



## Summary

This report shares the findings of a project to assess changes in feelings of self efficacy or self belief in carers of people living with dementia.

This project was prompted from the findings of an evaluation review completed by the University of West of Scotland and tide (together in dementia everyday) that highlighted the importance of context and relevance.



George Bandura states that ‘There is no all-purpose measure of perceived self-efficacy. The “one measure fits all” approach usually has limited explanatory and predictive value because most of the items in an all-purpose test may have little or no relevance to the domain of functioning. Moreover, in an effort to serve all purposes, items in such a measure are usually cast in general terms divorced from the situational demands and circumstances. This leaves much ambiguity about exactly what is being measured or the level of task and situational demands that must be managed.”

The impact and relevance of situational demands is significant in carers of people living with dementia, as the role lacks control or predicatability.

However, the General Scale of Self-Efficacy (GSEF) continues to be widely used to measure changes in a persons feelings of self belief.

### Key messages:

- self-efficacy is people's beliefs in their capabilities to exercise control over their own functioning and over events that affect their lives.
- measuring changes in self-efficacy helps to identify the factors influencing our motivation, well-being and personal accomplishment.
- using a general scale to measure self-efficacy creates ambiguity about what is being measured and the benefits of interventions.
- studies should use both quantative and qualitative methods for measuring changes in self-efficacy, and should recognise the lack of predictability associated with a carers journey.
- High levels of self-efficacy is linked to positive outcomes, including resilience, good health and improved performance.

## Introduction

Caring for a loved one with dementia is not a chosen role, or a role that everyone will feel skilled or qualified to undertake, but it is becoming a more common demand on families as the population ages. Currently there are over 55 million people living with dementia in the world (920,000 in the UK) with 10 million new cases reported each year.

The impact of caring for someone living with dementia as a family member or informal carer is significant. Carer groups are asking for more research into the affect this role has on the carer, and the economic and social impact on wider society.

Formal research relies on standard and well established tools for measuring the impact on carers, including measures of mental and physical health and feelings of self efficacy. This project was set up to investigate feelings of self-efficacy in carers, in order to better understand the impact of situational demands and the challenges it brings to measuring changes in self-efficacy.

The research was focused specifically on carers of people living with dementia to ensure it reflects the specific situational and emotional demands of this carer role. A carer is defined as a family member, including spouse, daughter, son or friend who takes on the role of providing physical and emotional support to someone living with dementia.

The report follows the following format:

**Section 1** provides background information about the project.

**Section 2** provides an insight into the main themes identified in the academic research.

**Section 3** describes the approach and the mapping workshop

**Section 4** describes the conditions of self-efficacy and success

**Section 5** describes the characteristics of self-efficacy - outcomes

**Section 6** describes the domains of function - outcomes

**Section 7** describes the conditions of success - outcomes

**Section 8** outlines the recommendations and next steps

## Section 1: About the Self Efficacy Project

tide (together in dementia everyday) was set up as a charity in 2019, but was formed in 2015 by our founder members, who established a Carers Call to Action (CC2A) at the Dementia Action Alliance, hosted by the Alzheimers Society. However, the CC2A only covered England in 2015, which prompted tide to establish a UK wide charity recognising the value that carers of people living with dementia provide across the 4 nations, in terms of their lived experience and emotional resilience.

tide provides a platform for carers to connect, develop and influence and part of this development relates to building self-efficacy.

The project on self-efficacy arose as the result of an evaluation review completed by the University of West of Scotland aimed at measuring changes in levels of self-efficacy within tide carer members.

However, the evaluation used the General Self Efficacy Scale, which did not account for situational demands, or context. This resulted in an evaluation report that was ambiguous and lacked the necessary insight.

This project aims to identify an adapted method for measuring changes in self-efficacy in carers, that allows for an element of context.

### About the Team

tide joined up with West Lothian College and Carers of West Lothian to create a project team with a range of skills, including research, project management, social care support & management with a good understanding of the benefits of self-efficacy.



Funding was provided by Life Changes Trust as part of the evaluation report implementation, with resources from tide, West Lothian College and Carers of West Lothian.

The project was completed in July 2022, but implementation will be phased over a longer period, as part of wider plan to raise awareness of carers of people living with dementia.

