

SIDE BY SIDE

Caring for Families Living with Dementia

May 20, 2020

TERMINOLOGY

Participant – person living with dementia

Care Partner – aka “family caregiver”

Informal Care – unpaid care, typically provided by family, friends, and neighbours

WHAT IS SIDE BY SIDE?

Church-hosted respite

Organized informal care

Fellowship, meaningful connection

Ministry of presence

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CHANGING CONTEXT

Caring at a distance during pandemic

- ✓ provide resources and links
- ✓ share activity suggestions
- ✓ phone visits
- ✓ cards and letters
- ✓ virtual program online

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DEMENTIA

Umbrella term for a set of symptoms

Most well-known symptom is memory loss

Progressive – slow/steady or fast/step-wise

Every journey is unique

Over 150 different kinds of dementia

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LIVING WITH DEMENTIA

Long progression

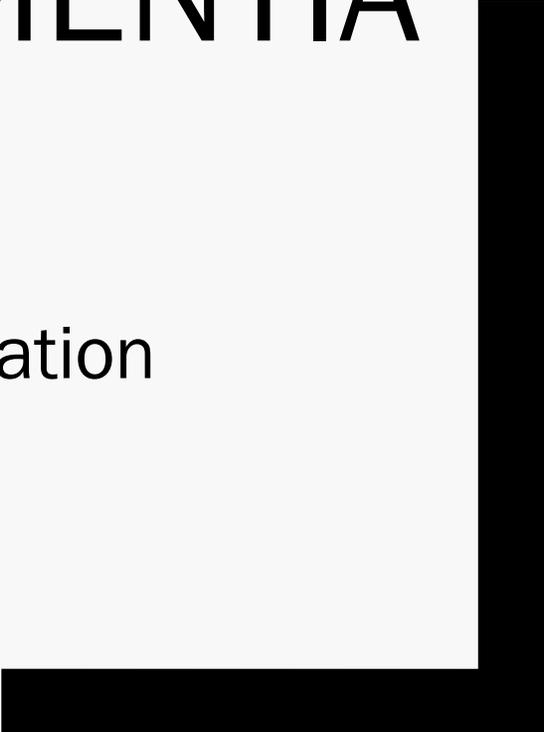
Caring 24/7

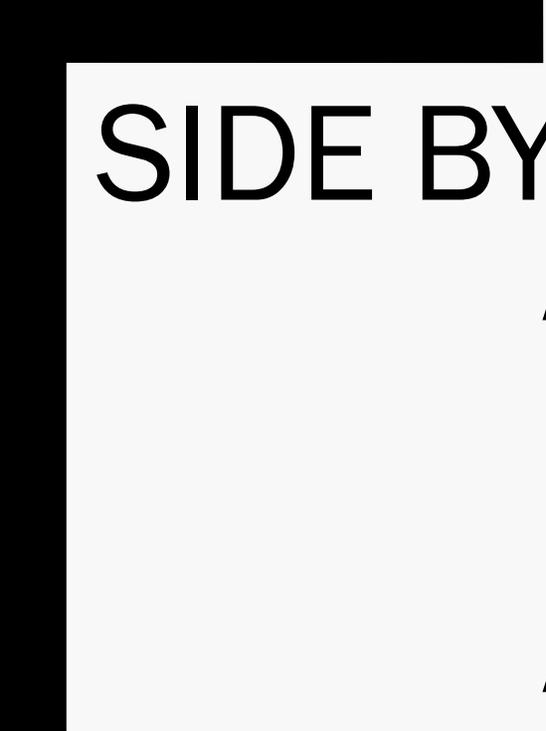
Constant change and adaptation

Coping with loss

Handling new roles

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SIDE BY SIDE BEGINNINGS

Awareness of need

Prayer for guidance

An answer to prayer



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HOPES AND DREAMS

- Congregations discerning a call to walk alongside families living with dementia
- A Canada-wide network of programs
- Partnering in and with community

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HOPES AND DREAMS

“To think that places of worship could be transformed into places of respite during the day with meaningful and engaging programmes is truly radical. This is truly a niche wherein all faith traditions need to heed the call to open their doors to the wider community, especially ones with unique needs such as dementia.”

