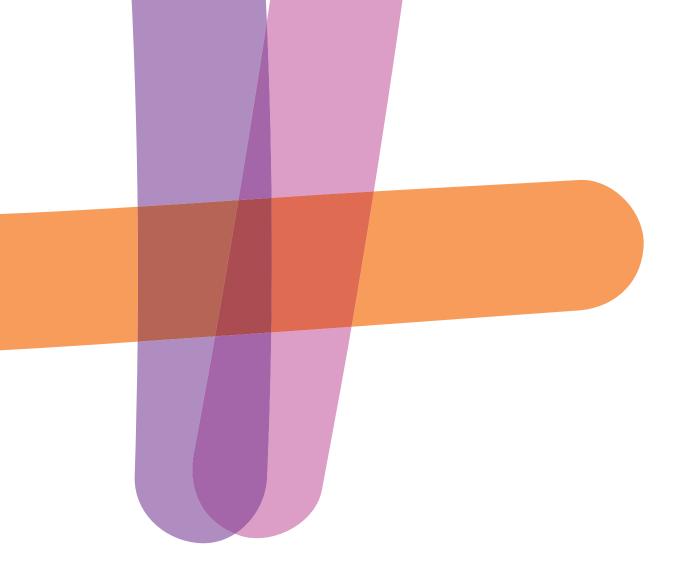


Arts on Prescription at Home Goal Setting Artist Guide

Setting goals and evaluating meaningful outcomes for people living with dementia who are participating in arts on prescription at home (AoP@Home) programs



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Background

People who join an arts program do so for a variety of reasons: sometimes it is to fulfill a lifelong dream, sometimes it is revisiting an old passion or hobby, and some people just want to try something new.

Participatory arts programs for people with dementia involve a professional artist guiding the participant through active art-making over a series of sessions. The participatory nature of the program puts the focus on engagement in the process of art-making, as opposed to specific psychological outcomes as per 'art therapy'.² The program can take many forms, for example, group-based,

at-home, and dyadic programs where family carers are also active participants. This guide pertains to goal-setting in a one-toone context within an arts on prescription at home (AoP@Home) program. AoP@ Home programs are run using a structured, evidence-based approach whereby professional arts delivering the programs have completed specific training around delivering participatory arts programs with people living with dementia.³⁻⁵ The professional artist's role in facilitating the participatory arts program is integral to the positive outcomes achieved.⁶ Research supports the use of AoP programs to improve wellbeing and mental health in older people⁷, and generate positive outcomes for people with dementia and their family carers through sense of achievement, social interactions, and opportunities to be absorbed in the process of art-making.4

Given the evidence supporting positive outcomes, AoP programs should be considered as a reablement intervention. Reablement in dementia is about supporting functional ability to maintain wellbeing. A person's functional ability is made up of their intrinsic capacity (the combination of a person's physical and cognitive abilities) and their environmental modifiers (the environments in which that person lives i.e. home, community, society, and the factors within these environments that might impact on the person e.g. support people, physical environments, social policies and systems).⁸ The International Classification of Functioning, Disability and Health (ICF) provides a broad biopsychosocial framework to describe health and functioning within the context of a disability, such as that resulting from dementia.⁹ Figure 1 illustrates how the range of interconnected individual factors for an individual with dementia can be mapped out using the ICF, including consideration of engagement in arts programs.

Whatever an individual's reason for engaging in an AoP@Home program, it is useful for artists to be able to identify and document why each participant decides to join an arts program so we can tailor their sessions accordingly and support them to achieve their goals.

Goal Attainment Scaling is a person-centred approach to evaluation that aligns with the ICF and provides a measure of functional outcomes.^{9, 10} Goal Attainment Scaling-Light¹¹ is relatively rapid to use in clinical practice and facilitates individualised goal setting to capture personal client preferences and needs. In order to apply Goal Attainment Scaling-Light, it is necessary to first identify goals in partnership with the client, and second, define identified goals using a SMART framework.

A guide to setting goals and evaluating meaningful outcomes for people living with dementia who are participating in an AoP@Home program

This guide presents a practical, dementia-specific model of using Goal Attainment Scaling to measure meaningful outcomes for participants from AoP@Home programs.

The model involves using a novel, combined, stepped approach to assessment, through:

01	Choosing goals with clients using a newly developed Arts Goal List;
02	Defining and transforming these goals using a new dementia-specific adaptation of the SMART (specific, measurable, achievable, relevant and time-bound) Framework; and
03	Scoring using the Goal Attainment Scaling-Light adaptation of Goal Attainment Scaling to record and evaluate program outcomes.





