

Assisting Carers of People with Dementia through Dementia Education and Training for Carers (DETC)



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UNSW
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DCRC
Dementia Collaborative
Research Centres



Australian Government
Department of Health and Ageing

Presentation goals

- Understand the benefits of DETC.
- Provide an overview of an evidence-based approach to dementia education using the **Allen's Cognitive Levels (ACL)** theory.
- Appreciate how the ACL model gives direction for service provision in dementia care in the DETC e.g. developing care plans, identifying effective prompts and cues.

Background to the DETC project

- 2009 Federal Dept Health and Ageing funded the Dementia Education and Training for Carers (DETC) project.
- Our DETC project uniquely developed
 - individual dementia assessment and
 - carer education
 - in the home environment
 - using the Large Allen's Cognitive Levels (LACL) screening tool.

DETC project outcomes

The DETC project aims to empower carers with:

- an increased understanding of the impact of dementia on the individual, helping carers cope and thereby **reduce carer stress**.
- be more confident in managing difficult behaviours displayed by the person with dementia.
- Increase the quality of life for the person with dementia and their carer.



Carer's comments

"I felt so relieved when your assessment of my wife confirmed what I'd been feeling. You were the only people who understood my wife's abilities and what I was going through.

Because my wife could still hold a conversation no one else believed me, not even my family. The doctor told me she was fine. I used to think that I was going crazy."



Carer's comments

"Hi Rosemary,

Thank you for all the information you gave me on Tuesday. Whilst it was confronting it only confirmed what I already knew deep down.

Can you please email me a copy of the Social History Activity Sheets. This will be a great help for me.

Kind regards

Susan"

Allen's Cognitive Levels

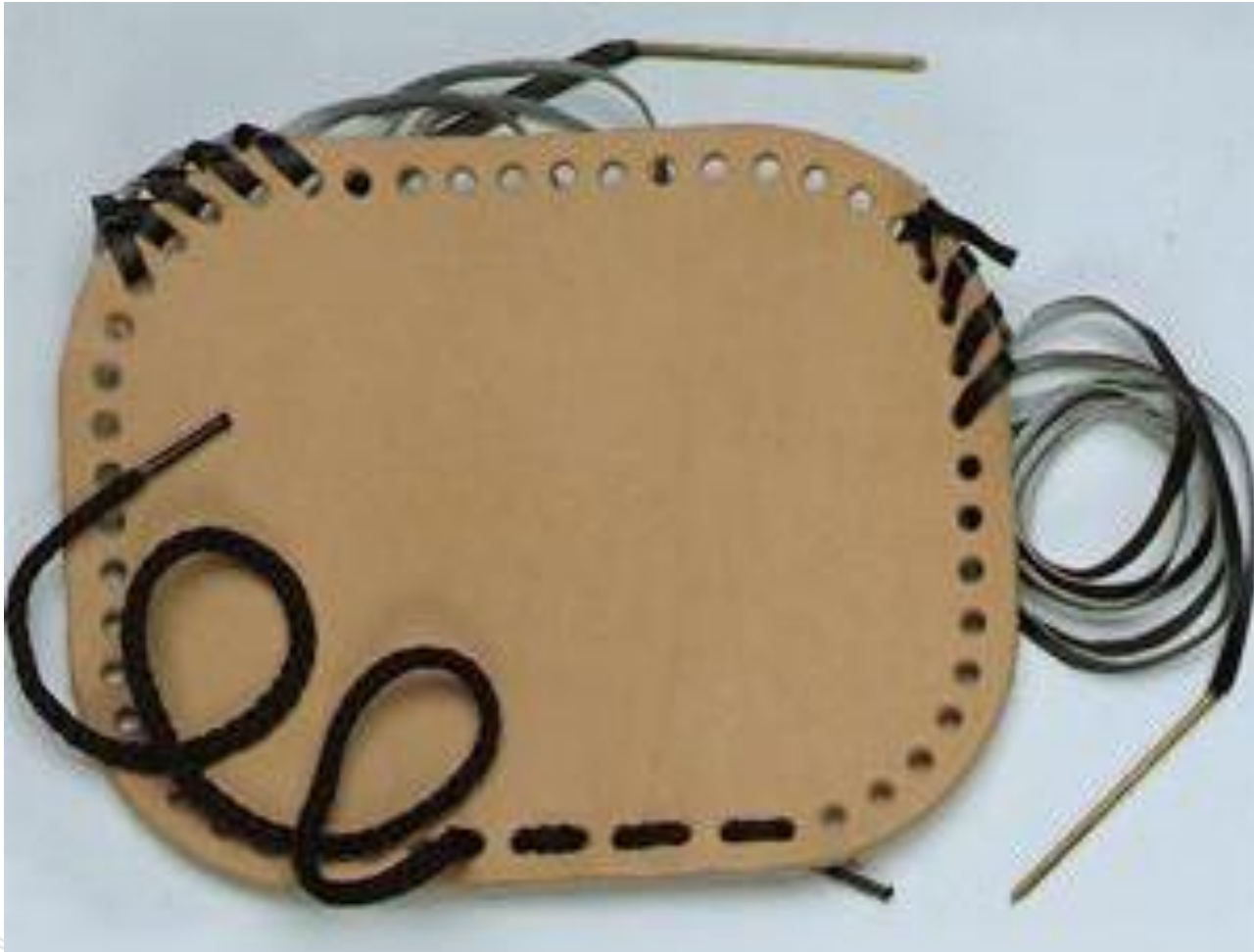
Level 6:	Planned activity	Symbolic cues
Level 5:	Independent learning	Related cues
Level 4:	Goal-directed activity	Striking visual cues
Level 3:	Manual actions	Tactile cues
Level 2:	Postural actions	Proprioceptive cues
Level 1:	Automatic actions	Subliminal cues