--Matt Dineen, Dementia Advocacy Canada

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SIDE BY SIDE WEBSITE

<https://www.sidebyside.care>

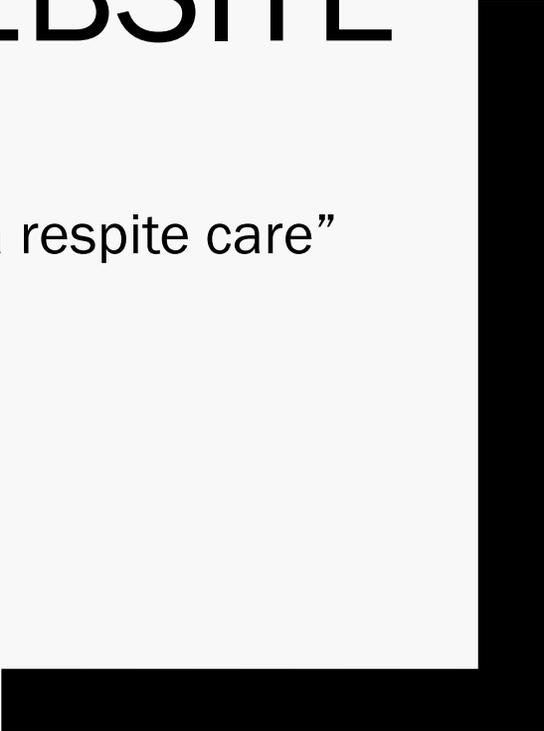
“Helping churches start hosting dementia respite care”

Admin Resources

Program Resources

Guidelines for starting a program

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WHAT IS SIDE BY SIDE?

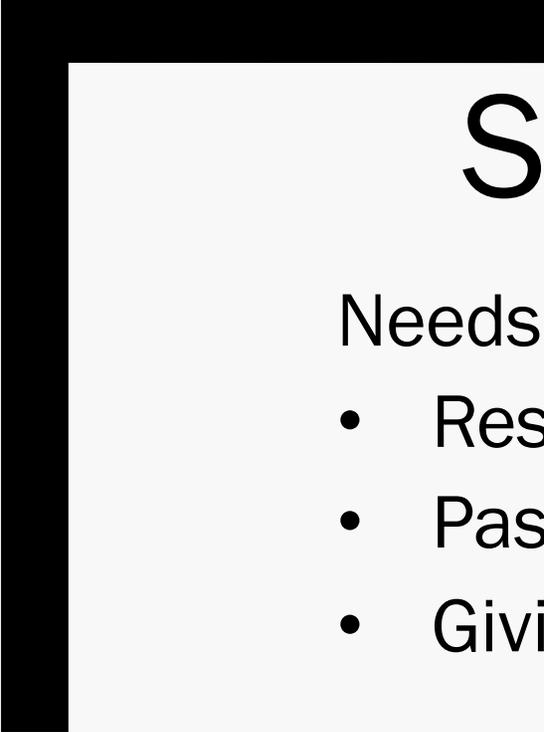
Church-hosted respite

Organized informal (unpaid) care

Fellowship, meaningful connection

Ministry of presence

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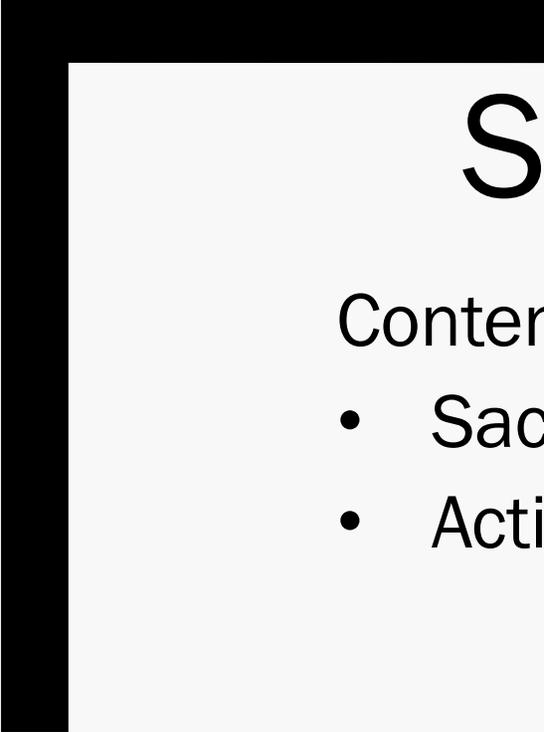
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Needs:

- Respite / Fellowship
- Pastoral Care / Outreach
- Giving / Receiving

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SIDE BY SIDE

Content:

- Sacred / Secular
- Active / Quiet



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SIDE BY SIDE

Companions and other volunteers:

- Walk alongside
- Encourage and reassure
- Support only as needed
- Enjoy friendship
- Model joy – emotional contagion

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A TYPICAL DAY

Morning Coffee

Brain Gym[®]

Devotion

Gentle Exercise

Creative Time

Music Therapy

Light Lunch

Bocce Ball

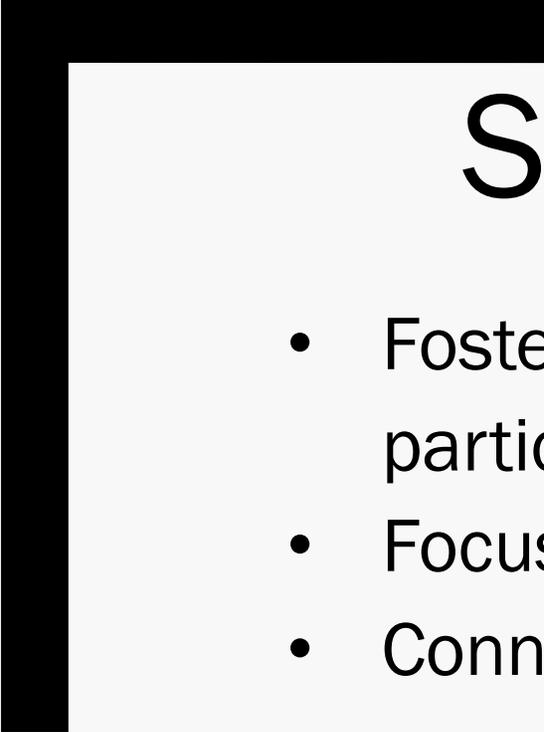
Sing-along

Afternoon tea

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- Warm welcome
- Each person is a loved child of God
- Everyone wears same kind of nametag
- Meaning and purpose are important

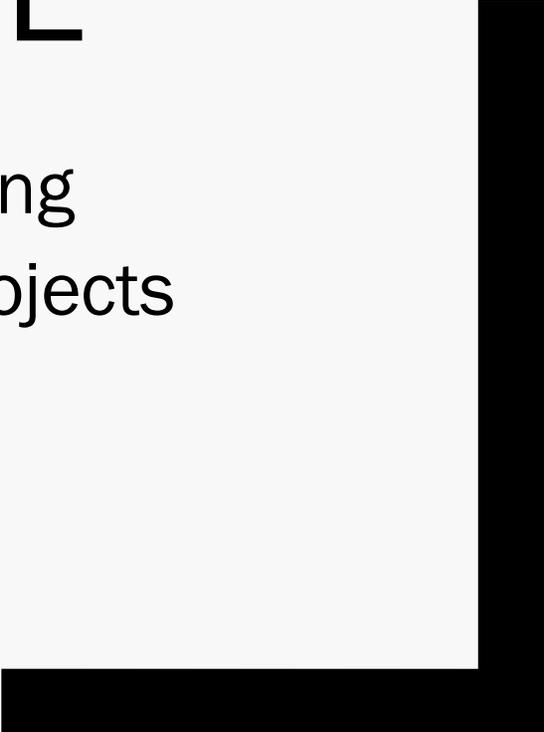
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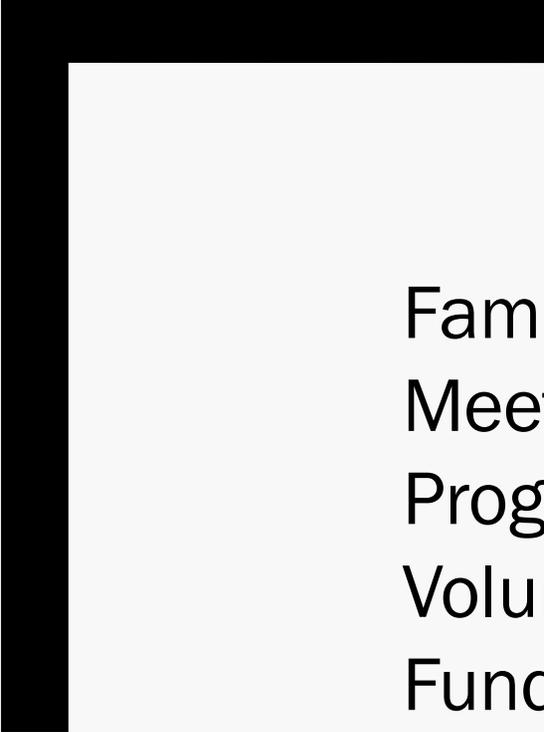