Figure 1: Factors to be considered in establishing realistic goals when designing arts programs using an ICF framework

Arts programs Media:

- Visual arts
- Music and performance
- Creative movement and dance

Format:

- Individual
- Dyadic

Environment

Home, community, broader society

Environmental factors

- Built environment
- Equipment/technology
- Social support eg. family carer
- Funding availability and access
- Service availability and access
- Attitudes to reablement in dementia



Disease e.g. dementia

- Dementia stage
- Dementia symptoms
- Comorbidities, injury, pain

Intrinsic capacity

Mental and physical capacities e.g.:

- Functional cognition, memory
- Physical ability
- Communication ability
- Sensory capacities (e.g. see, hear)
- Mental health

Personal factors

- Age, sex
- Education
- Personality
- Past experiences

Goal setting and evaluation

- Choose goal(s)
- Define 'SMART'ly
- Score using Goal Attainment Scaling-Light

Functional ability Abilities to:

- Meet own basic needs
- Move around
- Learn, grow and make decisions
- Build and maintain relationships
- Contribute

This figure provides an overview of the determinant factors that make up functional ability (ICF activity & participation): an individual's intrinsic capacity (ICF body functions & structure) and their environment (ICF contextual). Artists should consider each potentially contributory factor to a person's functional ability, including any disease (ICF health condition) or personal factors (ICF contextual) and these should be addressed when setting goals and planning the AoP@Home program.

WHO^{8,9}

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Process of assessing meaningful outcomes

for people with dementia engaged in an AoP@Home program

01	Choose – From the AoP@Home Goal List Identify personally meaningful and desired goal(s) in partnership with the client
02	Define – SMART Goals using the Framework Define and transform identified goal(s) to be Specific, Measureable, Achievable, Relevant, and Time-bound (SMART)
03	 Score - using Goal Attainment Scaling-Light a) Prior to beginning the AoP@Home program, rate the client's current level of functioning towards their SMART goal b) At the end of the program (or another pre-specified time), rate the client's level of attainment towards that goal

People with dementia and goal setting

It is important that each client with dementia is supported to make decisions around the goals they hope to achieve when participating in an AoP program, through a process of supported decision making.⁷ Support for decision-making involves practical steps that can be applied to help the person make an informed decision about what goals they might prioritise as personally important. Sinclair et al.¹² suggest some specific supported decision-making strategies:

- Allowing extra time
- Providing information about the program and what goals might be possible
- Using short sentences, addressing one idea at a time, and pausing between sentences to give the person plenty of time to process the information

- Repeating and reinforcing information; waiting for acknowledgement to ensure person has understood
- Communicating transparently using multiple sensory modalities (auditory, visual)
- Relating new information to familiar concepts that the person already understands; translating jargon and simplifying abstract concepts
- Presenting options one at a time, and breaking decisions down into stages
- Demonstrating curiosity and interest in understanding the person's wishes through body language
- Taking breaks as needed



Development of this guide

Development of the AoP@Home Goal List

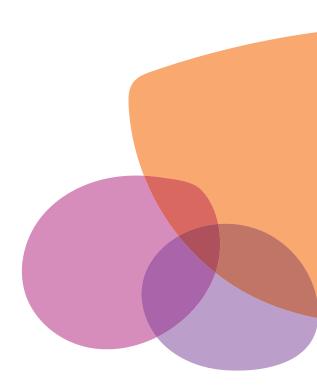
People living with dementia may need support in identifying personalised goals in a therapeutic context. The AoP@Home Goal List was originally compiled from previous AoP program outcomes via an established Arts on Prescription service. This goal list was then piloted in a hybrid effectivenessimplementation pilot of AoP@Home to generate the list included in this guide. During this pilot study, both people with dementia and family carers identified goals for their AoP@ Home programs.³ This list is not intended to be exhaustive, but intended to auide agal setting with people living with dementia (and family carers) who are participating in an AoP@Home program.

Dementia-specific adaptation of the SMART Framework

Once client goals have been identified, they need to be transformed into SMART goals in order to apply Goal Attainment Scaling-Light evaluation. SMART goals are Specific, Measurable, Attainable, Relevant, and Timebound.¹³ The framework presented here (Table 2) provides a novel dementia-specific structured framework to assist artists in rapidly setting SMART goals and identifying varying potential attainment levels for clients engaged in an AoP@Home program.

