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The Aphasia Communication Team (TACT): A supportive, motivational, practical, and educational community for people with aphasia

Parallel 4: Empowering people living with aphasia: sharing learning through community groups

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I have no conflicts of interest to declare

The Aphasia Communication Team (TACT)

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- Established in 2018
- Founders: Dr Marina Charalambous and Prof Maria Kambanaros
- Collaboration between the **Cyprus Stroke Association** and the **Department of Rehabilitation Sciences** at the Cyprus University of Technology
- Methodology was based on the Talkback Groups in Australia



TACT groups aim to provide opportunities for:

- mutual/peer **support**
- buddy **system**
- **education** on aphasia
- total **communication**
- **living well** with stroke and aphasia



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Key ingredients of TACT groups are:

- **Recognition** of achievements & changes in health
- **Information Swapping**, as no one knows everything
- **Social Opportunities** to mingle/ become friends



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Support and Communication Groups run by TACT:

- People with chronic aphasia
- Younger people with aphasia
- Aphasia Cooking Club
- Stroke Aphasia Choir



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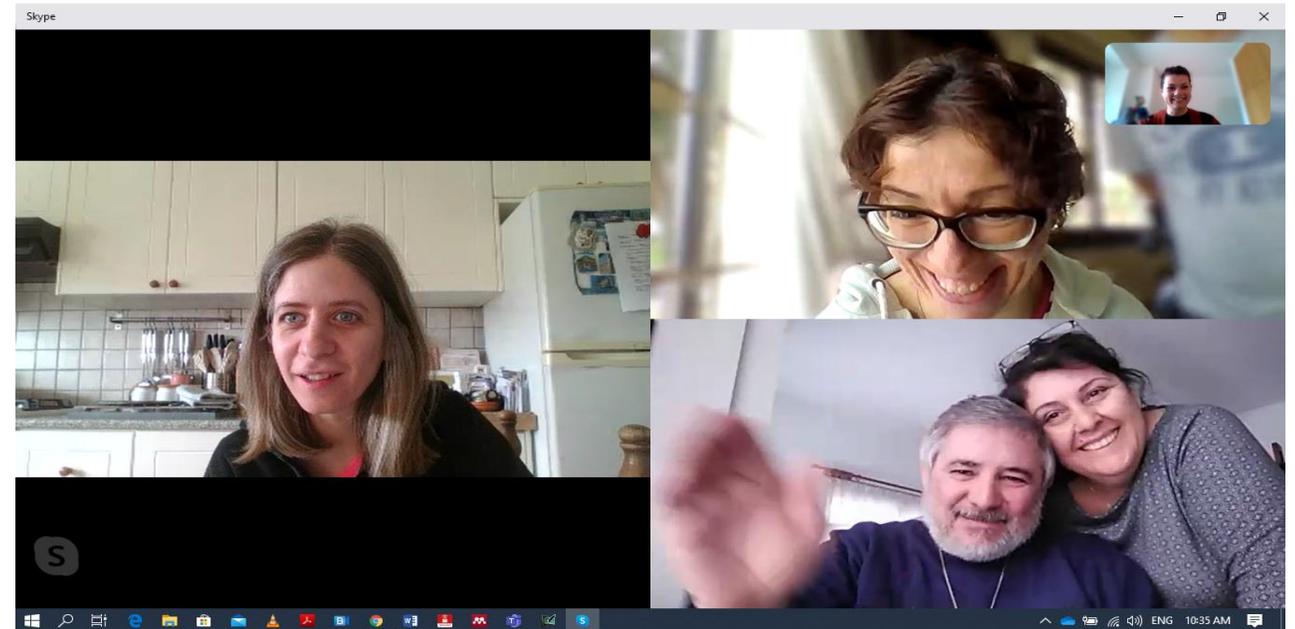


Groups meet once a week for 2 hours:

- **Total communication:** signing, gestures, drawing, writing, speaking
- **Technology** (tablets, laptops, apps)
- Hybrid option if needed



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The Stoke Aphasia Choir- Music Therapy Group

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Participants:

- people with aphasia
- communication buddies
(SLT students)
- carers
- music therapist



