Funded by
NIHR | National Institute for Health and Care Research
Rare Dementia Support
Advice Community Learning

Improving Wellbeing Associated with Rare Familial Dementias (IWARF):

Development, Refinement and Early Evaluation of an ACT-Informed Intervention

Tuesday-0989
P3-11

Hayes, O[1,4], Tsipa, A[1], El Baou, C.[1], Rossi-Harries, S[2], Zimmerman, N[3,4], Crutch, S[3,4], Harding, E[1,3], Rohrer, J[3], Greaves, C[5], Stott, J[1], Brotherhood, E[3]

[1]Department of Clinical, Educational and Health Psychology, University College London, London, United Kingdom, [2]Department of Psychology, Sport and Geography, University of Hertfordshire, Hatfield, UK, [3]Dementia Research Centre, Queen Square Institute of Neurology, University College London, London, United Kingdom , [4]Rare Dementia Support, University College London, London, United Kingdom, [5]Faculty of Medicine, University of Liverpool, Liverpool, United Kingdom

Background

Familial frontotemporal dementia (fFTD) and familial Alzheimer's Disease (FAD) are inherited neurodegenerative conditions associated with substantial psychological burden.

Individuals may face uncertainty regarding future disease onset, family planning, caregiving responsibilities and genetic testing decisions. Despite these challenges, there are currently no evidence-based psychological interventions designed specifically for this population.

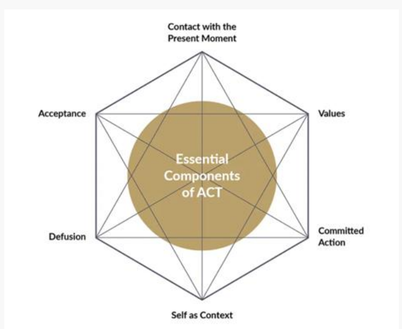
To address this unmet need, we developed **Improving Wellbeing Associated with Rare Familial Dementias (IWARF)**, an online blended intervention informed by Acceptance and Commitment Therapy (ACT) and designed to support wellbeing and psychological flexibility in people affected by familial dementias.

Why ACT?

ACT focuses on developing **psychological flexibility**: the ability to remain engaged with meaningful life activities whilst making space for difficult thoughts, feelings and uncertainty.

Core ACT Processes

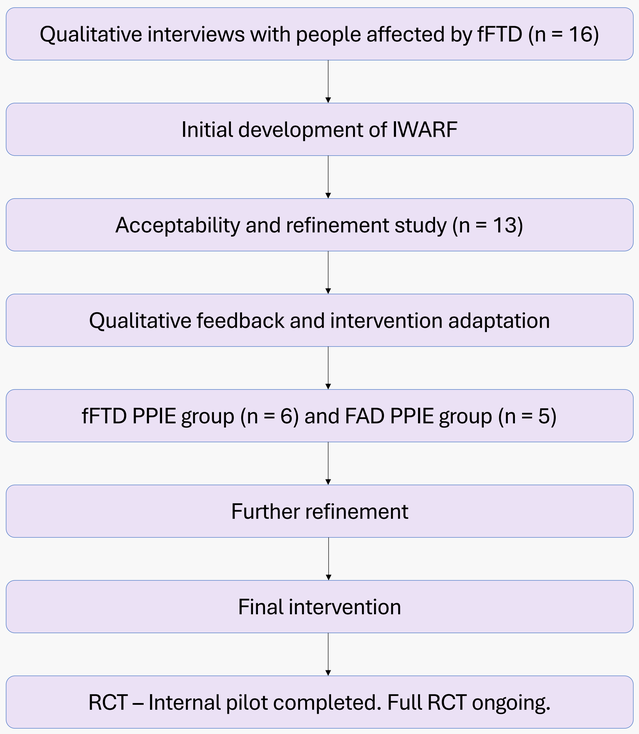
Acceptance: Making space for unpleasant thoughts and feelings
Cognitive defusion: Gaining distance from thoughts rather than getting caught up in them
Present-moment awareness: Developing mindful awareness of current experience
Self-as-context: Developing a flexible sense of self that can observe thoughts, feelings, and experiences without being defined by them
Values clarification: Identifying what matters most
Committed action: Taking meaningful, values-based action



Development of IWARF

IWARF was developed through an iterative process informed by research, clinical expertise, participant feedback and patient and public involvement and engagement (PPIE).

Development Pathway



IWARF Intervention

Duration: 9 weeks
Digital Modules: 8
Facilitator Check-ins: 3
Delivery: Online
Theoretical Framework: ACT

Module Content

IWARF PROGRAMME	
1. IWARF INTRODUCTORY VIDEO	
2. INFORMATION ABOUT FAMILIAL FTD/FAD	
fFTD	*fAD*
3. INTRODUCTION TO LIVING WELL AT-RISK	
3.1 Introductory video	
3.2 Getting caught up in difficult thoughts and feelings	
3.3 Values	
CHECK IN 1	
4. WORRY	
4.1 Worry and low mood	
4.2 Worries that won't go away	
UNKNOWN / KNOWN CARRIER	*NON-CARRIERS*
5. DEALING WITH UNCERTAINTY	5. SURVIVOR GUILT & ANGER
6. WORRY ABOUT SYMPTOMS OR STATUS	
CHECK IN 2	
7. LIVING WELL AT-RISK	
7.1 Avoidance and coping	
7.2 LIVING WELL AT-RISK	
8. MANAGING ISOLATION WITH SUPPORT	
CHECK IN 3	

Facilitator-Led Check-ins

Three structured online sessions supported:

- Reflection on module content
- Practice of ACT skills
- Integration into everyday life
- Troubleshooting barriers to implementation

Refining IWARF: Key Adaptations

- **Improving accessibility:** e.g., adding workbook summaries, downloadable resources
- **Improving engagement:** e.g., balancing content, email reminders, progress indicators
- **Improving relevance:** e.g., flexible "pick and choose" approach, broadening emphasis on wellbeing beyond illness-specific concerns, adding alternative ACT metaphors and exercises

Internal Pilot Results from RCT

The refined IWARF intervention is currently being evaluated through an RCT. The internal pilot for which used the first 9 months of data.

Internal Pilot Progression Criteria (Red, Amber, Green)

Recruitment: green, 28% of total sample
Attendance at check-in sessions: green, 83%
Engagement with online resources: green, 94% of users used the system more than once.
Retention and follow-up: 87% completed the primary outcome measure at 6-months

Key Learnings

- **Psychological support is needed:** There is a clear need for accessible psychological support tailored to the unique experiences of people affected by familial dementias.
- **Online delivery is feasible:** A fully online format offers a scalable approach capable of reaching people affected by familial dementias across the UK.
- **Lived experience strengthens intervention design:** Iterative PPIE involvement improved acceptability, relevance and accessibility.
- **ACT as a useful framework:** ACT appears to offer a helpful framework for supporting people to respond to uncertainty and difficult emotions arising from realistic concerns about the future, while continuing to engage in valued activities.
- **Facilitators with specialist knowledge enhance engagement:** Facilitators' specialist knowledge of familial dementias was consistently highlighted as valuable, helping participants feel understood and supporting the application of ACT skills in everyday life.

Take-home message

IWARF is the first ACT-informed intervention specifically developed for people affected by familial dementias and has been refined through participant and PPIE involvement prior to evaluation in an RCT.
People affected by familial dementias require tailored psychological support. IWARF represents a novel approach designed specifically for this population and has the potential to improve access to evidence-based psychological support for people affected by familial dementias.