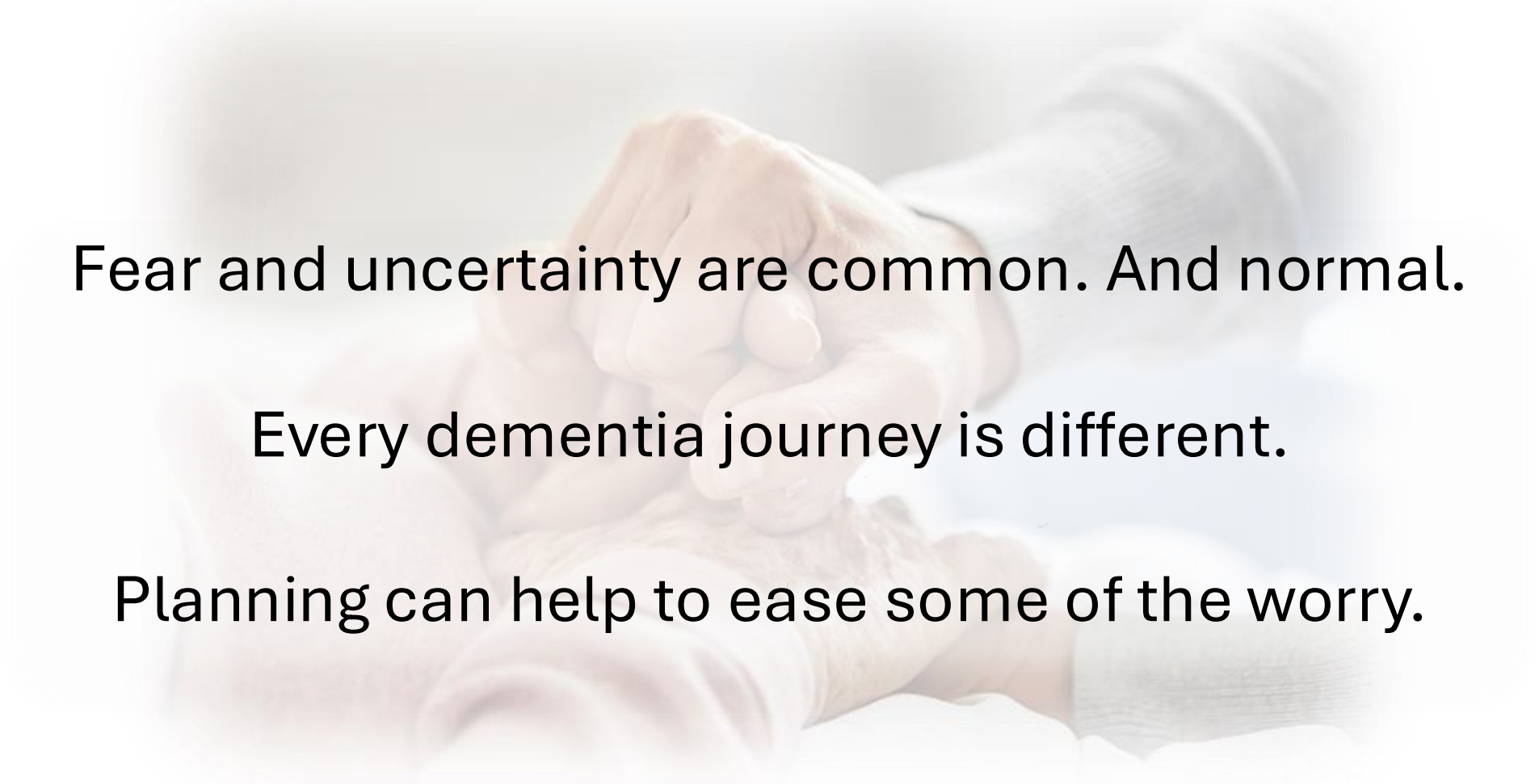


First Link® Dementia Helpline: Confidential support is just a phone call or email away.

Dementia Helpline at
204-932-6622 or 1-800-378-6699

Email support@alzheimer.mb.ca.