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Young people with aphasia



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Topics:

- **Dating**
- **Friendship**
- **Finances**
- **Going back to work**

are the most important



The Aphasia Cooking Club

- Young people with aphasia and SLT students are preparing meals, which at the end of the program resulted in an Aphasia Friendly Recipe book



Assessment Procedures

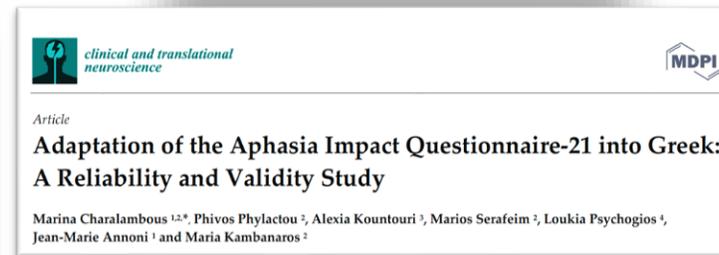
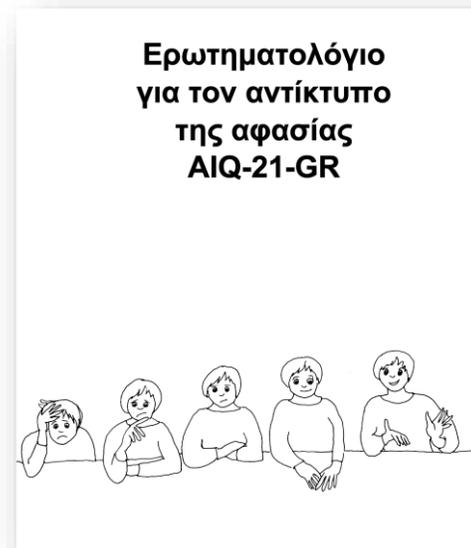


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Standardized Assessment Tools

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Scenario Test- GR

Functional communication

AIQ-GR

Aphasia impact in QoL

CETI-GR

Carers perspective

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The research team



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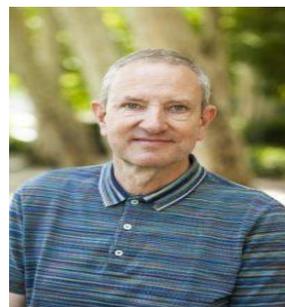
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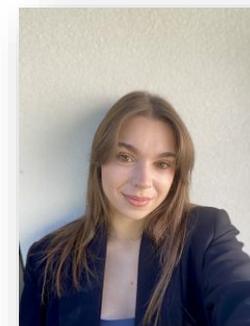
Marios Serafim SLT



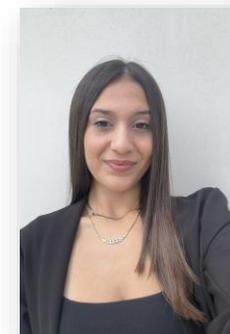
Thekla Elriz SLT



Ioanna Triantafillidou SLT



Eleutheria Antoniou SLT



Maria Christodoulou SLT



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TACT Publications

The Aphasia Cooking Book

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Σχολή
Επιστημών Υγείας

Τμήμα
Επιστημών Αποκατάστασης
Λογοθεραπείας

Βιβλίο Συνταγών Φιλικό Προς την Αφασία "Aphasia Cooking Club"



SLT_490 - Κλινική Άσκηση III- Πλαίσιο Ενηλίκων

Ακαδημαϊκή Υπεύθυνη: Δρ. Μαρία Καμπανάρου

Υπεύθυνη SLT_490- Κλινική Άσκηση III : ΜαρίναΧαραλάμπους, ΕΕΠ

Φθινοπωρινό Εξάμηνο 2019

Τεχνολογικό Πανεπιστήμιο Κύπρου
Aphasia Cooking Club
Σεπτέμβριος- Δεκέμβριος 2019

1



1. ΠΛένω λαχανικά
2. κόβω αλλαντικά
3. κόβω ντομάτα και αγγουράκι
4. απλώνω Cream cheese τортίγια
5. βάζω αλλαντικά και λαχανικά τортίγια
6. τυλίγω τортίγια

