

Aphasia **A S K**
action. success. knowledge

Therapist Manual

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The objectives of this manual

The objective of this manual is to provide a guide for the structure of the Aphasia ASK therapy for patients with aphasia and their families. This manual describes the ways in which Aphasia ASK treatment program should be delivered as part of a clustered randomised control trial. This manual should be referred to in order to enhance treatment fidelity.

Background

The role of the speech pathologist

Speech Pathology Australia (SPA) acknowledges the critical role speech pathologists play in mental health services and that a diverse range of skills and knowledge of psychological models of interventions are needed (Speech Pathology in Mental Health Services Clinical Guideline, 2010). Speech pathologists are in a unique position to facilitate the psychological care of people with aphasia because of their expertise in providing communication support and their comprehensive understanding of the impact of communication disorders across all areas of patients' lives (Simmons Mackie & Damico, 2011). People with aphasia report difficulty accessing existing mental health services, intervention programs or support groups that can meet their needs because of their communication disability. In the Australian context, a 2012 audit of stroke services by the National Stroke Foundation highlighted a gap in mental health services and recommended the development of systems to address psychological and emotional support needs (National Stroke Foundation, 2012).

The Aphasia ASK program attempts to provide speech pathologists with a structured approach in order to meet the psychological care needs of both people with aphasia and their families. ***Is this the role of the speech pathologist?*** Yes, we believe so. For the client, a multifaceted approach to management of aphasia is positive, in that it can provide help that takes into account impairment, disability and well-being. However, the wider scope of the clients' needs may create uncertainties over professional boundaries and roles and lead to a sense of confusion for the practitioner. Counselling skills are crucial for the psychosocial management of patients with aphasia. Counselling services provided by speech pathologists may include patient education, affective support, and facilitating behavioural changes (Phillips & Mendel, 2008). Despite these skills being within their scope of practice,

many speech pathologists report feeling under-skilled counselling patients. We respect that some topics may feel unfamiliar or even daunting for the practitioner. These modules will hopefully allow a gentle, yet focused way to touch on topics that both practitioner and patient may not have previously known how to bring up. The explanation of activities and their rationale in this Therapist Manual acts as a guide to facilitate all parties through the program.

Stepped psychological care

The National Health Service of Great Britain and Northern Ireland proposes the use of stepped care for the management of mental health difficulties and the Department of Health in England provides guidelines for step care psychological intervention after stroke . Step-care models follow a hierarchical approach to psychological management with input from all appropriate multidisciplinary team members. “Low intensity” treatments are provided initially to patients alongside monitoring of psychological symptoms and where necessary patients are upgraded to “high intensity” treatments. Kneebone (under review) has proposed a detailed model of stepped psychological model of care after stroke consisting of 4 stepped levels shown in Figure 1. Level 1 of this model has been proposed to be appropriate for any patient with stroke and is primarily aimed at prevention of a mental health disorder. Example intervention activities from a stroke MDT at level 1 include:

- Providing advice and information for adjustment
- Goal setting
- Attendance at support groups
- Stroke befriending
- Music and art therapy
- Leisure rehabilitation

The Aphasia ASK program includes interventions promoted at level one of stepped psychological care.

