



THE ALZHEIMER SOCIETY *of* IRELAND

***“Funnily enough it gave a sense of hope”*: Comparing the delivery of a face to face family carer course to a fully online programme.**

Fergus Timmons, The Alzheimer Society of Ireland

Dr Martha Doyle, Institute of Technology Sligo

Dr Marita O’Brien, Independent Researcher

Presentation Content

- ASI Education and Training for family carers
 - Insights into Dementia
 - Home Based Care – Home Based Education
- Research Question
- Methodology
- Findings / Results
- Questions / Discussion

ASI – Education & Training

- Insights into Dementia Informing and Empowering Family Carers
- ASI delivering education / training for family carers looking after loved ones with dementia for almost 10 years
- Delivered nationally to 350 carers per year
- Delivered by internal staff who are trained as tutors
- 6 weekly evening sessions at 2.5 hours per session



Insights into Dementia - Informing and Empowering Family Carers



A programme of education
and training to support
family carers of people
with Alzheimer's and
other dementias.



Insights into Dementia

- Some Theoretical input
- Participative / Discussion based
- Tutor Facilitated
- Group Exercises

INSIGHTS INTO DEMENTIA - INFORMING AND EMPOWERING FAMILY CARERS

WHY UNDERTAKE INSIGHTS INTO DEMENTIA?

Carers are often left to cope with the consequences of a diagnosis of dementia in their families with little or no practical information to support them.

The Insights into Dementia—Informing and Empowering Family Carers programme is designed to help family carers understand the condition and increase their confidence in their ability to care.

The course also provides opportunities for carers to meet other carers and share their experiences.

Delivered by The Alzheimer Society of Ireland's experienced staff members, the *Insights* course will provide you with new information on dementia and give you time and space to reflect on your own caring experience, whilst listening to and learning from other carers' experiences.

The course is delivered in a warm, safe environment at a range of venues across the country. Please contact us for details of a course near you.

COURSE STRUCTURE

Week 1	Introduction to Dementia Changing Relationships
Week 2	Communication Responding to Changes in Behaviour
Week 3	Nutrition and Eating Well Engaging in Life Activities
Week 4	Assisting With Personal Care Safety at Home
Week 5	Looking After Yourself as a Carer Accessing Information
Week 6	Care Delivery Action Plan Certificate Presentation

National Helpline 1 800 341 341



THE ALZHEIMER
SOCIETY of IRELAND

COMMENTS FROM PREVIOUS COURSE PARTICIPANTS

"The range of topics was very good and I found them very beneficial. Being able to talk to other carers was very helpful also."

"It helped me to understand what I already know and to see situations in a different, more positive light."

"I enjoyed meeting other people with the same problems and hearing their solutions."

"The sharing was important."

"The course tutors were excellent—couldn't praise them enough."



THE ALZHEIMER
SOCIETY of IRELAND

Insights into Dementia – Informing and Empowering Family Carers

Artane / Coolock
Family Resource
Centre, Dublin,
November 2016



ASI Tutor Christine
O'Rourke presenting
to the group (above),
and left group takes
part in discussion
exercise.



Advent of Online Course



- Demand from family carers, but lack of resource internally
- Identified Erasmus+ European Community as funding source
- Project designed and application submitted March 2015
- Project accepted with delivery 1 Sept 2015 to 31 August 2017

Home Based Care – Home Based Education

Pan-European Project with ASI coordinating

Two other partners:



- Creating online education and training for family carers
- Used 'Insights' as basis for content and pedagogy



Home Based Care – Home Based Education: Cover Page

The screenshot shows the Moodle LMS interface for the course 'Home Based Care - Home Based Education'. The page is organized into a main content area on the left and a sidebar on the right. The main content area lists the course description and a series of weekly modules: 'Induction and Orientation', 'Week 1 Dementia and Changing Relationships', 'Week 2: Communication and Changes in Behaviour', 'Week 3: Healthy Living', 'Week 4: Person Centred Care', 'Week 5: Looking After the Carer', and 'Week 6: Course Review and Next Steps'. Each module includes a progress indicator. The sidebar contains sections for 'Course Licensing' (Creative Commons Attribution-ShareAlike 4.0 International License), 'Funding Credits' (Part funded by Erasmus+), 'Online users' (last 5 minutes, None), and 'Recent activity' (Activity since Wednesday, 23 August). The top navigation bar includes 'HOME', 'THIS COURSE', 'Turn editing on', and 'FULL SCREEN'.

- Fully online course
- Uploaded to Moodle LMS
- Facilitated by an ASI trained tutor
- Aims to provide family carers with an opportunity to share their experiences
- Uses Video Presentations, Forums, Choices

Key Research Question

Can our online course be as effective as our face-to-face provision?

Research Methodology (1)

Quantitative – Fergus Timmons administered electronically

Insights into Dementia – face-to-face

Pre-course questionnaire: 32 complete

Post-course questionnaire: 27 complete (20 pre and post)

Home Based Care – online

Pre-course questionnaire: 40 complete

Post-course questionnaire: 24 complete (14 pre and post)

Key Findings (1)

Please rate your understanding of dementia on a scale of 1 to 5 where 1 is very low and 5 is very high

Understanding Level	Face-to-face				Online Course			
	Pre course	Post Course	% change	Swing	Pre Course	Post Course	% change	Swing
1	10	3	-7	-33	18	0	-18	-45
2	33	7	-26		31	4	-27	
3	46	17	-29	63	46	16	-30	74
4	10	45	35		3	80	77	
5	0	28	28		3	0	-3	



Key Findings (2)