Τεχνολογικό Πανεπιστήμιο Κύπρου
Aphasia Cooking Club
Σεπτέμβριος- Δεκέμβριος 2019

7

Book Chapter



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 OPEN ACCESS PEER-REVIEWED CHAPTER

The Importance of Aphasia Communication Groups

Submitted: 27 September 2021 , Reviewed: 04 October 2021 , Published: 22 December 2021

DOI: 10.5772/intechopen.101059

WRITTEN BY

Marina Charalambous and Maria Kambanaros

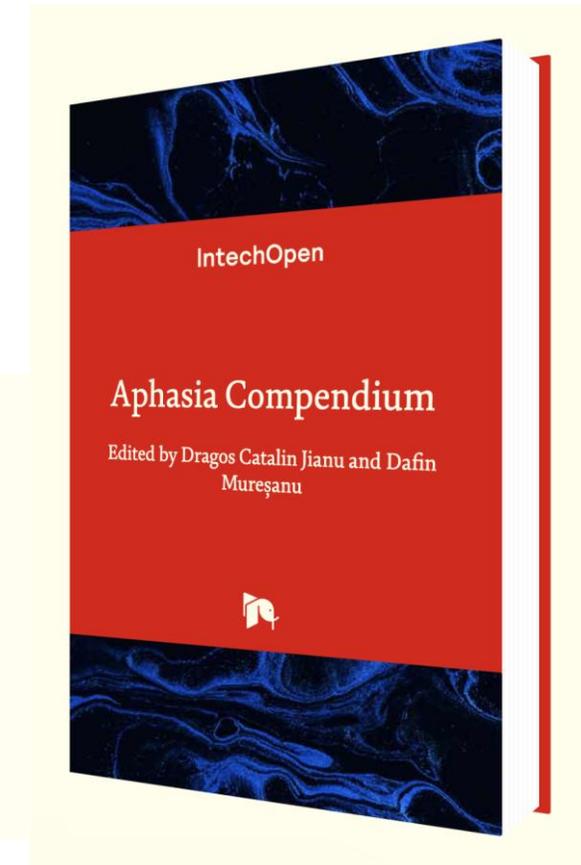
IntechOpen

The Importance of Aphasia Communication Groups

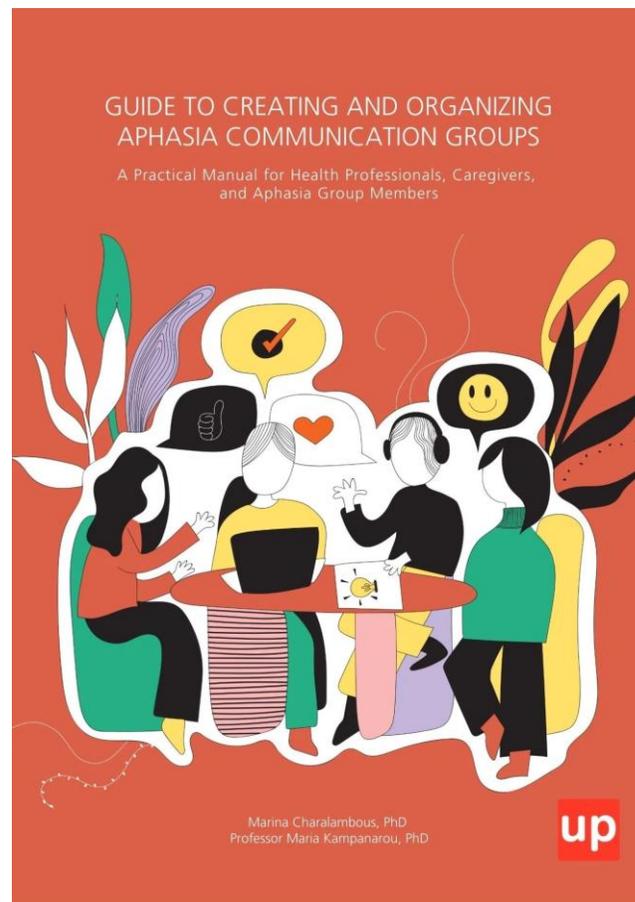
Marina Charalambous^{1,2} and Maria Kambanaros¹

