

A Goal-Driven Framework for Individualised Self-Care for Early-Stage Dementia

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Jonathan is a Post-Doctoral Researcher in the Smart Dementia Self Care Project in the Department of Computer Science at TU Dublin.

He was awarded a PhD by City, University of London, in 2019 for work applying machine learning methods to longitudinal health records for predicting likelihoods of future health events.

Previously, Jonathan had spent a number of years in the NHS in the UK as a medical physicist and systems analyst, working in diagnostic imaging, PACS, and hospital information systems management, and as Principal Evaluator in the PACSnet device evaluation group funded by the MHRA and NICE.

He is a Fellow of the Faculty of Clinical Informatics, a Member of the Institute of Physics and a Member of the Institute of Physics and Engineering in Medicine.

As a post-doctoral researcher in the Smart Dementia Self Care Project at TU Dublin, Jonathan is working on care qualities goal modelling.



Our Aim

Dementia is a progressive disease, characterized by an irreversible decline in the ability to care for oneself. There are benefits to individuals living with dementia in living independently for as long as possible, and there are societal benefits. We aim to develop tools that assist in extending this period of independent living and in maintaining quality of life during this period.

Activities

Our daily activities fall in to three main groups: those that are essential for survival, those that allow us to live with a degree of independence, and those activities that we find rewarding or meaningful in some way.

Activities of Daily Living: essential for survival

Instrumental Activities of Daily Living: needed for independent living

Meaningful Activities: pleasurable or otherwise rewarding

Examples for independent living

Activities of Daily Living: Bathing oneself; dressing oneself; toileting; transferring; continence; feeding (Katz, 1963)

Instrumental Activities of Daily Living: Uses the telephone; shopping; preparing meals; laundry; driving or using public transportation; medication; handling finances (Lawton and Brody, 1968)

Important to maintain these activities. It is a characteristic of dementia that once the ability to perform a task is lost, it is never regained.