Applying Goal Attainment Scaling-Light to AoP@Home programs for people living with dementia

Goal Attainment Scaling-Light involves clearly defining the expected outcome (achievement level 0) prior to beginning the program (baseline). At the end of the program, it is determined whether this goal was achieved as expected (0), a little more than expected (1), a lot more than expected (2), or if it was not achieved, whether it was partially achieved or no change (-1) or if it got worse (-2).^{11, 14} Goal Attainment Scaling-Light was originally designed for use in brain injury rehabilitation; we have adapted this method to fit within the delivery of AoP@Home programs to support wellbeing in people living with dementia (Table 3).



Putting it into practice

01 Choose – from the AoP@Home Goal List

Identifying personally meaningful and desired goal(s) in partnership with your client

The AoP@Home Goal list below was underpinned by the clinical experience of the Arts on Prescription team and directly informed via the goals that were set during a recent implementation pilot of AoP@Home.³

Use the AoP@Home Goal List below to guide a discussion with your client to identify personally meaningful and desired goals. Through this process, the person (and/or their family) should be prompted to consider a range of potential goals that they may identify as personally meaningful/important. Artists should consider applying the tenets of supported decision making to support clients in identifying their goals (see page 8).¹²

Figure 1 presents an ICF-mapped holistic overview of the range of factors to be considered for every client to ensure realistic goals are established. For example, a person's goal might be to regain their ability to dance a ballet routine. This will depend on their personal characteristics or 'intrinsic capacity' (e.g. physical and cognitive health and what is possible to achieve through therapy), as well as what social support they have and the environmental context of their home.⁸

The AoP@Home Goal List is arranged by goal category:

Below are some general categories under which participant goals may fall, and a few examples of how these goals might be expressed. The list of examples is by no means exhaustive, and a participant's goals may fall outside these general categories.

Skills Acquisition

This goal category relates to the specific artform and a participant's desire to engage in it for the first time. It may be that this is the first time they have had the chance to try it, or it may be something that has always been on their 'bucket list'.

Skills development

Some participants are not novices and are looking to develop existing skills or talents further. It may also be that they used to engage in an artform and would like to 'Reconnect with art in a new way'. Other participants may have kept up with their artform and have very specific creative goals about what project they would like to achieve (e.g. create series of artworks of Dahlias & special objects from my family that are around the house) or a 'string to their bow' they would like to add (e.g. would like to try painting).

Health and wellbeing

Participants may have goals that more generally relate to their overall health and wellbeing, particularly for the stage of life they are at.

Socialisation and social support

Another motivation to participate in an arts program may relate to the social engagement and enjoyment participants experience. Spending time with friends, meeting new people, or interacting with the artist can play a significant part in the decision to join a program.

Personal growth and achievement

Some participants may engage in a program out of an individual desire to grow, build confidence or achieve something entirely new.

AoP@Home Goal List

Skills acquisition

The desire to acquire a new skill/try something new e.g.

- I would like to try something new/try something different
- Experiment and learn with some new materials
- Explore creative experiences that I wouldn't normally do at home
- This is something I've always wanted to do but haven't had the chance
- Artist supporting how to set up a creative environment in the home to support creative routines

Skills development

Goals to develop skills e.g.

- Reconnect with art in a new way
- Reconnect with creativity through exploring new artforms and mediums
- See wife engaged and reconnect with art to "recapture her interest/passion in her art"
- I used to paint/play music/dance and would like to pick it up again
- I love painting/singing/drama and am looking to increase my skills
- I would like to move to this next level in my creative pursuit
- I've done something similar and enjoyed it
- To challenge and develop beyond colouring-in
- Carer exploring own creativity: "haven't done anything artistic since I was a child"

Socialisation and social support

- Connect with an artist for conversation and interest; "Better to have it 'in company"
- To be stimulated and socially connected; "see [her] engaged and stimulated"
- Connect and engage
- Goals for my mum To laugh and have fun
- She has been feeling low in her mood and finds it hard to be motivated or feel connected, so hoping to also feel reconnected and excited.
- Connect with family, daughter in new ways
- Carer: sharing and connecting with my husband in his interest and achievements
- Carer: A joint collaborative project with Mum. New ways to connect- sharing time together.

