

A real-word approach for evaluating motivational symptoms in dementia: development of ecological momentary assessments for apathy and anhedonia



Julie Behenská^{1,2,3}, Katia Andrade¹, Samuel L. Warren^{2,3}, Karim N’Diaye¹, Muireann Irish^{2,3}, Bénédicte Batrancourt¹
¹ Sorbonne Université, Institut du Cerveau - Paris Brain Institute (ICM), Inserm, CNRS AP-HP, Hôpital de la Pitié Salpêtrière, Paris, France;
² Brain and Mind Centre, The University of Sydney, Sydney, New South Wales, Australia;
³ School of Psychology, The University of Sydney, Sydney, New South Wales, Australia

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Apathy and anhedonia are traditionally assessed using standardised neuropsychiatric scales. We propose a more objective and ecologically valid approach by integrating behavioural and physiological data from wearable sensors with ecological momentary assessments (EMA).

INTRODUCTION	METHODS	OBJECTIVES	CONTACT
Apathy is highly prevalent, in behavioural variant frontotemporal dementia (bvFTD) and Alzheimer’s disease (AD), while anhedonia is particularly prominent in bvFTD¹. These symptoms are typically assessed using standardised neuropsychiatric scales, such as the Dimensional Apathy Scale (DAS)² and the Snaith-Hamilton Pleasure Scale (SHAPS)³. However, these instruments provide limited insight into their complexity and fluctuations. Ecological momentary assessment (EMA), also known as experience sampling, offers a promising approach to capture these phenomena in real-world contexts. This method is particularly well suited for improving the tracking of motivational disturbances.	Visit 1 Neuropsychological assessment Interview Delivery and setup of the equipment 14-day data collection at home Sensor-based data: Dyad (Patient, Carer), Healthy Control RP, Healthy Control NRP. Actigraphy / Gait analysis (accelerometer / gyroscope), Digital skin temperature, Heart rate (blood volume pulse), Electrodermal activity. Ecological Momentary Assessment: Carer EMA, Patient EMA, Healthy Control EMA. Standardised clinical anchor scales. Visit 2 Neuropsychological assessment MRI Scan Debriefing Hand back of the equipment BREAKFAST Beginning: ____ h End: ____ h → Time stamp Compared to before the disease onset, does your partner take initiatives to prepare/ eat breakfast? ☐ Yes ☐ No Regarding practical activities related to breakfast: beverages/food, clearing the table, washing dishes, etc. How did you perceive your partner’s initiative? Low 0 1 2 3 4 5 6 7 8 9 10 High → Initiation (self-generated behaviour) If applicable, how did you perceive the help your partner provided during breakfast? Inefficient 0 1 2 3 4 5 6 7 8 9 10 Efficient → Appropriateness of actions MORNING Date: ____ How do you feel this morning? ☐ Very bad ☐ Bad ☐ Neither well nor bad ☐ Well ☐ Very well Do you feel full of energy? ☐ Not at all ☐ A little bit ☐ Moderately ☐ A lot ☐ Very much → Arousal / energy Do you feel tired this morning? ☐ Not at all ☐ A little bit ☐ Moderately ☐ A lot ☐ Very much Do you feel motivated to start the day? ☐ Not at all ☐ A little bit ☐ Moderately ☐ A lot ☐ Very much → Motivation (internal drive)	This study aims to improve the assessment of motivational symptoms in dementia using a real-world, dyadic approach capturing symptom dynamics and carer insights. By combining the easily administrable EMAs with passive smartwatch data, it provides a practical, scalable framework for clinicians to assess apathy and anhedonia, advancing precision medicine through individualised, data-driven care.	Contact: Julie Behenská julie.behenska@icm-institute.org J. B. is funded by a PhD Fellowship from the IUIS: Institut Universitaire Economie de la Santé, Sorbonne Université. This work was partially funded by grants from the Malakoff Humanis company, malakoffhumanis.com and the French federation for research on the brain (Fédération pour la Recherche sur le Cerveau) by fund FRC 2020 “Le cerveau protégé de/par son environnement”. Another part of this study is supported by funding to ForeFront, a research group specialised in FTD and motor neuron disease, from the National Health and Medical Research Council (NHMRC; GNT1037746) and the Australian Research Council (ARC) Centre of Excellence in Cognition and its Disorders Memory Program (CE11000102). M.I. is funded by a Medical Research Future Fund Dementia, Aging, and Aged Care Grant from the Australian Government Department of Health and Aged Care (GNT2024329), and an NHMRC Investigator Grant (GNT2025228). The funders had no role in the study design, access to the data, or writing of this report. REFERENCES 1 Shaw et al., ‘Uncovering the Prevalence and Neural Substrates of Anhedonia in Frontotemporal Dementia’, Brain, 2021 2 Radakovic and Abrahams, ‘Developing a New Apathy Measurement Scale’, Journal of Geriatric Psychiatry and Neurology, 2021 3 Snaith et al., ‘A Scale for the Assessment of Hedonic Tone the Snaith–Hamilton Pleasure Scale’, British Journal of Psychiatry, 1995 ALZHEIMER’S ASSOCIATION AAIC 26