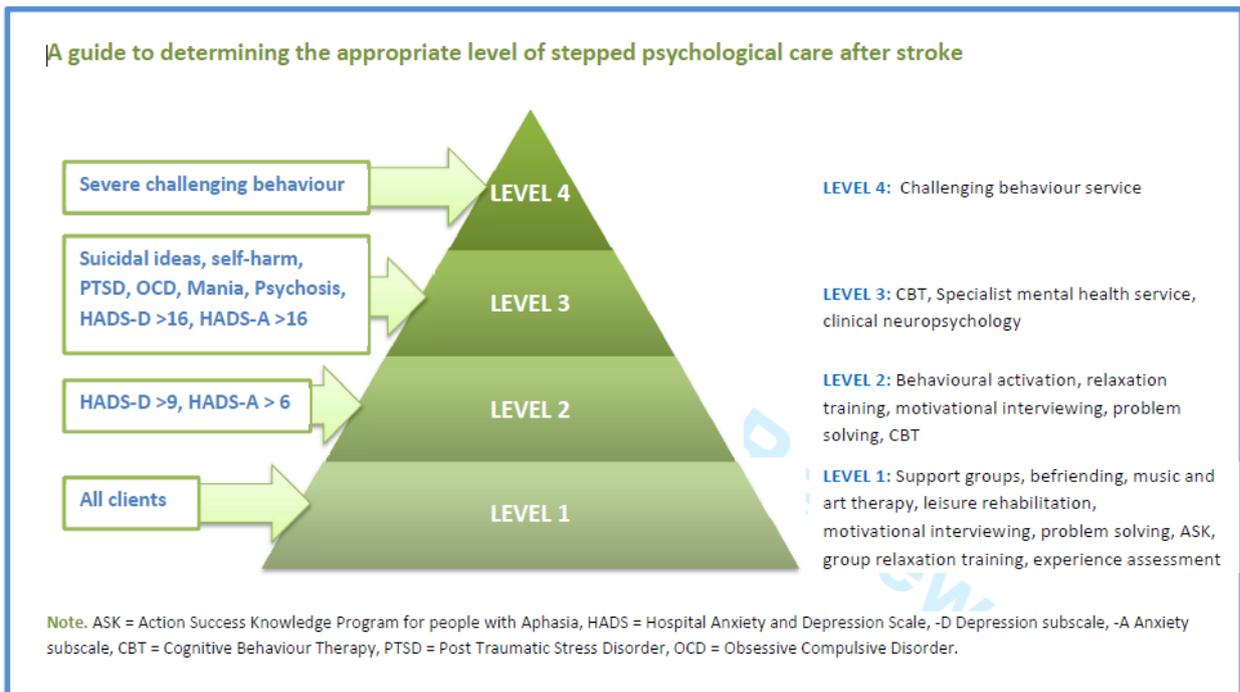


Figure 1. A revised model for stepped psychological care after stroke. Kneebone, I. I. (under submission). Stepped psychological care after stroke. University of Western Sydney.

Living successfully with aphasia

Several qualitative studies have explored the lived experience of people with chronic aphasia. Brown et al., 2010 interviewed 30 people with chronic aphasia about their perspective on what it means to live successfully (Brown et al 2012). Reported themes included doing things, maintaining meaningful relationships, striving for a positive way of life, and communication (Brown, et al., 2010). In two other separate studies the perspectives of family members and speech language pathologists on the meaning of living successfully with aphasia were also identified (Brown, et al., 2011a, 2011b). Seven overarching themes were found in a qualitative meta-analysis that integrated these three groups' perspectives (i.e., people with aphasia, family members and speech language pathologists) about living successfully with aphasia (Brown, et al., 2012). These included: participation, meaningful relationships, support, communication, positivity, independence and autonomy, and living successfully with aphasia as a journey over time (Brown, et al., 2012). Grohn et al (2014) conducted a longitudinal study exploring the views of people with aphasia during the first year post stroke. Findings from this study indicated one overarching

theme: “actively moving forward”. This theme highlighted how living successfully with aphasia was enabled across time by taking positive actions despite the sometimes overwhelming negative consequences of their stroke and aphasia. Data from the study highlighted the importance of participants being satisfied with and receiving ongoing rehabilitation services and suggested that formal support played an important role in contributing to perceptions of improvement and facilitated motivation and confidence across time. The study also highlighted how factors such as doing things, support, and a positive attitude and perseverance, which help to enable living successfully in people who have been living with aphasia for some time (Brown, et al., 2010), are also relevant for those earlier on in their journey. Hence, the content of the Aphasia ASK modules stems from this qualitative research of people with aphasia and their families say they needed to live successfully with aphasia.

The Aphasia ASK program

The principles of the Aphasia ASK program:

1. The person with aphasia and their family and friends are the primary targets of the intervention.
2. The delivery method has been informed by principles of behaviour change.
3. Collaborative learning is used throughout so that the speech pathologist is an equal partner in the process. Aphasia ASK is not a didactic or one way method of imparting knowledge. The expertise of participants is acknowledged.
4. All written information has been adapted using aphasia friendly formatting principles.
5. The delivery of the intervention should follow supported conversation principles for people with aphasia.

Who completes the program?

The modules are created to be completed with the patient and their family or friends that are attending the sessions.

Time to complete the program

The intervention package is designed to be completed over a six to eight week period, completing approximately one module per week. Individual needs in terms of intervention length, however, may vary.