Skills in the project team ranged from a background in social and health care and educational research to more direct involvement in working with people living with dementia. The mix of skills allowed us to think about

the outcomes and practical benefits of the project and to challenge current ways of working.

## Section 2: About the Research

The research was completed over December 2021 to May 2022 by the Research Leads from both West Lothian College and tide and focused on the published research on self-efficacy in carers of people living with dementia.

The benefit of conducting separate and independent research by West Lothian College and tide is that it helped to validate common themes and also identified unique aspects of self-efficacy, that provided a different perspective.

Research into wider use of self-efficacy in other industries was not included but was noted for investigation as a possible other use.

Research across 17 papers on self-efficacy in carers of people living with dementia identified the following critical factors in measuring feelings of self-efficacy:

- individual characteristics of the carer and relationship with loved one
- willingness to seek help from others and pay attention to own needs
- belief in ability to provide complex care that is unpredictable
- setting manageable goals for each caring responsibility
- attitude to caring responsibilities and feelings of choice
- willingness to adopt coping mechanisms or seek specialist information that helps to plan for future
- carer responsibilities can erode quality of life for carer, and wider family relationships, impacting mental and physical wellbeing
- self efficacy or personal resilience changes over time and depends on personal, environmental and social factors
- ability to accept the situational demands with feelings of resolve
- better socioeconomic status can provide better access to support
- levels of agreeableness resulted in improved resilience

## Section 3: About the Workshop

A semi-structured workshop was arranged in April 2022 to pilot a methodology for assessing key attributes to self-efficacy. The workshop was held online, to enable access to participants who felt uncomfortable in a face to face environment, and were supporting vulnerable adults.

**“The construction of sound efficacy scales relies on a good conceptual analysis of the relevant domain of functioning.”**

*Albert Bandura*

In order to create an effective method for measuring self-efficacy, Bandura is clear that we have to understand the context or domain of function. For example, a carer may feel successful in a management career where they hold multiple responsibilities but feel that they struggle to be heard by medical professionals when talking about their family needs.

As individuals, we operate across several domains and our self-efficacy can differ in each. It is therefore important that any methodology for measuring changes in self-efficacy reflects the multiple domains that a carer for someone living with dementia functions in.

With the **“My World Session”**, we will explore context and how that helps us understand the multiple domains that carers operate in, the intersections and the emotional and physiological feelings it evokes.

### **The Participants – Involving Carers with Lived Experience**

It is important that this research is based on the lived experience of carers of people with dementia and participants in the workshop will be recruited from the tide network of carers. The workshop was kept to a small group<sup>1</sup>, in order to test the methodology as a Pilot. Consent was completed for all participants and the workshop was recorded.

### **The Workshop Introduction**

In this workshop, the researcher explained the purpose of the workshop, the specific task and how the information will be collected and used. The researcher worked through a facilitated example of the mapping exercise, so participants could better understand the purpose.

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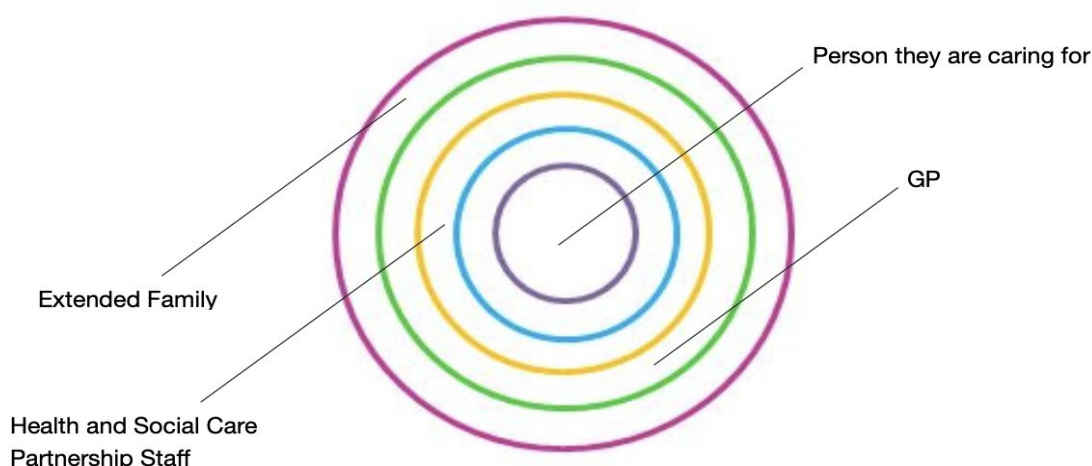
<sup>1</sup> Two carers of people with dementia attended the workshop. See section on Limitations.