Personal growth and achievement

- Build sense of personal achievement
- It would be good for me/my person to have a project/focus/something to work on
- Feel a sense of pride and achievement and filling up time in a positive way.
- "Do something productive, releasing energy because you achieve something"; "Energy, design and creativity."
- I wonder if it is something I'll be good at
- I want to get in touch with my creativity
- Hoping to also feel reconnected and excited "this sounds very exciting. I haven't been feeling excited about things lately"
- · Ideas to engage Mum creatively at home
- Carer: Cultivate creative experiences for self to bring relaxation and sense of achievement; "Open to see something that interests me"

Health and wellbeing

- I thought it sounded like fun/I think I would enjoy it
- "I love the time doing art to 'zone out' and 'tune out"
- I like to keep active/busy
- Improve movement; want to feel stronger, easier to move
- Keep my brain busy
- See mother engaged in something she enjoys, keep her as active as possible, to provide mental stimulation
- Goals for my mum loosen up, get off the couch
- It might help me to relax
- It's something to do/something to look forward to
- Respite for the carer: to be able to enjoy and relax with time to myself knowing that my husband is doing something he loves; help to relax and give myself some time.

02 Define – SMART goals using the dementia-specific Framework

Transform client identified goal(s) into defined SMART goals that are: Specific, Measurable, Achievable, Relevant, and Time-Bound (SMART).

Once the goal has been identified in partnership with the client, the artist needs to define and transform it into a SMART goal (see Table 1). The SMART Framework outlined in Table 2 provides artists with a range of examples to help in defining the goal explicitly using two broad domains:

- Support needed: artists should first consider the level of support needed in completing the goal activity i.e. how much assistance is needed from another person and is any equipment or change to the environment required;
- 2. Quantifiers: the quantifiers around the client's participation in the goal activity should then be defined. How will attainment of the goal be measured i.e. what percentage of engagement/ participation is expected, or what will the unit of measurement be?

The examples outlined in the Framework provide a set of variables and levels of attainment that may assist in setting comprehensive SMART goals and consistently quantifying varying attainment levels. This is not an exhaustive list and should be used as a 'prompt sheet' to help artists with rapidly considering a range of options that may apply to AoP@Home program goals for their clients with dementia and their family.



Table 1: SMART goal features

Specific	 The goal needs to be defined as explicitly and clearly as possible. What – what goal does the client hope to achieve? e.g. engage in a new activity, experience positive social interactions Who – who will be involved in attaining this goal? e.g. will the person's family member or carer play an important role in working towards this goal? How – how will this goal be attained? e.g. engaging in an AoP@Home program, learning to use new art equipment or strategies to compensate for a limitation secondary to their dementia Where – where will the goal be attained or the program be conducted?
Measurable	How will the outcome be measured? e.g. level of assistance required to complete an activity, length of time able to concentrate on an activity, length of time able to stand to do a painting
Attainable	In the context of the person's intrinsic capacity and their environment (refer to Figure 1), is the identified goal attainable?
Relevant	Step 1 of this process is about supporting the client to identify meaningful goals that they wish to achieve
Time-bound	What is a realistic time frame for this goal to be attained? E.g. at the end of the AoP@Home program; within 4 weeks

(Bovend'Eerdt et al. 2009; Bowman et al. 2015, Schut et al. 1994)^{13, 15, 16}

Table 2: Dementia-specific SMART Framework – example domains and scaling for setting SMART AoP@Home goals and defining attainment levels

People	Equipment
Assistance	Mobility/transfers
Completely dependent	Hoist/lifter, wheelchair, slide board,
2-person assist	raised chair, walking frame, walking stick
1-person assist	
Stand-by assistance	
Prompting	
Supervision	
Independent	
Initiation	Art equipment
Activity set up and physical prompting	Specialised instruments
Activity set up and verbal prompting	Specialised art materials
Activity set up and visual prompt (e.g. white board)	Timer
Verbal prompting, sets up own activity	
Visual prompt, sets up own activity	
Manages own prompting system e.g. following instructions	
Initiates independently	
Communication	Cognition/QOL
Single word instructions and physical cueing	Specialised instructions e.g. step-by-step with pictures
Single word instructions and visual cueing	
Single word instructions	
Use of communication technology e.g. ipad	
Reduced item choice when asked questions (e.g. 2 or 3)	
Time needed to process questions and respond	

