



Impact of Education in Behaviour Changes for Care Partners (family and friends) of People Living with Dementia

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Société Alzheimer Society

Understanding

Team

Flagging

Support

Interaction



Reflection and Reporting

A Learning Program for All



U-First!® Workbook



U-First!® Advanced Workbook



U-First!® for Care Partners Workbook



U-First! for Care Partners Goals

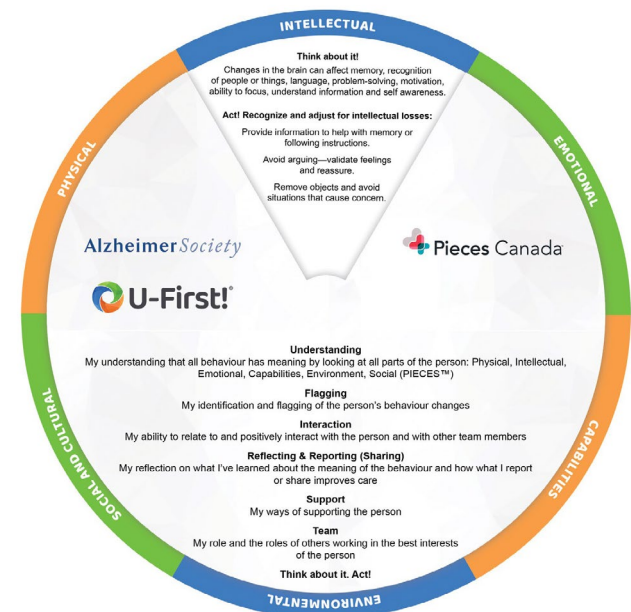
Increase Care Partner confidence and skills to understand and respond to behaviour changes in order to:

- Enhance well-being of Care Partners and those experiencing behaviour changes
- Increase confidence and ability to provide effective care
- Improve collaboration within the care team through common knowledge, language, and approach to care



About the Program

- 6-hour, dialogue-based workshop
- Receive a Participant Workbook & Wheel
- Focus on own role as a care partner
- Develop a Support Plan



Program Evaluation

- 2019 pilot evaluation
- 2020 Ontario Brain Institute, 2 year evaluation
 - Year 1 - Examine program impacts for care partners on a larger scale
 - Year 2 - Explore impacts of education for both staff & care partners within a health care setting, on collaboration



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Year 1 Evaluation Measures

- Satisfaction with and effectiveness of training format for program Facilitators (local Alzheimer Society staff)
- Satisfaction with the program for participants
- Impact of the program on Care Partner participant
 - knowledge
 - confidence
 - ability to report and share information
 - well-being (and for the person with dementia)
- Impact on frequency and severity of behaviours of concern
- Impact on collaboration within care team

Evaluation Methods - Participants

20 programs, 175 participants
(Oct. 2020 - May 2021)

- Pre-workshop survey (N=154)
- Post-program survey (N=125)
- 4-6 week post-program survey (N=102)
- 6-month post-program survey (N=35)
- 6-month post-program interview (N=8)

Program Impacts – Satisfaction

- Program length (83.5%)
- Materials (91.8%)
- Topics (93.3%)
- Learning activities (85.4%)
- Format (85.1%)
- Facilitators (94.2%)

Program Impacts – Usefulness

- 77.5% rate the program as ‘very’ or ‘extremely’ useful immediately following
- 78.4% rate program as useful at 4-6 weeks
- 85.7% rate program as useful at 6 months

Program Impacts – Knowledge & Confidence

- Significant increase in knowledge to recognize and respond to concerning behaviours (78.9%)
- Significant increase in confidence providing care (77.2%)
- Increased knowledge and confidence frequently reported at 6 months

My understanding the meaning of and reasons for my husband's behaviours and adopting helpful ways of responding and dealing with them. Accepting them as not personal, so stopping them from escalating.

It has given me more confidence as a primary caregiver to face new challenges as my mother-in-law's Alzheimer's progresses.

Program Impacts – Stress levels

- General Stress
 - Approximately half no change pre-program to 6-months
 - 60% of participants reporting ‘very high’ or ‘high’ general stress pre-program reported decreased stress at 6 months
- Stress related to behaviour changes
 - 57.6% did not report reduction in stress related to behaviour changes
 - 46.7% of participants who reported ‘very high’ or ‘high’ stress pre-program reported decreased stress at 6 months

I am more tolerant and patient.

Program Impacts – Well-being

- 27.2% reported increased well-being post-program and 33.3% at 6 months
 - 65.5% reporting ‘very low’ or ‘low’ well-being pre-program showed improvement at post-program and 100% at 6 months
- 94.1% ‘agreed’ or ‘strongly agreed’ the program made them feel not so alone at 4-6 weeks and remained high (88.5%) at 6 months
- Participants who reported the well-being of person they are supporting was ‘high’ or ‘very high’, increased from 25.1% pre-program to 35.5% at 6 months

Helped me develop strategies for self-care and support.

Program Impacts – Behaviour Changes

- Significant decrease in mean score of how concerning behaviours were pre-program to 4-6 weeks for all behaviours, except sexual behaviours
- Perceived severity of behaviours decreased 4-6 weeks post-program, and at 6 months (for losing one's way, physical and verbal outbursts, suspicion and delusion)

Husband is safe and now feels like I am his friend.

Program Impacts – Communication

- Mean communication scores did not significantly change pre-program to 4-6 weeks or 6 months
 - Improvement in individual scale items was seen (e.g. role clarity, clear goals)
 - 87.5% of participants reporting communication scores below mean pre-program reported improved communication at 4-6 weeks and 100% at 6 months

Ability to communicate more with the Care Team - I learned some strategies that I have been able to put into practice - a better 2-way communication.

Year 2 Evaluation Measures

Is Care Team collaboration improved when Care Partners and paid health care providers both take part in U-First! learning within a health care setting?

- Increased ability to report and share information
- Increased positive interactions
- Improved collaboration in health care settings

Evaluation Methods

For both Care Partners and Health Care Providers in 2 pilot sites:

- Pre-program survey
- 1-month post-program survey
- 1-month post-program interviews

Challenges Encountered

- Identifying willing pilot sites during pandemic (e.g. staff shortages)
- Determining which health care providers worked with residents with dementia and their care partners
- Contacting health care providers

Insights Gained

- Care Partners expressed:
 - staff, especially new staff, would benefit from more training on working with residents with dementia
 - Communication often initiated by the Care Partner
 - Difficult to establish relationships with health care providers due to turnover and busy schedules
 - Unclear about which staff are on a resident's care team and who to talk to
- Health Care Providers expressed:
 - Feeling challenged to provide care partners with the right amount of information, discuss changes they observe, advocate for the people they support and take family care preferences into consideration

Key Learnings

- U-First! for Care Partners successfully increases care partner knowledge and confidence and decreases isolation even over time
- Participants with perceived high levels of stress, low well-being experience the greatest benefits in these areas
- Care partner perceptions of degree of concern about behaviour changes is positively impacted by participation in the program
- Benefits to collaboration within care team with education for both staff and care partners requires further exploration

Next Steps

Further evaluation related to education for staff & care partners in a health care setting

French version of program available soon!

Expanding virtual access across Ontario & Canada

Accessing the Program

- Currently available in Ontario, New Brunswick, Nova Scotia, PEI
- Intake through provincial/local Society to determine fit
- U-First! for Health Care Providers visit www.u-first.ca


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Alzheimer Society


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
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