Participants were given a leaflet ahead of the workshop with some information.

## The Workshop – Mapping Exercise

In this part of the session, participants completed a map made up of concentric circles that shows their world (their domains of functioning) - from closest to furthest away. This might include individuals, friends, family, work or institutions, organisations, like tide or Carers of West Lothian, or any grouping that makes sense to them.

Participants were then encouraged to complete the mapping exercise a second time, considering their role as a carer, and to consider what changed. Participants were asked to reflect on the process.



Participants were given time to reflect on each aspect of the map, with little direction or input from the researcher.

## The Discussion

Participants were encouraged to share their thoughts on the process of creating the maps, talking about the relationships between the people and organisations in their domain of function.

Participants were asked to share what changed when they considered their role as a carer, if anything, and if they identified anything new or surprising during the exercise.



Open-ended facilitation methods, created space for participants to talk about any feelings they have about the process, and to be prompted by other participants, sharing similar experiences.

### The Workshop Outcome:

Participants used the Mapping Exercise to reflect on their domains of function, identifying the factors that impact their daily lives, and create a personal “context”, ahead of the next session.

### The Research Outcome:

The Mapping Exercise was shown to be a creative way to introduce quite a complex subject, and enabled carers to share insights on their domains of function, which research has shown is key to assessing changes in self efficacy.

In addition, running a Pilot of the Mapping Exercise in a small group, allowed the researcher to gain additional insight on the tools and methodology, to identify anything that can be amended for future or larger workshop groups.

## Section 4: Conditions for Self-Efficacy & Success

“There is no all-purpose measure of perceived self-efficacy.”

*Albert Bandura*

In order for self-efficacy to be present and realised, there are conditions which must exist. These may interlink and the presence or absence of one can impact on the presence or absence of others.

**Well-Functioning Skills:** When people are able to determine what tasks need carried out; thinking about and creating differing courses of action; conceptualising what milestones they might meet along the way



as well as the self-creation of incentives to combat stress. Informally, we talk about this activity as **“Making a Plan”**.

**Process Of Co-Development:** When people feel able to achieve anything, anywhere, even when they may not feel not as capable as others. An example of this would be the “sense of ability” that can be installed in the student body at private schools - students perceive themselves as capable across multiple and differing subjects, without evidence to support this self-belief. It is instilled as a cultural or social belief of capability that transfers to an individual who is part of a collective Group. Informally, we talk about this as the **“I’ve Got This”** factor.

**Moments of Powerful Mastery:** When people realise that they have performed brilliantly. This moment can act as a testimony to their capacity and capability to effect personal changes and provide a sense of validation or ‘proof’ of a persons capability. These moments can transform and restructure people’s self efficacy beliefs, and can create leaders of social or environmental change. There is evidence of this characteristic in tide (together in dementia everyday), where carers have gone from managing challenges on a local level, to talking at the UK and Scottish Parliament on the need for social change in relation to carers of people with dementia. We talk about these as **“Hole in One”** moments.

## **The Workshop – Conditions for Self-Efficacy & Success**

The researcher continued the semi-structured workshop to identify the conditions for success for carers of people living with dementia.

In this part of the workshop, the researcher built on the Mapping Exercise and asked carers to share specific and recognisable moments in time where they have experienced a feeling of success or celebration for a personal achievement. The researcher encouraged participants to think about the conditions of that event – or to identify what helped them to achieve the success.

The event did not need to relate to their role as a carer, as the aim was to get participants to think about the conditions of the event, whether that

was related to support from family, professional training, or personal goal.

The researcher asked participants to share details of the event, the circumstances leading up to it, who or what helped, whether they “**Made a Plan**” and the moment they realised ‘**I’ve Got This**’ and that feeling on ‘**Hole in One**’ and powerful mastery.