Level of functional cognition can fluctuate due to tiredness, sickness and stress

Can do, will do and may do

- ACL's principles of "*can do/will do/may do*" in the DETC
 - LACLS assessment establishes what the person with dementia cognitively **can do**.
 - Explain that what a person with dementia **will do** depends on how relevant & meaningful a task is for them.
 - Identify what they **may do** when procedures &/or steps in activities of daily living (ADLs) are simplified &/or the environment is modified.

Using the LACL screening tool

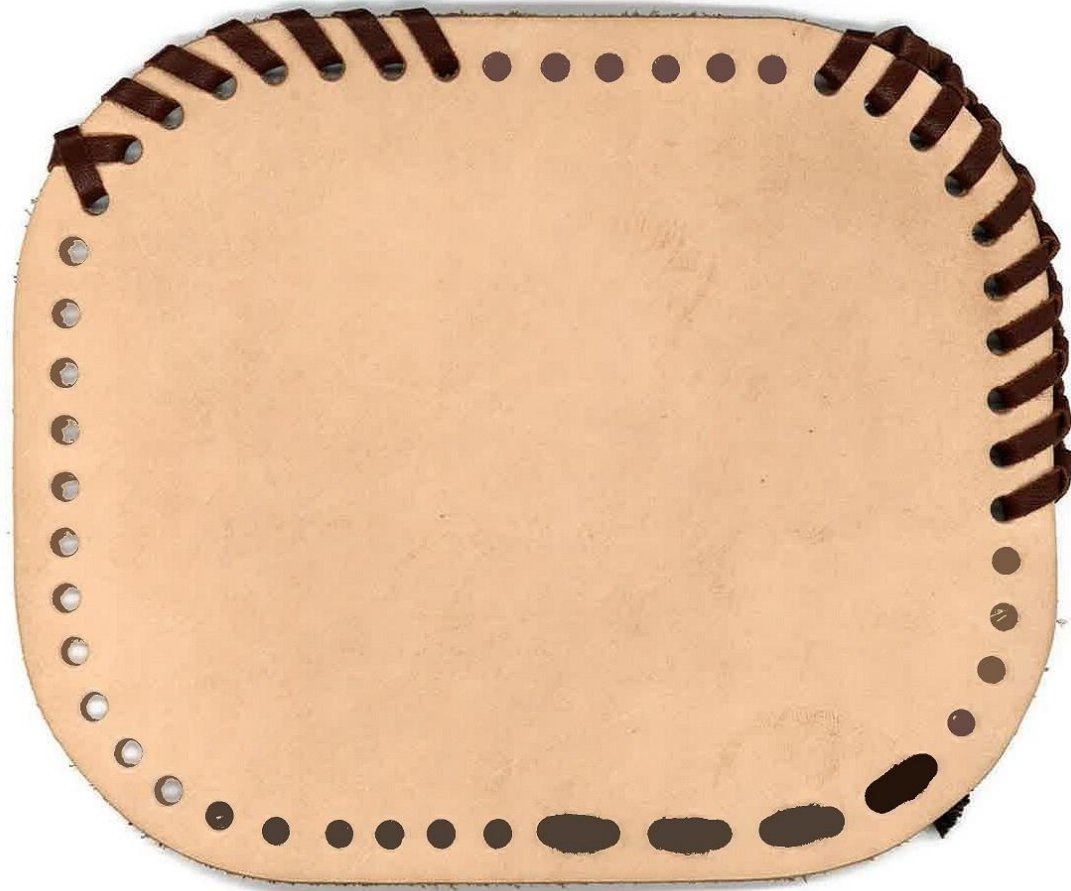


Running stitch

Whip stitch

Single cordovan stitch

Completed assessment – 5.2

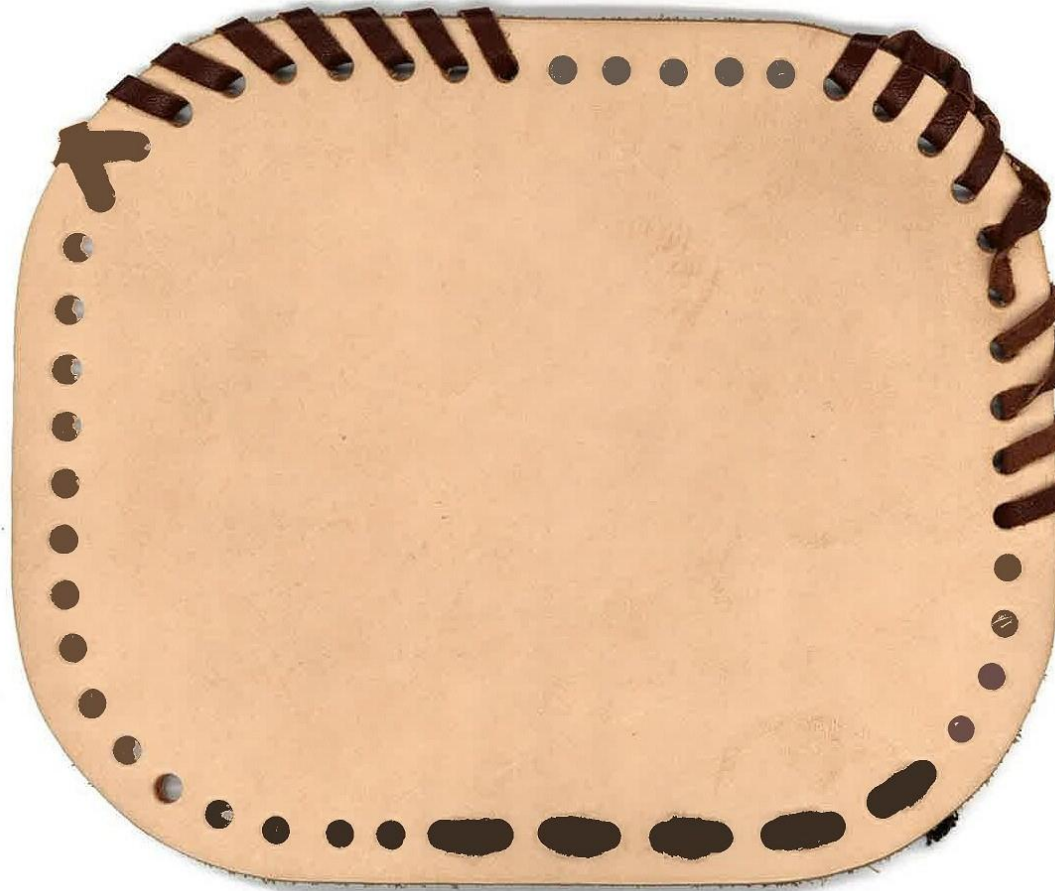


Completed assessment – 5.2

Examples:

- Requires some words and sentences to be either repeated, or changed to simpler wording, to ensure what is being said is understood.
- Vague understanding of the need to take medication.
- Requires assistance with daily activities for at least 3 hours over the 16 hour wake period.
- Analogous age 11-13 years.