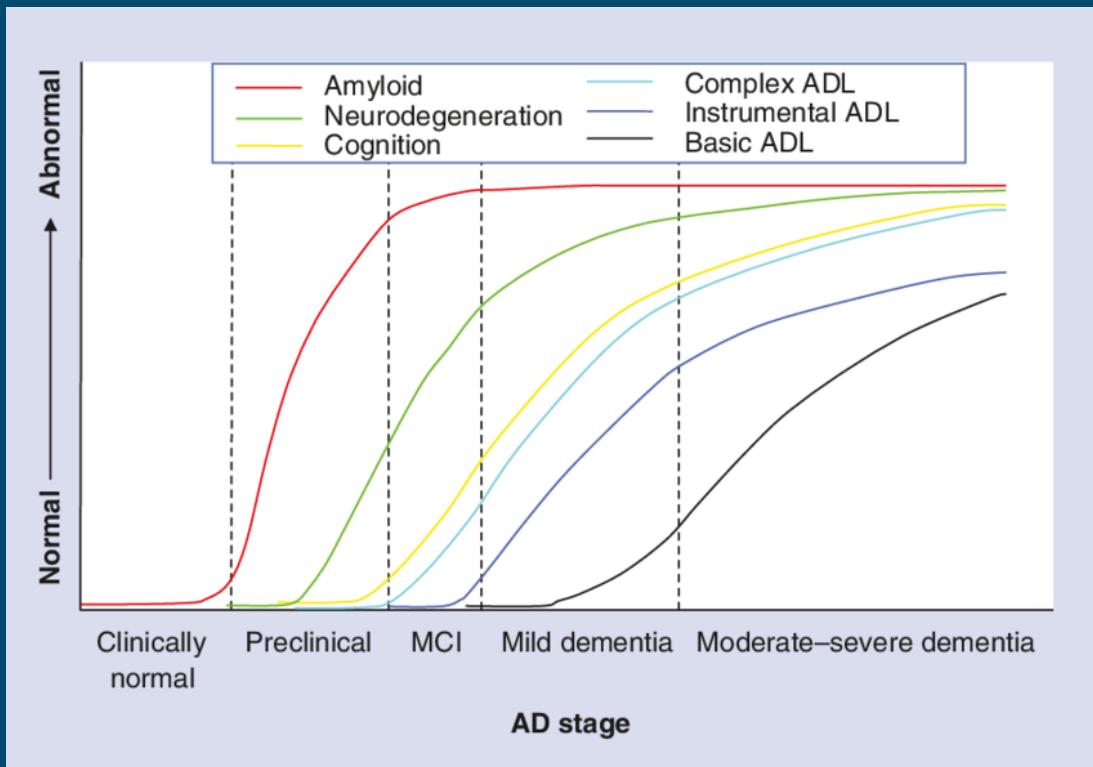
Examples for meaningful activities

Meaningful Activities: A much wider range of activities: we encourage our participants to choose which activities are important to them

Examples: Being outside; meeting friends for coffee; listening to music; gardening; playing board games; exercising; going to church (from Teri & Logsdon, 1991)

Maintaining performance of these activities can help maintain quality of life and the activities of daily living

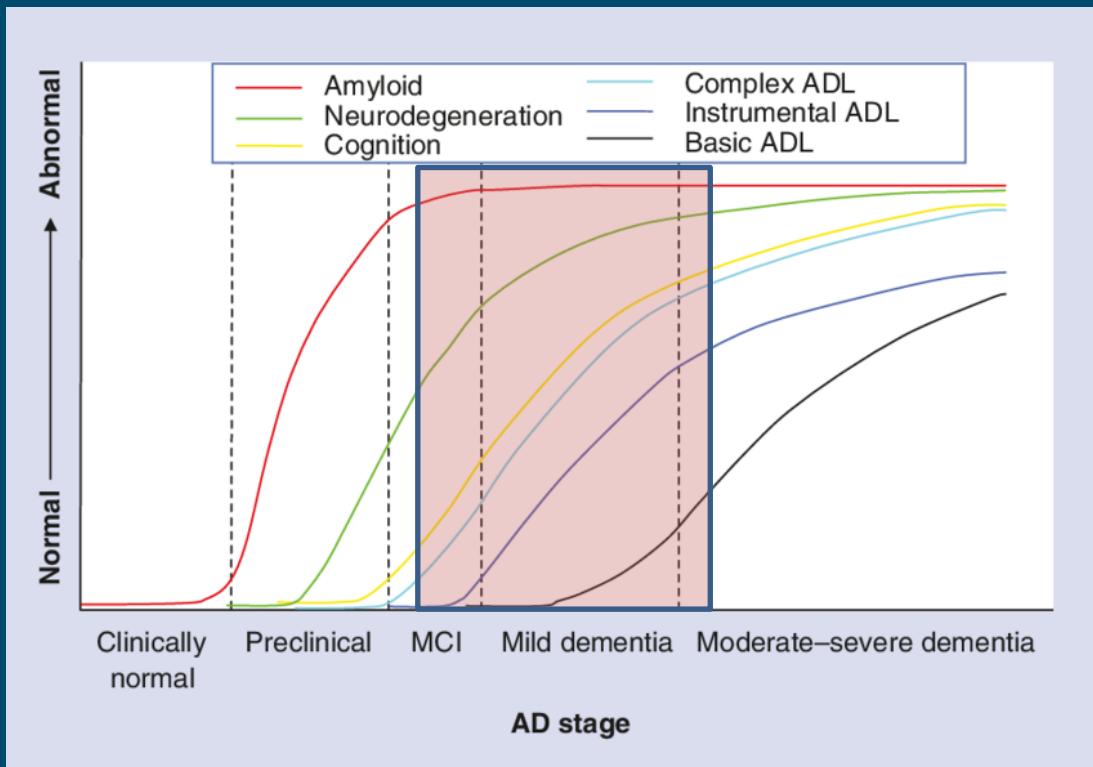
Stages of Alzheimer's Disease



A hypothetical model of changes over time of various biomarkers and activity impairment.