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A guide on how to organize and run communication groups



PAOLI (People with Aphasia and Other Layperson Involvement)
Πλαίσιο καθοδήγησης για την ενεργώ συμμετοχή ατόμων με αφασία και του κοινού (ppr) σε ομάδες

Φάση 1: Εισαγωγή

- Δημιουργία συνεργασιών
- Στρατολόγηση εταίρων-ασθενών
- Απόκτηση ενημερωμένης σγκατάθεσης
- Εισαγωγική ενημέρωση
- Εκπαίδευση εταίρων-ασθενών
- Δημιουργία διαύλων επικοινωνίας
- Ενσωμάτωση επικοινωνιακών συντρόφων

Φάση 2: Ανάπτυξη

- Ενωσιολογικός σχεδιασμός
- Καθορισμός προτεραιοτήτων
- Επίτευξη συναίνεσης
- Μεθοδολογία συν-σχεδιασμού
- Ανάπτυξη ερευνητικής πρότασης

Φάση 3: Εφαρμογή

- Αποτελέσματα και εφαρμογή
- Διάδοση και βιωσιμότητα

Συνεχείς διαδικασίες

- Υποστήριξη/αυτοαξιολόγηση
- Παρακολούθηση και αντίκτυπος

Διάγραμμα 2. Πλαίσιο PAOLI για την ενεργώ συμμετοχή ατόμων με αφασία και του κοινού (PPR) στη συν-δημιουργία ομάδων επικοινωνίας

Scientific Article *Frontiers in Stroke*



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The coproduction of a multilevel personal narrative intervention for people with aphasia in a community communication support group—A pilot study

Charalambous et al., 2024



frontiers | Frontiers in Stroke | Original Research | Published: 27 July 2024 | doi: 10.3389/fstro.2024.1393676

Check for updates

OPEN ACCESS

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CITATION
Charalambous M, Symeonis RT, Theodorou E and Kambanaros M (2024) The coproduction of a multilevel personal narrative intervention for people with aphasia in a community communication support group—A pilot study. *Front. Stroke* 13:1393676. doi: 10.3389/fstro.2024.1393676

INTRODUCTION: People with aphasia (PWA) face challenges in sharing personal stories due to communication difficulties. Discourse treatment in aphasia focusing on personal narrative macrostructure has yet to receive the attention this warrants of researchers and clinicians. Emerging person-centered approaches involve coproduction and codesign with PWA for meaningful discourse treatments. Few studies explore discourse treatment's impact on functional communication. This pilot study aims to explore whether the use of the coproduction approach in the development of a multilevel personal narrative intervention at the group level increased the production of macrostructure elements in trained and untrained narrative discourse contexts, improved aphasia severity and functional communication skills, and advanced quality of life of the participants with aphasia.

METHODS: An ABA design was followed featuring a pre-treatment baseline assessment phase, a treatment phase, and a post-treatment assessment phase immediately after treatment was completed. Three people with chronic stroke-induced aphasia, three communication partners, and a moderator took part in the study. All participants were members of a university-led community aphasia communication group. The research protocol consisted of eleven, two-hour, weekly sessions over an 11-week block. Nine treatment sessions were carried out following codesign and coproduction methods that focused on participants with aphasia producing words, sentences, and total communication strategies to express macrostructure elements in their personal stories. Assessment measures were collected at baseline and post-treatment to evaluate improvements in trained and untrained narrative abilities, aphasia severity, functional communication, and the impact of aphasia on quality of life.

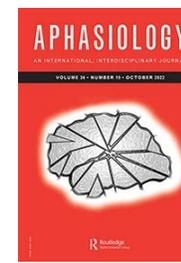
RESULTS: Multilevel personal narrative therapy improved the narrative skills of the participants with aphasia at the macrostructural level of narrative discourse. Improvements were also observed in functional communication and quality of life post-treatment.