Completed assessment – 4.2

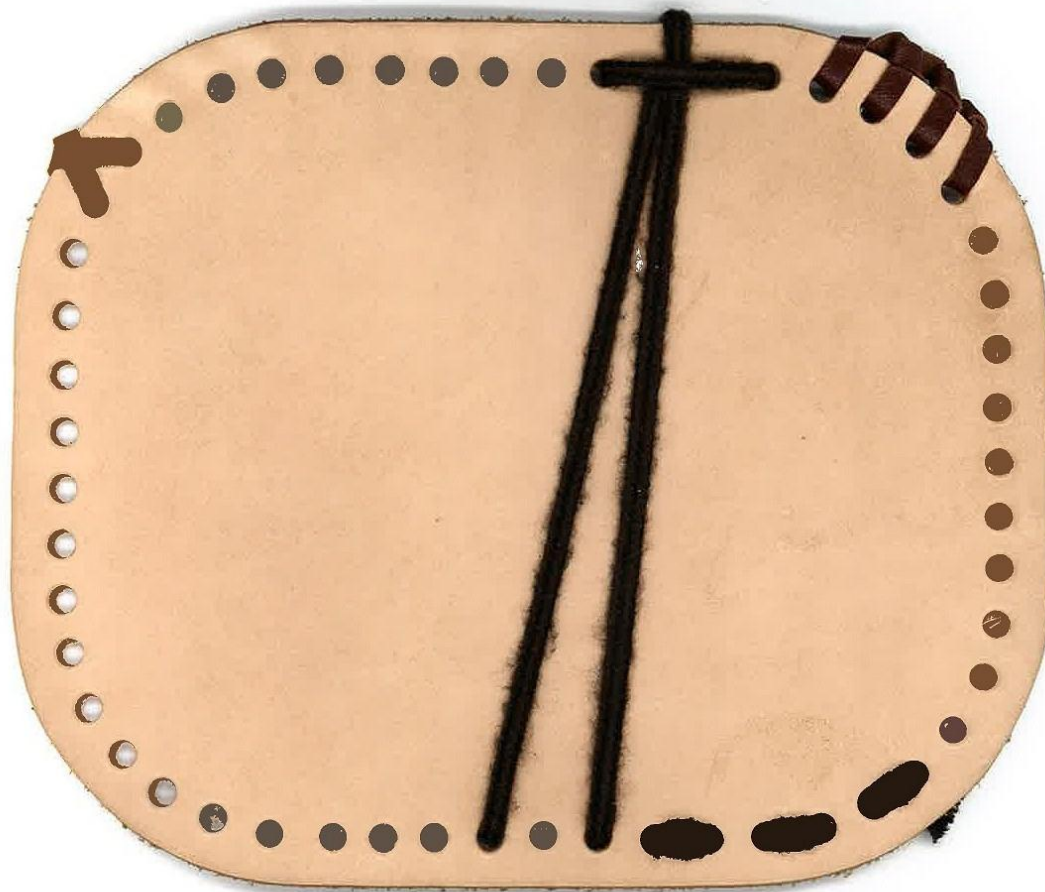


Completed assessment – 4.2

Examples:

- Is able to walk on rough terrain, use stairs and negotiate objects lying in their path.
- Might pick up a hair brush or comb and only attempt to brush the front of the hair.
- Requires assistance with daily activities for at least 6 hours over the 16 hour wake period.
- Analogous age 5 years.

Completed assessment – 3.2



Completed assessment – 3.2

Examples:

- Has a very limited understanding of the need to use the bathroom.
- Does not notice changes in the walking surface or changes in the environment.
- Will have no awareness of the need for medication.
- Requires assistance with daily activities for at least 9½ hours over the 16 hour wake period.
- Analogous age 18-24 months.

Validation by carer

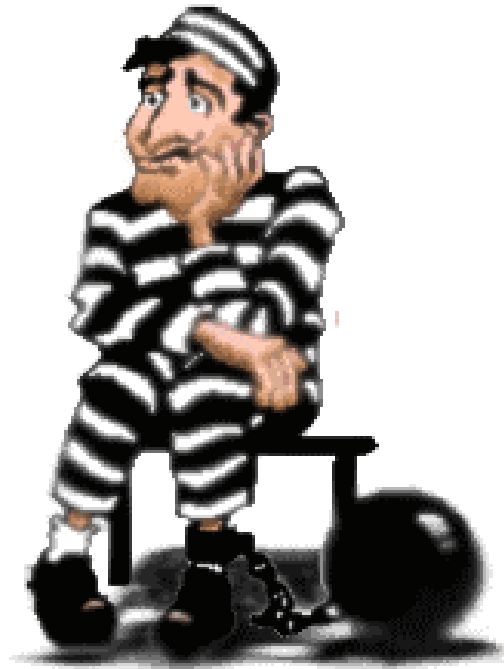
- Carer informs whether it's a “good day or bad day”?
- Discuss outcome of LACL assessment with carer e.g. ACL 3.2
- Focus on validating the “Can Do” with the carer.
- Routine task inventory for additional validation.