The researcher adopted an open-ended approach to capture situational data that provided insight on the conditions for success, with the added benefit of context. The key data points in the discussion, including specific references to the conditions of the success, and the domains of function which provide critical situational demands and context.

The researcher looked for evidence of the attributes identified in academic research (Page 5). The description of the events, circumstances and outcomes, including the emotional and physiological impact of the events were noted and analysed for themes or characteristics.

In addition, participants were asked to provide feedback on the exercise itself, what worked well, what could have been better and on what aspects of the workshop could be adjusted for larger groups.

**“It was a very interesting session, I had expectations....but it surprisingly took me down another path. The outcomes were surprising, and very thought provoking.”**

*Workshop Participant*

The Workshop Outcome:

The researcher established a rapport in the workshop, and created a feeling of trust and openness, during the Mapping Exercise. This enabled participants to share insights on their personal life and lived experience as a carer, which prompted an open discussion on the subject of personal achievement, in face of adversity.

Participants were asked to share thoughts on the approach and whether the discussion gave any additional insight on the conditions of success or created additional or unexpected outcomes of benefits.

Participants noted the relaxed atmosphere of the workshop and

**Section 5: Research Outcomes: Characteristics**

The findings showed that the characteristic of self-efficacy, identified in the desk based research, were evident in participants at the workshop, including:

- willingness to seek help from others and pay attention to own needs
- willingness to set manageable goals for caring responsibility
- willingness to adopt or adapt coping mechanisms or seek specialist information that helps to plan for future
- willingness to accept the situational demands with feelings of resolve

Participants noted that the workshop, including the open discussion on self-efficacy helped to provide insight on their own characteristics, their personal successes and their relationship with the person living with dementia.

Participants noted that a willingness to seek help from others was the reason for joining tide (together in dementia everyday) and the benefits were evident, in their willingness to adopt and adapt coping mechanisms, which including paying attention to their own needs.

The researcher did not capture aspects of socio economic status of participants or assess the relative access to services, but participants shared personal circumstances that highlighted the importance of knowing your rights of access to social and health care services.

Overall, participants felt that the workshop was a positive experience and the semi-structured, facilitated approach worked well.

The workshop provided insight into participants views of the world around them and their ability to deal with challenging circumstances, and willingness to adopt strategies for success.

Sharing stories of personal success with other carers helped to create feelings of Powerful Mastery, reinforcing feelings of self-efficacy.

## **Section 6: Research Outcomes: Domains of Function**

The findings showed that the Domain of Function changed materially depending on the level of direction given by the researcher and the mindset of the participant.

Domain of Function provides situational context and the workshop confirmed that context is critical in assessment of self efficacy or any other aspects of the role as a carer, as it reflected a different lived experience to other roles or areas of their life.

One participant mapped the Domain of Function in relation to their role as a carer, without guidance, as this was their current reality. It included doctors, social care, health practitioners, with limited space for other individuals including wider family members or friends.

**“I don’t choose to surround myself with social services and health practitioners, but that is the reality of a carers role!”**

*Carer*

Another participant mapped the Domain of Function in relation to family and friends, but noted the change in mood and feeling, when asked to reflect their role as a carer, noting a downward shift in energy and positivity, when considering their role as a carer.

Participants noted the impact of Domains of Function and confirmed the research findings that carer responsibilities can erode quality of life for carer, and wider family relationships, impacting mental and physical wellbeing. Changing the Domain of Function completely changed the mental and physiological characteristics of the participant.

Participants also noted that feelings of self efficacy change over time and depend on personal, environmental and social factors. Identifying and mapping the Domain of Function enabled participants to capture the situational demands, which have an impact on feelings of self-efficacy.

Participants noted the limited scope for choice or ability to control or change the situation but noted that this was not a reflection of their feelings towards the person being cared for but a reflection of the situation itself.

## **Section 7: Research Outcomes: Conditions for Success**

The findings showed that the Conditions for Success were not as expected and largely driven by necessity.

Conditions of Success were not always accompanied by positive feelings in the participant, even though the outcome was positive.

Powerful Mastery was driven by negative situations that compelled carers to take action to resolve, with no positive examples of self efficacy.

One participant shared an experience of staging a 'sit in' at the local doctors surgery, in order to receive end of life care for her dying mother.