DISCUSSION: The involvement of participants with aphasia in the codesign and coproduction of the treatment context for the group intervention facilitated improvement in narrative skills, functional communication, and overall quality of life with aphasia. It is recommended that researchers and clinicians consider using content from the personal narratives of clients with aphasia to



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Co-creation of FRIENDS tool



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FRIENDS
Functional Rating of Interaction
Engagement Needs and Difficulties Scale

FRIENDS® (Functional Rating of Interaction Engagement Needs and Difficulties Scale)
was co-created by Charalambous et al. in 2025

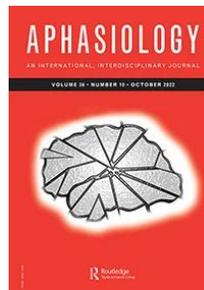
⌚ During the past four weeks...

It was easy to talk to a friend when I needed to

NEVER 1 ALMOST NEVER 2 SOMETIMES 3 ALMOST ALWAYS 4 ALWAYS 5

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Scientific Article *Aphasiology*



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APHASIOLOGY
<https://doi.org/10.1080/02687038.2025.2569045>

Routledge
Taylor & Francis Group

OPEN ACCESS

The co-creation of the functional rating of interaction engagement needs and difficulties scale (FRIENDS) with people with aphasia

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ABSTRACT

Background: Friendship is vital for the well-being and social integration of people with aphasia (PWA) post-stroke. The impact of chronic aphasia on the friendships and social engagement of PWA is often overlooked by rehabilitation clinicians. Aim: To co-create the Functional Rating of Interaction Engagement Needs and Difficulties Scale (FRIENDS), a self-report aphasia-friendly tool, in collaboration with PWA, and test its psychometric properties.

Methods: A Patient and Public Involvement approach was adopted, involving 3 PWA and a caregiver as research partners across eight co-design meetings. FRIENDS' psychometric properties were evaluated with reliability and validity measures. The psychometric study involved 166 participants: 62 PWA, 50 people with stroke without aphasia, and 54 healthy controls.

Results: FRIENDS demonstrated excellent internal consistency (Cronbach's $\alpha > 0.960$) and high test-retest reliability (ICC ≥ 0.99). The results demonstrated a significant difference amongst the three groups ($p < 0.001$), which verified known-groups validity. Significant correlations between FRIENDS and measures of aphasia severity, functional communication, and quality of life supported the tool's convergent validity. Results derived from analyzing the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) report supported its content validity.

Conclusion: FRIENDS is a psychometrically sound, patient-reported outcome measure, developed to rate changes in the friendships of PWA. Co-created with PWA, FRIENDS offers a broad view of chronic aphasia's impact on friendships, aiding clinicians in co-developing functional intervention plans, enabling person-centered care, and improving the social life of PWA.

ARTICLE HISTORY

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KEYWORDS

Aphasia; co-creation; friendship scale; patient and public involvement; psychometric testing; stroke

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FRIENDS: Measuring Friendship in Stroke Aphasia

THE PROBLEM

- Aphasia affects more than language.
- It reshapes friendships.
- Friendship impact is rarely measured during aphasia rehabilitation.

THE SOLUTION

To co-create and validate an aphasia-friendly, self-report tool:

Functional Rating of Interaction Engagement Needs and Difficulties Scale
Developed with people with aphasia (PWA), not just for them.

THE CO-CREATION TEAM (PPI*)

- 3 PWA + 1 caregiver + 3 communication partners + 3 researchers
- 8 co-design meetings
- Lived experience embedded
- Aphasia-friendly content and design (10 items)

THE VALIDATION STUDY (N = 166)

- 62 People with Chronic Aphasia
- 50 People with Chronic Stroke (no aphasia)
- 54 Healthy Controls

Psychometric Strength

- Internal consistency: Excellent (Cronbach's $\alpha > .960$)
- Test-retest reliability: Excellent (ICC $\geq .99$)
- Known-groups validity: Significant ($p < .001$)
- Convergent validity: Correlations with aphasia severity and QoL*
- Content validity: Excellent (COSMIN framework)

WHY "FRIENDS" MATTERS

FRIENDS makes friendship:

- Visible to rehabilitation clinicians
- Measurable during therapy
- Clinically actionable for goal setting