From: Marshall et al (2012)

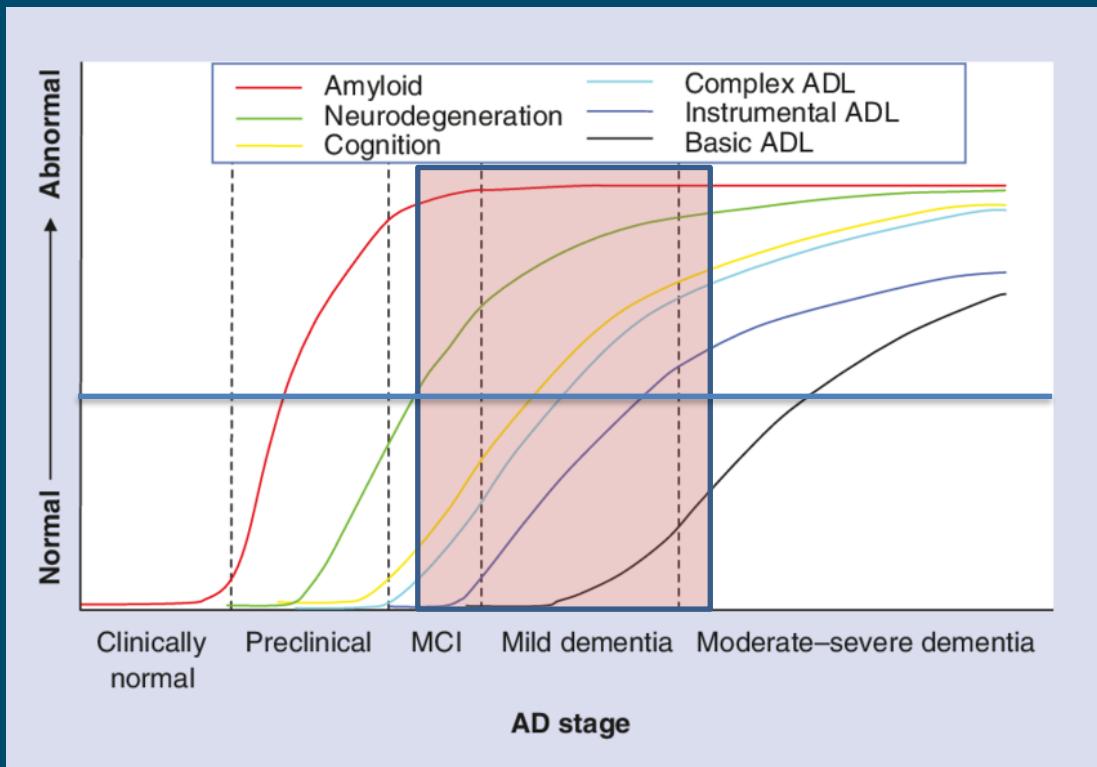
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Activity maintenance

In order to maintain the benefits of independent living, we aim to encourage people living with dementia to perform a selection of activities as frequently as possible and with as high achievement as possible.

Activities of Daily Living: standard for all

Independent Activities of Daily Living: standard for all

Meaningful Activities: selected by individuals or taken from their care plan

Activity achievement

Activity achievement can be monitored by self-reporting via an app, or by use of sensors.

When a decline in achievement of an activity is detected, appropriate action can be triggered

- Suggestion of an alternative activity
- Notification of family carer
- Notification of healthcare professional

For activities monitored by sensors, we believe we can monitor changes in achievement with finer granularity than the traditional binary questions

Activity examples

Activity source:	(I)ADL	Care plan	PLWD/Carer
Specific activity:	Preparing a meal	Walking outside	Visiting a friend
Optionality:	Core	Core	Optional
Frequency goal:	Once a day	Once a day	Once a week
Duration goal:	20 minutes	60 minutes	120 minutes
Duration data source:	Sensors/app	Sensor	App
Achievement goal:	Successful preparation	Walk 2.5 km	Visit friend
Average frequency:	5/week	6/week	0.8/week
Average duration:	24 minutes	55 minutes	140 minutes

Summary

- Individual and societal benefits of maintaining activities
- Activity achievement can be encouraged and/or monitored
- Decline in activity achievement can be detected and appropriate actions taken

References

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Acknowledgements



This presentation is based upon works supported by the Science Foundation Ireland under Grant No. 19/FFP/6917.