Other Resources used in DETC

- Social History Activity Sheets – collection of social information for activity & care planning for day centre or RACF staff. Each sheet can be completed as a individual reminiscing activity.
- Early Stage Functional Observation Scale is a set of descriptors of the person with dementia's;
 - *Participation in Activities
 - *Memory & Attention Span
 - *Social Behaviour
 - *Physical Mobility
 - *Activities of Daily Livingas observed by the carer & used to flag significant change.
- Information on activities for people with dementia – provides advice on how to adapt activities to enable participation

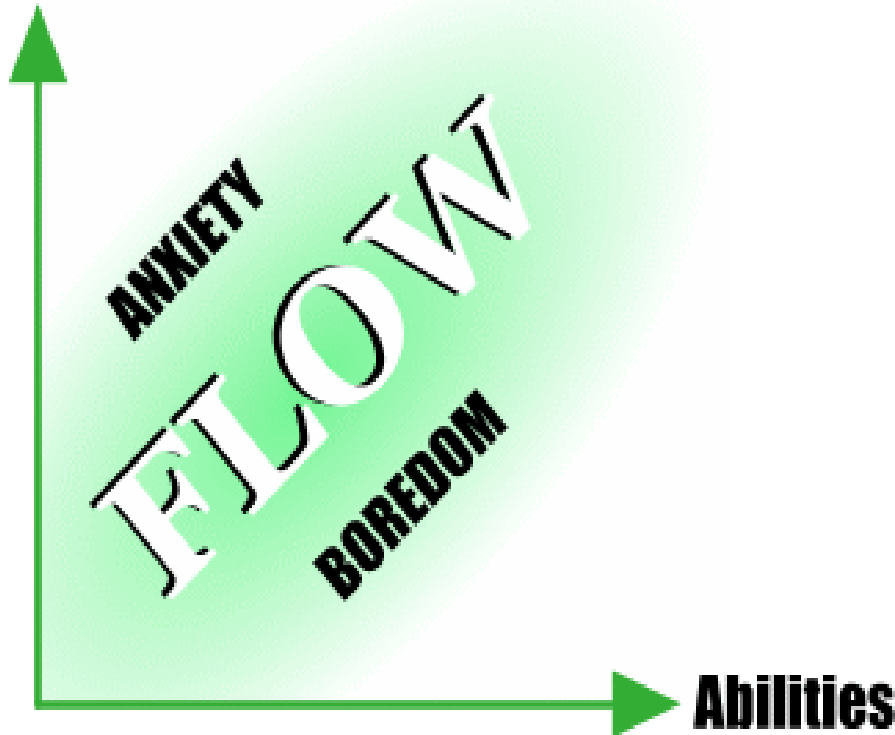
Engaging in Activities

It's only when we can't engage in activities that we realize how important they are to our overall well being.



Prof. Mihaly Csikszentmihalyi's **Model of Flow**.

Challenge



The **flow** channel occurs where the person's abilities and the activities degree of challenge **are in step**.

Boredom = the person's skills completely outstrip the degree of challenge.

Anxiety = the challenges utterly exceed the person's ability. This leads to frustration and they often just stop.

Getting the Activity Balance right



relies on understanding the individual's;

- capabilities – cognitive, physical, sensory and emotional.
- environment – both physical and social.
- values, interests, past & present roles.

Activities must always be gender, culture and age appropriate.

Benefits of Activities

The memory of exactly what they did may not last, but the **emotion of how they felt** when doing the activity will **linger**.