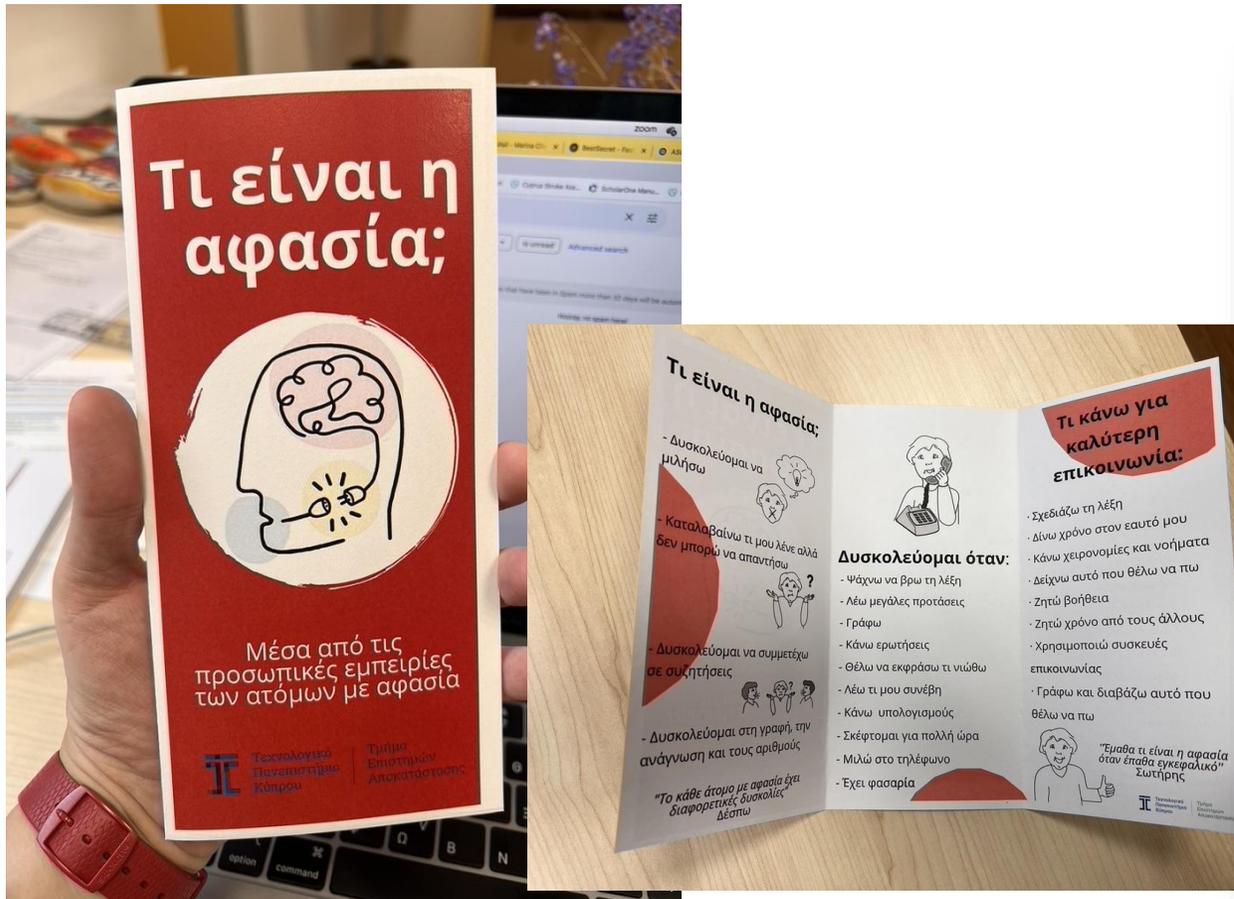
Charalambous et al. (2025). The co-creation of the functional rating of interaction engagement needs and difficulties scale (FRIENDS) with people with aphasia. *Aphasiology*, DOI 10.1080/02687038.2025.2569045

Charalambous et al. (2025).
The co-creation of the functional rating
of interaction engagement needs and
difficulties scale (FRIENDS)
with people with aphasia. *Aphasiology*,
DOI 10.1080/02687038.2025.2569045

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Co-creation of Aphasia Leaflet

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Συμβουλές για καλύτερη επικοινωνία