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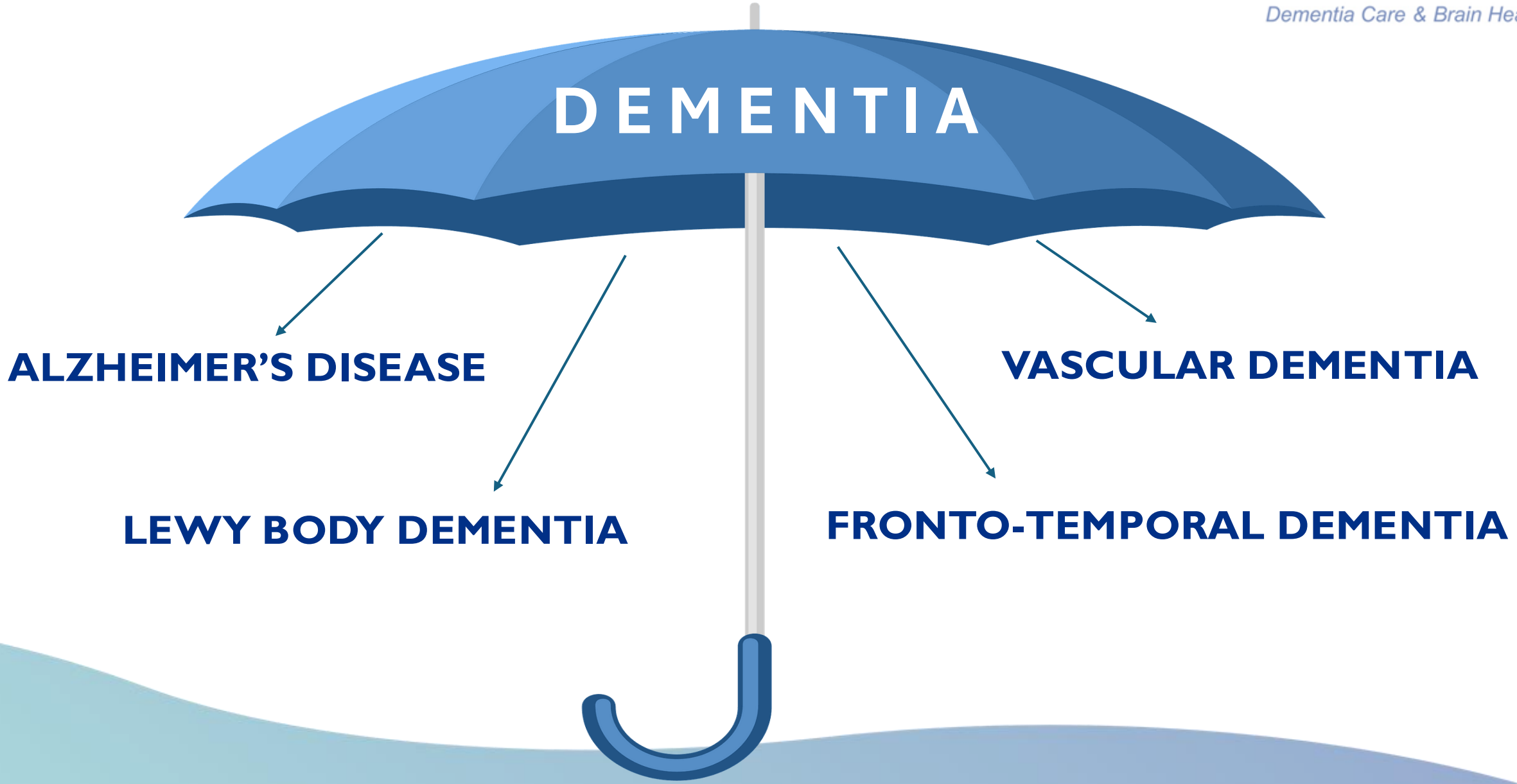