When to commence the first session

The intervention is designed to commence as early as possible after the stroke to fulfil the need of greater education and support in the rehabilitation stage. Factors such as the patient's medical stability, level of fatigue and willingness will impact upon the timing of the program. It is hoped the program will commence alongside the usual care speech pathology services the participant is receiving.

Aphasia ASK materials

Eight participant workbooks have been developed for the face to face Aphasia ASK sessions. The workbooks contain structured learning content, discussion items, practical exercises, and additional independent activities. **It is important to note the modules do not have to be administered in the order of format presented in this manual.**

The Aphasia ASK workbooks consist of an introductory **"Before You Begin"** booklet. The "Before we begin" booklet is provided to the patient prior to the commencement of the program. The before you begin booklet provides participants with information about the aphasia ASK program and a "your needs" quiz that needs to be completed for the first session.

Figure 12. Participant workbooks included in the Aphasia ASK program.



Once providing participants with the before you begin booklet, the first session **“Your Goals”** establishes the goals for the program using collaborative goal setting techniques. A decision making tool is included in the goal setting session to identify which of the content modules each participant would like to complete. ***Hence, not all content modules are required to be completed and their completion is left to the discretion of the therapists and participants. Completion of each of the introductory, goal setting, and a summary final session, however, are required.*** The content module titles that can be prioritised in the Aphasia ASK program are:

- **“Living the learning”**
- **“Not just words”**
- **“Finding the positive”**
- **“Stay connected”**
- **“Your story”**

Prioritising the modules form the basis of the goals that will be covered in future weeks. During this process, the patient and/or their family and friends may bring up other topics or areas they wish to know more about. In such instances, the therapist will need to provide

attention to these areas where relevant. Whilst the modules cover a wide range of topics, they may not cover every individualised need. The content modules are designed as a guide and should be incorporated with clinical skill and knowledge to ensure the program is person-centred and modified as needed for each person with aphasia. Upon completion of the content modules that have been prioritised the **“Summing Up”** module is used to review the progress of the participants’ goals. A diagram of the program and how they should be administered as well as overview of each of their aims is provided in figure 2 and table 1, respectively.

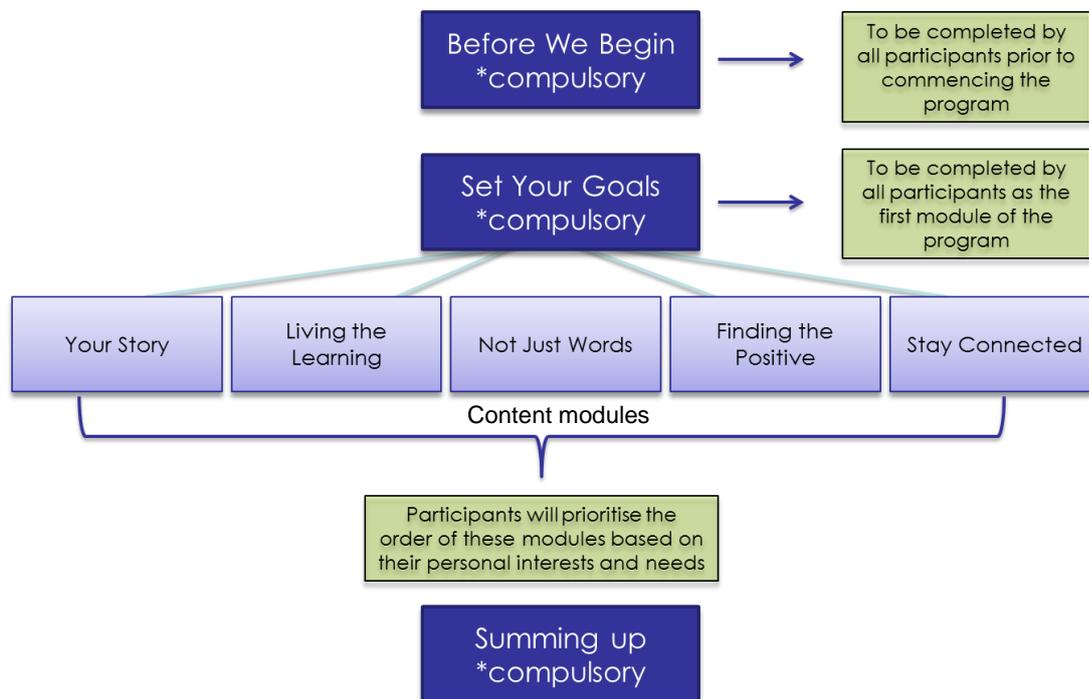


Figure 2. Diagram of the Aphasia ASK program

**Note: The number of modules that the participant completes is left to the discretion of the therapist and the participants. However, participants must be involved in 3 content modules and there must be a minimum total contact time of 3 hours face to face with a therapist for the intervention to be considered completed.*

Table 1: Overview of Aphasia ASK modules.