- Μίλα αργά και καθαρά
- Περίμενε να απαντήσω
 - Δείξε εικόνες
- Κάνε νοήματα, γράψε
- Πες μικρές προτάσεις
 - Μην μιλάς δυνατά
- Πες το ξανά με απλά λόγια
- Μη στέκεσαι πολύ μακριά μου
 - Μη μιλάτε όλοι μαζί

"Χρειάζομαι περισσότερο χρόνο να βρω τη σωστή λέξη"
Ζήνων

Τεχνολογικό Πανεπιστήμιο Κύπρου | Τμήμα Επιστημών Αποκατάστασης



Το φυλλάδιο δημιουργήθηκε από τα μέλη της ομάδας αφασίας της Πανεπιστημιακής Κλινικής Αποκατάστασης του ΤΕΠΑΚ

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Ζήνωνας Αρέστη
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Εποπτεία: Δρ. Μαρίνα Χαραλάμπους



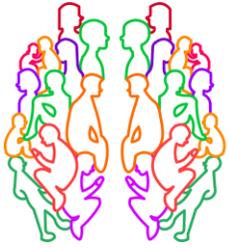
CO-RESEARCH LAB
PATIENT AND PUBLIC INVOLVEMENT

Τι είναι η αφασία;



Μέσα από τις προσωπικές εμπειρίες των ατόμων με αφασία

Τεχνολογικό Πανεπιστήμιο Κύπρου | Τμήμα Επιστημών Αποκατάστασης



ARYAS
YOUNG STROKE

Accessible Resources for Young Adults with Stroke (ARYAS)



Funded by
the European Union

Project Number: 2025-1-CY01-KA220-ADU-000350166

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YOUNG STROKE

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the European Union

SAFE
STROKE ALLIANCE FOR EUROPE

European Life After Stroke Forum

Project Number: 2025-1-CY01-KA220-ADU-000350166

Stockholmsmässan, 9-10 March 2026

ARYAS (Accessible Resources for Young Adults with Stroke) Erasmus+ Project: Co-Creating Accessible Resources Across Europe

Charalambous, M.¹, Grigoriou, S.³, Duarte, E.², Figarola, J.², Miró, S.², Hertz, A.³, Lauridsen, J.³, Eckhardt, F.⁴, Naggi, K.⁴, Gomes, B.⁵, & Ferreira, S.⁵

¹Cyprus University of Technology, ²Stroke Foundation Barcelona, ³Danish Stroke Association, ⁴Aphasia Association Hungary, ⁵Virtual Campus, Portugal

3 MAIN OBJECTIVES

- Objective 1 – Establish co-design groups for active involvement**
To establish inclusive co-design communities across Europe that actively engage young people with stroke, caregivers, and health professionals, reducing isolation, strengthening peer networks, and ensuring meaningful participation throughout the project.
- Objective 2 – Co-develop educational resources for YPwS**
To co-create accessible, aphasia-friendly digital and print educational resources that support rehabilitation, learning, and communication for young people with stroke, while ensuring transparency, adaptability, and long-term usability.
- Objective 3 – Raise public awareness about stroke and aphasia in young adults**
To raise public awareness of young stroke and aphasia across Europe through inclusive, co-designed campaigns that challenge misconceptions, promote understanding, and foster active community engagement.

CO-DESIGN AND ENGAGEMENT METHODOLOGY

- More than 40 young people with stroke, their caregivers, and professionals actively involved. **+40**
- Four co-design groups establish in Cyprus, Spain, Hungary and Denmark.
- Strong peer networks created to foster inclusion, encourage mutual support, and reduce feelings of isolation.

CO-DEVELOPED EDUCATIONAL RESOURCES

- WEBSITE
- MOBILE APP
- VIDEOS
- PODCASTS
- LEAFLETS

THE EU PARTNERS

Cyprus University of Technology, Fundació Ictus, AFÁZIA EGYESÜLET, virtualcampus, Hjernesagen

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Take home message: Make it special



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Celebrate special occasions, e.g., birthdays, achievements
(drinks and food are always appreciated)





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Thank you for your attention

(PS. It takes a village to move a mountain)

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