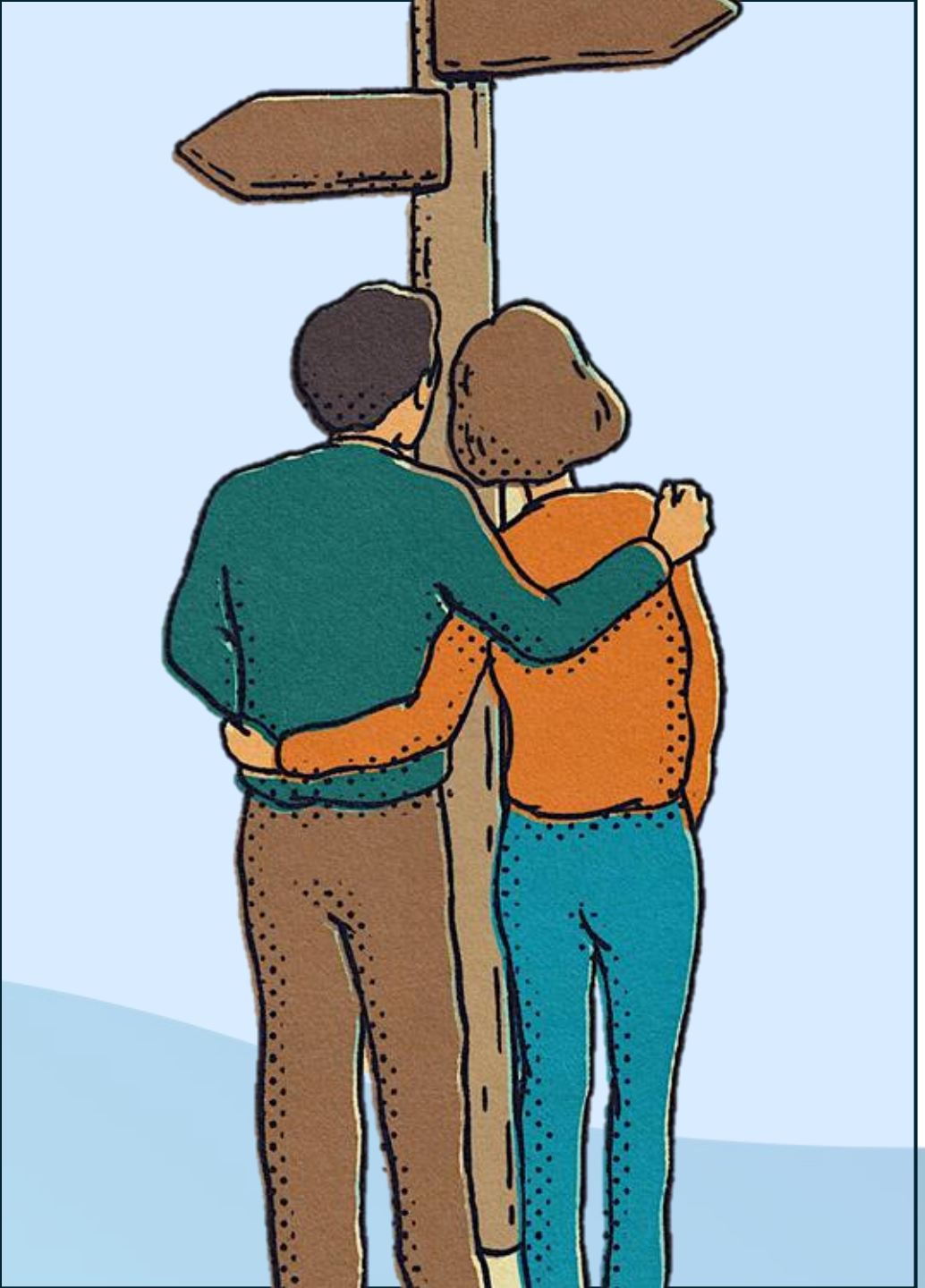
Fear and uncertainty are common. And normal.

Every dementia journey is different.

Planning can help to ease some of the worry.

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Different Dementias =

Different Symptoms,

Different Progression,

Different Care Needs.

10 Possible Signs of Dementia

Ten common signs of dementia are described below. If you are concerned about any of these changes in yourself or someone else, contact a health-care provider or your local Alzheimer Society.

Disorientation in time and place

Not knowing what day of the week it is or getting lost in a familiar place.





Loss of initiative

Losing interest in spending time with friends and family and in taking part in activities. Needing prompts to become involved.

Misplacing things

Putting things in strange places, like a remote in the refrigerator.





Changes in mood, behaviour and personality

Experiencing severe mood changes or behaving out of character, such as being suspicious or withdrawing.

Difficulty doing familiar tasks

Forgetting how to do something you've been doing your whole life, such as preparing a meal or getting dressed.





Problems with abstract thinking

Having difficulty managing finances or not knowing what numbers are and how they are used.

Impaired judgment

Not recognizing a medical problem that needs attention or wearing light clothing on a cold day.





Changes in language and communication

Forgetting words, substituting words or using the wrong words that don't fit the conversation.

Memory changes that affect day-to-day abilities

Forgetting who a family member is or not remembering new information.