I know where to find relevant information to help me in my caring role

	Face-to-face				Online Course			
	Pre course	Post Course	% change	Swing	Pre Course	Post Course	% change	Swing
Totally disagree	0	0	0	-21	3	0	-3	-25
Disagree	21	0	-21		22	0	-22	
Neither disagree or agree	21	7	-14		22	4	-18	
Agree	44	60	16	34	41	68	27	41
Totally agree	15	33	18		14	28	14	



Key Findings (3)

To what extent do you agree with the statement 'I feel I can influence my loved one's behaviour'

	Face-to-face				Online Course			
Impact	Pre course	Post Course	% change	Swing	Pre Course	Post Course	% change	Swing
Totally disagree	0	3	3	-4	0	4	4	-2
Disagree	13	6	-7		14	8	-6	
Neither disagree or agree	52	32			32	16		
Agree	35	55	20	23	46	64	18	18
Totally agree	0	3	3		8	8	0	



Research Methodology (2)

Qualitative –Dr Martha Doyle & Dr Marita O’Brien

- 80 people who had participated in the Insights into Dementia face-to face course and the on-line course invited to take part in qualitative research
- 17 responded- 9 face to face course / 8 on-line course
- 12 people took part in 3 focus groups in Dublin, Limerick and Co. Meath
- 4 one to one interview
- One person was away on extended holiday during fieldwork phase and was unable to take part.

Motivations for Completion

- To meet other people in a similar situation and share experiential and practical knowledge
- To know how to respond better to their relative/spouse with Dementia
- To demystify and better understand the condition
- To affirm they were caring appropriately for their relative/spouse
- To support parent who are acting as full-time carers and share learning with family members
- To help parent with Dementia to understand the condition
- To better understand condition and what might lie ahead

Benefits of Course Completion

1. Improved knowledge of communication skills
2. Increased knowledge on how to assist in daily activities
3. Increase in assuredness and acceptance

1. Communication Skills

- Not to project their own feelings of frustration and tension
- Attribute communication difficulties to the illness rather than the person
- Familiarity with triggers that may result in increased agitation
- A greater sense of tolerance and improved relationships

1. Communication Skills

“I think my communication improved. I was more conscious of ...you know not getting impatient. Because...now I understood, you know, what was happening. I understood you know why this was happening and why...he would...my Dad would do a certain thing. And it just makes you a bit...you know... now I knew before there’s nothing you could do about it. But I just think it reinforced you...it gave you the information that you could say, right, OK, well, he’s doing this now, so I can do x...to respond to that.” (Sarah, daughter, F2f)

“It makes you conscious of what you are going to say and what you are going to do. Because the person you are dealing with ...cannot...so you have to be tolerant and think...and...and if they say something...ah that’s great...you know...that sort of thing.” (Fred, partner, on-line)

2. Knowledge How To Assist in Daily Activities

- Enhanced feeling of self-efficacy and control
- Increased knowledge of the strategies they could use to bring about an improvement in everyday activities
 - Getting rid of patterned carpets, table cloths or plates
 - Avoid mixing of food and medication
 - Ensuring food is sufficiently soft for those with difficulties swallowing
 - Importance of drinking water to ensure bowel motion retained
 - To cut down the variety of clothes choices – the laying out of clothes to minimise choice and confusion
 - Active living and different games and activities to do with their relative such as the rummage box, importance of music

3. Assuredness & Acceptance

- An increased sense of assuredness and acceptance

“I think I was less frustrated afterward, more...I just felt more in control...you know more hopeful too...I definitely feel more confident about it, definitely...I felt I was really in the dark before you know...definitely.” (Rita, parent f2f)

3. Assuredness & Acceptance

- Better control ones own responses and acceptance of situation

“I understand that this is the illness and if something doesn’t work you just leave it” (Jim, f2f)

“Well what I got from the course was that you need to do whatever you need for yourself, to actually help you cope...that’s really important” (Sarah, daughter, f2f)

“I’m a pretty relaxed person, but...I just...found myself so angry...and...annoyed at her constantly. So, it helped me with that. I’m a lot more chilled out now in myself...because I have to be” (Kay, daughter, on-line).

“Funnily enough it gave a sense of hope. Again I felt a bit of a fraud on the course...from the point of view that...if Dad was going to get dementia...this wasn’t the worst one to get...or the worst type to get.” (Bernie, daughter, on-line)

3. Assuredness & Acceptance

- Enhanced sense of reassurance that they are doing the right thing

“I think it’s made me a little less stressed about it. Because one of the worries you have all the time is...you don’t know what you are doing...and you don’t know whether you are doing it right...and whether what you are doing is...and it was reassuring...that...you know...like...we have got a lot of this covered already...we are...we are generally doing...what seems to be a recommended way of doing things”. (Tina, daughter, on-line).

Discourse Community

- The sharing of intimate stories within a supportive, empathetic community can help to resolve complex deep-rooted emotions such as guilt, fear and upset:

“When I first found out Mum had Alzheimer’s I immediately rang her friends and told them...and then I regretted that...but I did that through...panic or fear or...needing some help. But I shared that...and then the response I got back really helped with that...and I don’t feel guilty about that anymore.” (Kay, daughter, on-line).

Motivated To Take Action

- Participation in the course spurred a number of respondents to seek further information

“And so what it did is, it gave me a kick start...So it was very...it was very motivating. And not daunting...that this isn't...you know...Dad is...Dad is still Dad...it's just a different phase of his life...But you know, just to make his life as easy...and for everybody else. So from that point of view...I found it very good...that it made me want to learn more.” (Bernie, daughter, on-line)

Discussion

Thanks for Listening!

Any Questions?



THE ALZHEIMER
SOCIETY *of* IRELAND