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- Foster purpose by facilitating participation in mission projects
- Focus on ability
- Connection matters

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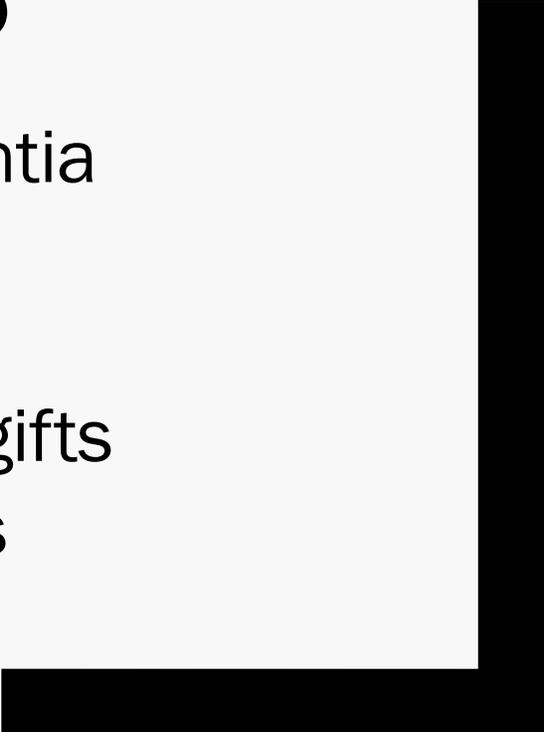




ELEMENTS

Families living with dementia
Meeting space
Program coordinator(s)
Volunteers with different gifts
Funding for program costs

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CHURCHES CAN HELP

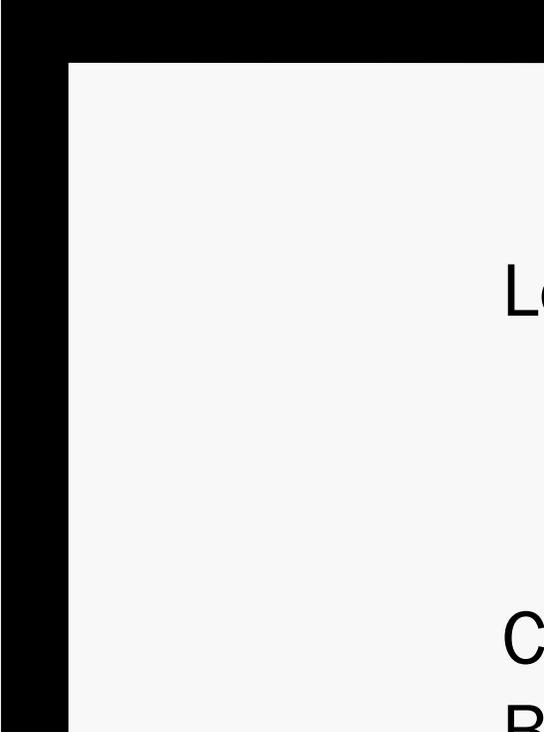
- ✓ Families living with dementia
- ✓ Meeting space
- ✓ Program coordinator(s)
- ✓ Volunteers with different gifts
- ✓ Funding for program costs

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CHURCHES CAN HELP

- Familiar place for congregants
- Spiritual nurture resonates
- Volunteers are cohorts - older adults with wisdom and shared experience of world events that have shaped participants' lives.