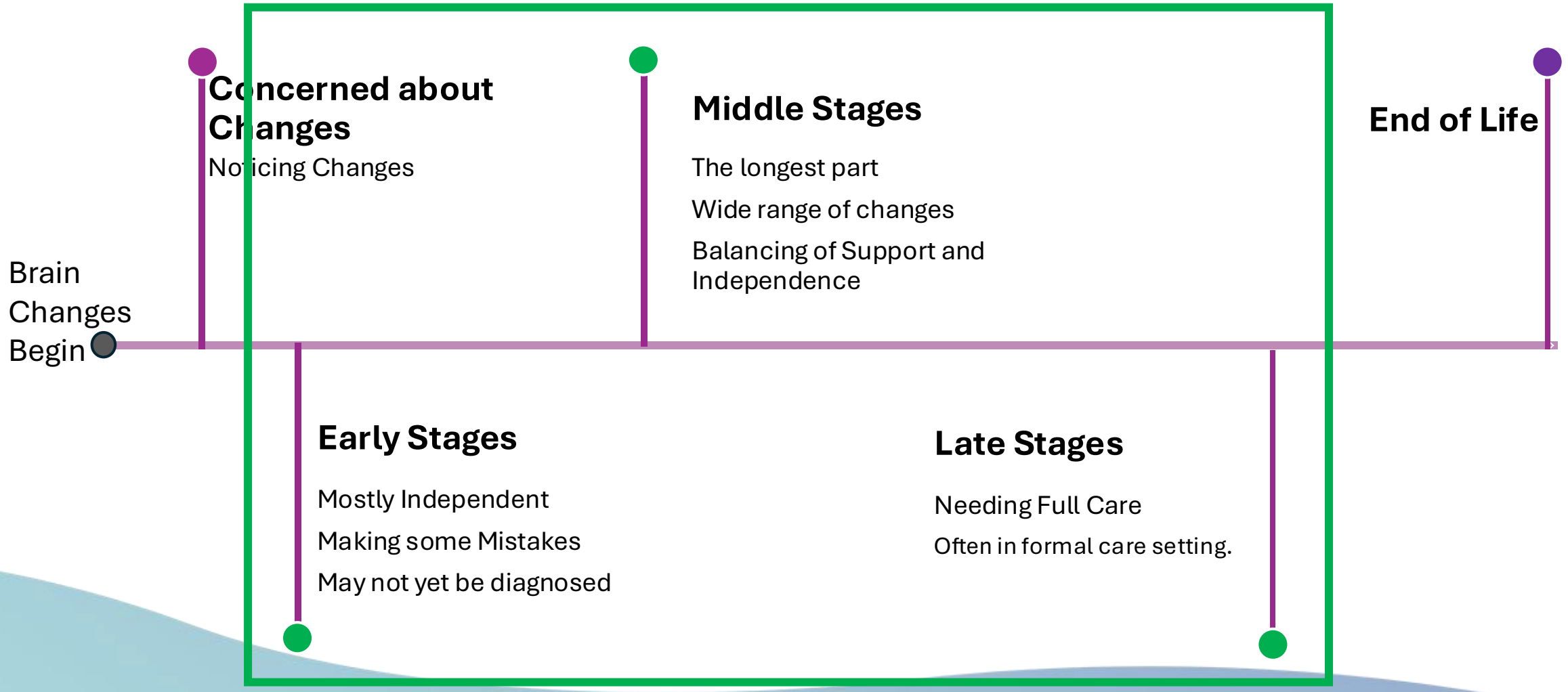


Changes in sight or motion

Not seeing objects when walking or difficulty placing items on a table.



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Outline of Session

Common Changes

Care Partner Experiences

Action Steps

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Early Stages

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Early Stages

Person with Dementia

Memory and Cognition

Difficulty retaining recent information or events

Making mistakes

Good with long term memory

Can usually still express wishes, values and make decisions

Safety

Decreased safety awareness

Trouble with complexity – tasks and concepts

Self protection and desire for independence often remains strong

Mood and Behaviour

Increase in anxiety and worry

Increased irritability

Withdrawal from activities

Decreased social graces

Change in reasoning

Daily living

Preference for familiar things or routines

Needs more reminders or systems

Still independent with most aspects of personal care

Communication

Word Finding

Trouble Following Discussions

Repetitive Questions or Stories

Conversation skills remain

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Early Stages – Care Partner's Experience

Relief or optimism.

Fear and uncertainty.

Sense of urgency.

Frustration.

Loss and grief.

Noticeable relationship shifts.

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ACTIONS

Financial and Future Planning

- Make sure important documents are in place
- Review financial sustainability

Supports and Resources

- Build Your Support Network (i.e. ASM, Family and Friends etc)
- Join DFC programming, ADP etc.