(Adapted from Bovend'Eerdt et al. 2009)¹²

Examples of support needed

Examples of quantifiers

Environment	Quantifiers	Timeframe
Physical Reduce distraction (visual, noise) Enhance lighting Colour contrast materials with environment	Engagement/ participation Passive Active observation <25% participation 26-50% participation 51-75% participation 76-99% participation 100% participation	Time to evaluate attainment e.g. by the end of the program
Activity Reduce activity materials Reduce activity steps Modify activity	Measurement Activity length (mins) e.g. time taken to complete painting, time spent engaging with family members Activity regularity e.g. times/week engaging in art Time of day Amount e.g. painting a full picture, reciting a full verse	
Social Limit number of people in an interaction Support in maintaining social contacts (scheduling, attending, participating)		

Case example for setting SMART goals

Mrs Smith

Health condition/s, personal factors, external environment	Challenges in intrinsic capacity	Functional ability
 82 years old Moderate dementia (GDS 5) Becoming more frail Lives with husband who is her carer They live in an independent unit within an aged care village Has HCP funding 	 Difficulty with problem solving Able to recognise the goal of an activity, but struggles with initiation and often becomes confused with sequencing of the steps Independently manages glasses to support vision Can read and follow 	 Manages own basic everyday activities Is requiring increasing help from husband to organise shopping (writing lists, gathering groceries and paying) Has been struggling to manage meal preparation (timing, sequencing of steps, physically standing in
 Enjoys spending time with their adult children 	 basic written instructions Gets fatigued after standing for >30 mins 	the kitchen)

Choose:

Client reported goal:

Person with dementia: "I used to enjoy art and would like a project for me to do"

This goal links with the AoP@Home goal list items on skills development and personal growth and achievement.

Define:

Case information will be used to transform the client identified goal into a SMART goal.

Current function towards goal: Mr Smith has been concerned over Mrs Smith's lack of activity engagement throughout the day. While she is unable to manage tasks she previously did, sometimes Mr Smith will set Mrs Smith up with a task such as stirring a pot or peeling carrots (such that she is providing <25% of the effort towards the meal).

SMART goal (specific, measurable, achievable, relevant, and time-bound): By the end of the 8-week AoP@Home program, Mrs Smith will be able to engage in a chosen art activity

once per week (providing 51-75% of the effort) with assistance (set up and prompting) from Mr Smith.

AoP@Home activities:

Mrs Smith will develop skills in following purpose-made, step-by-step, instructions for her favoured art activity. Mr Smith will develop skills in setting up the activity (i.e. setting the art materials out onto the table, ensuring the table is uncluttered to help Mrs Smith attend to the task) and verbal prompting to engage Mrs Smith in the activity, and assist in progressing to the next steps when needed. Mr and Mrs Smith will learn alternative strategies to support Mrs Smith's engagement while managing her fatigue, for example, sitting at a table when engaging in the activity.

Score:

This case example is continued after the next section on scoring using Goal Attainment Scaling-Light.

03 Score – using Goal Attainment Scaling-Light

- a) Prior to beginning the AoP@ Home program, rate the client's current level of functioning towards their SMART goal.
- b) At the end of the program (or at another pre-specified time), rate the client's level of attainment towards that goal.

Once the goal has been identified (step 1) and the parameters defined 'SMART'ly (step 2), the Goal Attainment Scaling-Light scoring system may be applied to determine the client's level of attainment at the end of their AoP@Home program. Table 3 presents a practical tool for using the Goal Attainment Scaling-Light approach.^{11, 14} This tool allows artists to score Goal Attainment Scaling-Light using a verbal description of functioning with no need to apply the numerical scoring system.

However, the scoring system has been linked with the verbal scoring system to facilitate broader AoP@Home program monitoring.

The process of applying Goal Attainment Scaling-Light is as follows:

- 1. The client's expected outcome towards the goal should be recorded (the SMART goal that has been developed in steps 1 and 2 of this guide).
- 2. Prior to beginning the program ('baseline') the client's level of functioning towards their identified goal should be rated as either having some function (-1) or no current function (-2; there is no possibility for the client to become worse in function towards this goal).
- 3. At the end of the program ('after AoP@ Home program' – or at another prespecified time), the client's goal will be revisited and their level of function towards that goal rated again. At this point, it will be determined whether the goal was achieved as expected (0), a little more than expected (1), a lot more than expected (2), or if it was not achieved, whether it was partially achieved or no change (-1) or if it got worse (-2).^{11,14}

For a more detailed guide on using Goal Attainment Scaling and calculating Goal Attainment Scaling scores in a rehabilitation setting, see Turner-Stokes (2017).¹⁴ This guide by Turner-Stokes also includes a scoring algorithm to account for instances where a client has set more than one goal.