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SAFETY

Leading With Care

- *Security checks*
- *Training*
- *Covenant of Care*

Communication plan

Buddy groups

BUILDING RELATIONSHIP

- Time together with participants
- Regular communication with care partners
- Social time at program includes care partners at beginning and end of day
- Care Partner Gathering, if possible

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VARIATIONS

Side by Side In Calgary:

- Varsity Acres Presbyterian Church
- Jewish Family Services Calgary

First Baptist Caregiver Support Group

Conversation Cafés (social, not respite)

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VARIATIONS

First United Methodist Church, Lawrenceville, GA

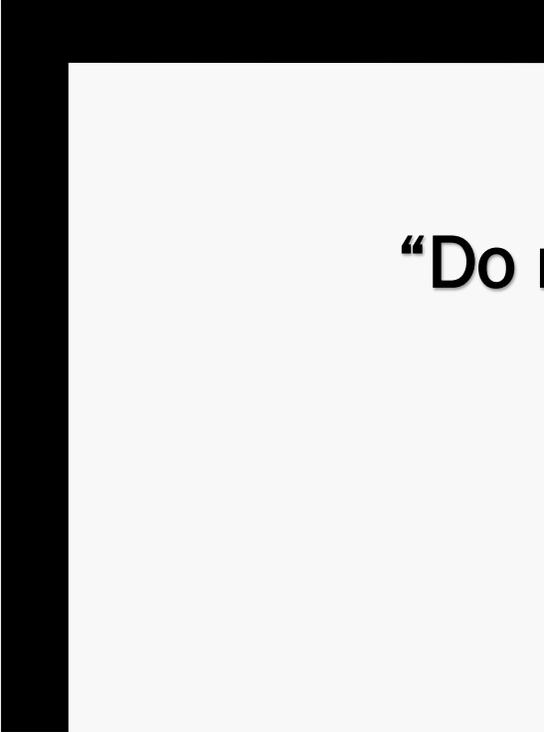
- Grace Arbor began in 2005
- Five participants, two days a week
- Book “Walking With Grace” by Robin Dill
manual based on experiences at Grace Arbor

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VARIATIONS

First United Methodist Church, Montgomery, AL

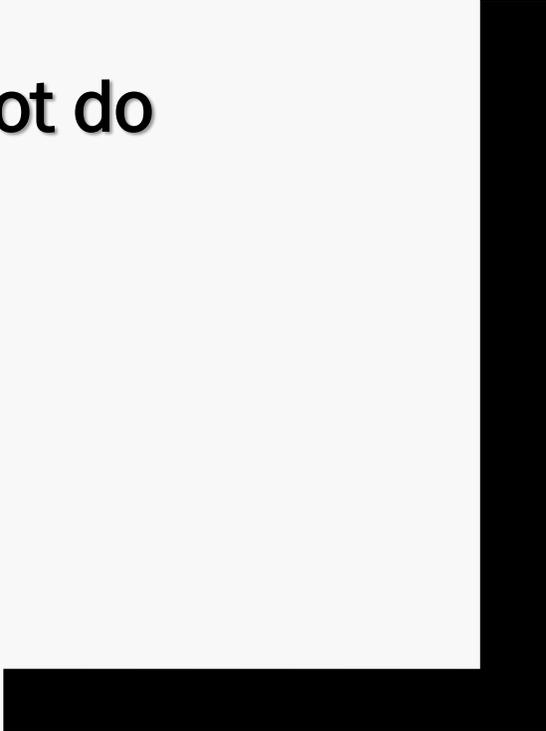
- Respite Ministry started in 2012, 2 days/wk
- In 2018, 4 days/wk with 80 participants (ages 52-95), 199 volunteers
- Respite For All Foundation provides training



**“Do not let what you cannot do
interfere with
what you CAN do.”**

– John Wooden

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SIDE BY SIDE ONLINE

Variation: a response to CoVID19

- Zoom call twice a week
- Incorporates familiar elements of the in-person program
- Maintains relationship and sense of community until we can meet again

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SIDE BY SIDE ONLINE

Variation: a response to CoVID19

- Not everyone can transition to online
- Potential for a community-wide

Conversation Café

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Each person you care for
will change you,
leaving an imprint on your heart.

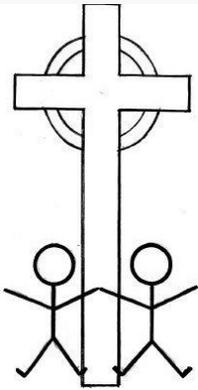
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