Learning and Skill Building

- ASM Family Education – First Steps, Care Partner Essentials
- Independent Research or other organizations
- Key Skills to Start Using
  - Connect don't correct/Don't argue
  - Apologize (even if it's not your fault)

Conversations

- Driving, Living Alone, Values and Wishes

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The Hand Off – Early Stage

- Maintaining independence and dignity as things are changing

- Still Independent (I learn and support)
- I fill in the gaps (we do together)
- I do most – you do what you can
- I do all and carry your voice

Common questions in the early stages

- How do I offer help without making my person feel that I'm “taking over”?
- Why doesn’t my loved one want to talk about their diagnosis?



Middle Stages:

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Middle Stages

Person with Dementia

Memory and Cognition

Living more in the moment

Maybe repetitive

May not recognize losses

Wide range of changes

Difficulty with complexity

Sensory processing changes

Safety

Object and place recognition challenges

May not dress appropriately

Wandering and fall risk increases

Not safe to drive or stay home alone

Mood and Behaviour

desires control but needs help

May exhibit unusual behaviour

Apathy, irritability, clinging

Confabulation, delusions

Behaviour as communication

Daily living

Needs more cueing

Partnering for tasks

Sleep may become an issue

May not willingly accept offers of help.

Communication

Grammatical errors

Trouble Following Discussions and instructions

May not express needs using words

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Middle Stage – Care Partner Experience

- I don’t really like my person anymore
- I feel like a parent rather than a partner/child.
- I feel like I just have a handle on things and then they change again.
- Other people just don’t get it!

ACTIONS

Financial and Future Planning

- Making sure documents are in place and when to start acting
- Financial sustainability

Supports and Resources

- Home Care or other Housing Options
- Family and Friend Network
- Support Groups and Plan for Self Care

Learning and Skill Building

- Continue Education – Next Steps series - Responsive Behaviours, Sleep, Providing Hands on help
- Independent Research or other organizations
- Key Skills to Start Using
  - Simplify and Shorten – 1 idea at a time for tasks
  - Asking Why

Conversations

- Home vs More, Shift in Who is involved in the conversation

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The Hand Off – Middle Stage

- Still Independent (I learn and support)
- I fill in the gaps (we do together)
- I do most – you do what you can
- I do all and carry your voice

- POA and HCD are in use, Care Partner is managing most of the decision making and day to day. Person with Dementia is included where possible but this becomes increasingly difficult as changes happen.

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Common questions in the middle stages

- How long can my person continue to live at home?
- My person is behaving in ways that are disruptive or distressing. What do I do?

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Late Stages

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Middle Stages

Person with Dementia

Memory and Cognition

Decreased awake time

Less alert, more passive

Limited abilities

Safety

Risk for falls

Needing equipment (wheelchair, lifts etc)

Risk for skin issues, contractures

Eating and Swallowing issues

Mood and Behaviour

Behaviour as communication

May express needs more physically or nonverbally.

Calling out

Daily living

Receiving 24/7 support

Limited participation in care tasks.

Alternate living situation (LTC)

Communication

Limited or no words

Relies on nonverbal expressions

Music, Rhythm, Touch

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Late Stage – Care Partner Experience

- Shift of responsibilities when the person moves to full time care

- Emotions
    - Guilt,
    - Grief,
    - Fear,
    - Relief
    - Etc. Etc.

ACTIONS

Financial and Future Planning

- End of Life Care – decisions
- Future planning now put into action
- Finances support comfort and care

Supports and Resources

- Long Term Care
- Support Groups

Learning and Skill Building

- Continue Education – Next Steps series – Comfort Care and Promoting Physical Comfort, End of Life
- Learning about what care looks like
- Independent Research or other organizations
- Key Skills to Start Using
  - Connecting without Conversation
  - Making meaningful visits

Conversations

- Connecting with the Care Team, values and wishes expressed.
- Changing expectations and priorities

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The Hand Off – Late Stage

- Primary 24/7 to Consultant

- Still Independent (I learn and support)
- I fill in the gaps (we do together)
- I do most – you do what you can
- I do all and carry your voice

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Common questions in the late stages

- How do I share my concerns with the care team?

- Why is my person still declining in care?

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In Summary…

- The Road is Rocky
- Preparation is Important
  - Conversations
  - Learning about Dementia
  - Building your support system
  - Documents in Order
- We are here for you!

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Resources You May Want to Have

- Preparing for In Home Help
- Future Planning Checklist
- Dementia and Living Alone
- Dementia and Driving
- All About Me – Alzheimer Society Canada
- Community Resources Guide
- Health Care Directive – MB Health