Table 3: Goal Attainment Scaling-Light scoring system for people withdementia engaged in an AoP@Home program

Beginning of AoP@Home program – date:			Scoring
Regarding the AoP@Home goal, do they have:		No current functionSome function	-2 -1
After AoP@Ho	me program – dat	te:	
Was the goal achieved?	Yes	 A lot more A little more As expected 	+2 +1 0
	No	 Partially achieved No change Got worse 	-1 -1/-2 -2

Adapted from Turner-Stokes (2009, 2017) and O'Connor & Poulos (2021)^{1, 11, 14}

Case example continued: Scoring Goal Attainment Scaling-Light for Mrs Smith

Mrs Smith's SMART goal: By the end of the 8-week AoP@Home program, Mrs Smith will be able to engage in a chosen art activity once per week (providing 51-75% of the effort) with assistance (set up and prompting) from Mr Smith.

Goal Attainment Scaling-Light scoring for Mrs Smith

Baseline

Goal level	Score	Reasoning
Some function	-1	When Mrs Smith has been set up with a task such as painting or drawing, she is able to engage in that task and provide <25% of the effort towards that task.

Post AoP@Home Program

Goal level	Score	Reasoning
Goal achieved as expected	0	By the end of the AoP@Home program, Mrs Smith was able to engage in weekly art sessions providing up to 75% of the effort towards the tasks with set-up and support from the artist and/or Mr Smith.

Glossary

Activities of Daily Living (ADLs): ADLs, or everyday living activities, are the varying tasks that we all complete on a daily basis. They range from basic activities (e.g. bathing or toileting) to more complex tasks (e.g. cooking a meal or doing the shopping). Limitations in being able to carry out these activities can impact on a person's independence and quality of life.

AoP@Home: Participatory arts programs whereby a professional artist engages a person with dementia (and their family) in participatory art-making in their home.^{3,4}

Commonwealth Home Support Programme (CHSP): the CHSP is an entry-level program for older people who need assistance, aimed at providing support to maintain independence in the community and remain living at home.¹⁸

Goal Attainment Scaling: A person-centred tool that is useful both as an outcome measure and in supporting communication and decision-making with the client and between practitioners.²¹ In the context of AoP, Goal Attainment Scaling involves identifying an individual's aims for their AoP program and using a systematic approach to scoring their level of attainment towards this aim at the end of the program.

The original process of Goal Attainment Scaling involves a number of steps, as follows: $^{10,\,22}$

- Identify at least three personally meaningful intervention goals in partnership with the person with dementia, the practitioner, and where appropriate the family/support people (one Goal Attainment Scale for each goal);
- 2. Determine the current level of functioning associated with that goal (baseline);
- Set the follow-up time period for measurement of goal attainment;
- 4. Formally set the goal. Note that the 'expected outcome' is set to '0';
- 5. Identify and record the other possible attainment levels:
 - a. 'much less than expected' = -2,
 - b. 'somewhat less than expected' = -1,
 - c. 'somewhat better than expected' = 1, and
 - d. 'much better than expected' = 2;

At the end of the intervention (or specified time-frame), the attained level of functioning is recorded.

Home Care Packages (HCP): a HCP provides a package of services, often including case management, to support older people to live independently in their own homes. A HCP provides more comprehensive services for people with higher needs than available through the Commonwealth Home Support Program (CHSP). In order to access a HCP, an ACAT/ACAS assessment is required to confirm the level of support required.²³

International Classification of Functioning, Disability and Health (ICF): The International Classification of Functioning, Disability and Health (ICF) provides a broad biopsychosocial framework to describe health and functioning within the context of a disability, such as that resulting from dementia.⁹ Applying the biopsychosocial model in this way has previously been described as a useful tool to guide practice in dementia.¹⁷

Reablement: Reablement is an intervention approach that promotes the regaining or maintenance of functional performance in older people.¹⁹ For people with dementia, reablement is about maintaining function for as longas possible, regaining lost function, or even improving everyday function.²⁰

SMART goals: SMART goals are Specific, Measurable, Attainable, Relevant, and Time-bound.¹³

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