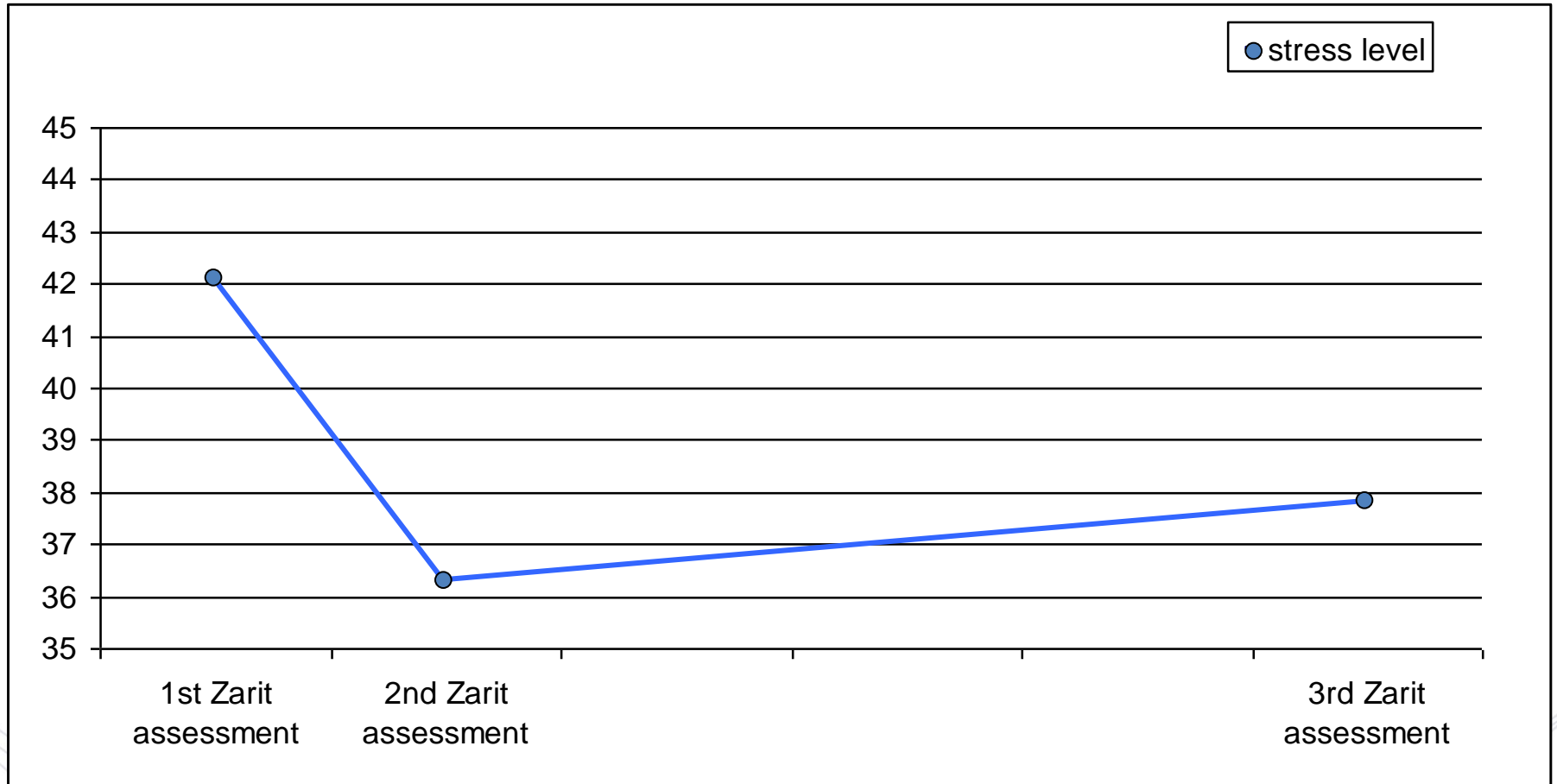
Enjoyment doesn't require memory.

DETC Evaluation Study

- Pilot study on the ability of the DETC to reduce carer stress.
- 15-20 carers in the Nepean area.
- Involves a measure of carer stress (Zarit Burden Interview-12), and additional control items.
- Test-retest format.

Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
1 st Zarit assessment	2 nd Zarit assessment				3 rd Zarit assessment
DETC					

Initial Results



DETC Evaluation Study

- Results will be published and reported to University of NSW, Dementia Collaborative Research Centre, and will be utilised as part of our continuous quality improvement process.
- Estimated time of completion is August, 2013.