It showed all the signs of self efficacy, from 'Making a Plan', to 'I've Got This' with a remarkable level of focus on the end goal. However, it was driven by a poor experience with the health provider and a necessity to take action.

This experience showed an ability to adopt and adapt approaches to the circumstances and consider the level of action required to get the necessary response and outcome. However, it did not result in positive feelings of self-efficacy, as it was driven by a desperate need to take action and receive the level of support required but denied.

**"I joined the tide network to help ensure that other carers of people with dementia do not have the same experiences that I have had."**

*Carer*

Another carer shared an experience of creating a 'risk assessment' for the local authority to adopt during locked down. This was the result of frustration on the lack of action and willingness by local authorities to make a decision, despite the impact that social isolation was having on people in the community. A failure to take considered action, was having as much of an impact as taking action, and it was clear that social services waiting on someone else to make the decision, with no plan of action.

Again, the success of this action was driven by necessity, and even though it generated some benefit, the participant did not feel a sense of achievement or success at the outcome.

## Section 8: Findings & Recommendations

- This review and workshop has confirmed the importance of capturing situational data when assessing changes in feelings of self-efficacy in carers of people living with dementia, and highlights the challenges of adopting a general self-efficacy tool for measuring change.
- This review has highlighted the fact that not all feelings of self efficacy are driven from positive experiences and many conditions of success, in particular, when considering carers of people living with dementia are driven by desperation and necessity.
- This review has created a workshop methodology that would benefit carers of people living with dementia and provide greater insight into complex areas, using simple tools and techniques.

The following key recommendations have been identified as part of the pilot workshop on Self Efficacy:

1. tide (together in dementia everyday) will adopt the workshop methodology, including the Introduction, Mapping of My World (Domains of Function); Conditions of Success and Open Discussion into a new online workshop for carers of people living with dementia, and offer it to a wider network, including tide members, and [Carers of West Lothian](#) or carers within [West Lothian College](#), as part of the current tide [Carer Development Programme](#). See notes on workshop size.
2. An additional, potentially face to face workshop could be developed as an opportunity to further develop the tools aimed at gaining insight into the characteristics and conditions of success.

Additional recommendations were identified as part of the pilot workshop on Self Efficacy:

3. The observations in relation to the importance of capturing the Domain of Function and Conditions of Success in providing insight on the situational demands, when measuring self-efficacy for carers of people living with dementia, should be presented in an event aimed at professional health and social care providers, and researchers, as evidence to support Bandura's findings on the importance of capturing situational demands.
4. The observations in relation to using the GSES of self-efficacy to measure changes in carers of people living with dementia should be shared with grant and trust funders, in order to demonstrate the challenges in using only quantitative data to measure outcomes, in a webinar, or on a one to one basis – helping to provide insight to grant funders.

The additional benefit of this approach to studying self-efficacy, is that it can be used for any group, including young carers, or students to gain greater insight into the situational demands and conditions of success, which could help individuals achieve their personal goals.

## **Section 9: Limitations & Observations**

Data in this evaluation was gathered during a 4 hour workshop, which was recorded for insight and analysis but transcripts were not documented.

The number of participants was limited to 2 carers, due to availability during a period of significant carer demands. However, the small group provided opportunity to cover discussion on domains of functions and conditions of success in detail. This provided valuable insight and helped to create a 'safe space' with time to explore complex topics in



detail, encouraging people to take time to explore the conditions of success, with support from the Group.

Small groups, with 2-4 participants is a recommendation for future workshops, as it enables a bond to be created across the group, prompting thoughts on how feelings of self efficacy have changed, dependant on personal, environmental and social factors.

This type of focused workshop would work well as part of the Carer Development Programme and would build on other topics covered in the Programme, including:

- Speaking with Impact
- Setting Up a Local Carer Group

## **Acknowledgements**

We thank Life Changes Trust for the opportunity to explore the topic of Self-efficacy, following the output of the evaluation report by University of West of Scotland.

We thank West Lothian College for their support, technical skills and insight, and recognising the value of the topic and sponsoring the project.

We thank Carers of West Lothian for their support, on a practical and emotional level, providing insight on the challenges facing carers of people living with dementia.

We thank our tide carer members for volunteering to attend and participating in such an open and constructive manner, with their usual good humour and sensitivity.

The following research papers were used as part of the desk based research:

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