Workbook name	Overarching Aim of Module	Subsequent Aims of Module	Activities/Resources	What you need to prepare for this module
<p>Before we begin *must be provided to participants before the commencement of the modules</p> 	<p>To introduce the background of the research, the intervention program and its aims.</p>	<ul style="list-style-type: none"> - To introduce clinicians and participants to each other - Reinforce participant timetable/bookings to complete the sessions 	<ul style="list-style-type: none"> - Your needs quiz 	<p>-Folder for participants to keep the modules in week to week</p> <p>-List of appointment times and locations for participants</p>
<p>Your goals *this is a compulsory module for everyone completing the program</p> 	<p>To ensure the program is a proactive, person centred and goal oriented process</p>	<p>For the person with aphasia and their family to:</p> <ul style="list-style-type: none"> - Develop a collaborative relationship between all participants and the speech pathologist. - Develop clear goals and priorities for the Aphasia ASK Program. 	<ul style="list-style-type: none"> - Your needs quiz (completed in before we begin booklet). - Topics decision aid sheet. - Goal attainment scaling (GAS) framework. <p>Example Homework:</p> <ul style="list-style-type: none"> - Patient/ Family discussion/decision of goals if cannot be finalised in first session 	<p>Ensure the participants have completed the “Your needs” quiz in the before you begin booklet.</p> <p>-Video camera to film session</p>

Module name	Overarching Aim of Module	Subsequent Aims of Module	Activities/Resources	What you need to prepare for this module
<p>Living the learning</p> 	<p>To increase the participants knowledge of aphasia/stroke information and where to access more information if needed.</p>	<p>For the person with aphasia and their family to:</p> <ul style="list-style-type: none"> - Have increased knowledge of aphasia and other relevant rehabilitation topics - Be able to access resources and information when needed 	<ul style="list-style-type: none"> - Information preference choice - Information topic choice <p>Example Homework:</p> <ul style="list-style-type: none"> - Watch DVD - Read sections of the AAA guide - Read and reflect on information sheets provided. - Provide information to friends and family 	<p>Have a copy of the Aphasia and You video and the Australian Aphasia Guide to give to participants.</p> <p>-Video camera to film session</p>
<p>Not just words</p> 	<p>To promote effective communication between the person with aphasia and their friends and family</p>	<p>For the person with aphasia and their family to:</p> <ul style="list-style-type: none"> - Develop or enhance the use of communication strategies. 	<ul style="list-style-type: none"> - Communication support training - Rate your conversation <p>Example Homework:</p> <ul style="list-style-type: none"> - Practice one communication strategy - Family to keep a diary of communication strategies that are successful - Practice having a conversation - Video tape a conversation. - Invite a friend over to learn/use/practice communication strategies. 	<p>Knowledge of the communication support needs of the person with aphasia and their family member(s).</p> <p>-Video camera to film session</p>

Module name	Overarching Aim of Module	Subsequent Aims of Module	Activities/Resources	What you need to prepare for this module
<p>Finding the positive</p> 	<p>To promote a positive point of view throughout rehabilitation</p>	<p>For the person with aphasia and their family to:</p> <ul style="list-style-type: none"> - be able to incorporate simple activities that promote positivity into their daily life. 	<ul style="list-style-type: none"> - Positive and negative coping strategies - A good thing happened <p>Example Homework:</p> <ul style="list-style-type: none"> - Complete a good thing each day and write in diary. - Planned leisure time - Track weeks progress in a diary. 	<p>-Video camera to film session</p>
<p>Stay connected</p> 	<p>To enable the participants to maintain relationships and build new relationships</p>	<p>For the person with aphasia and their family to:</p> <ul style="list-style-type: none"> - Be able to use simple strategies to stay in touch with friends. - Learn how to connect with other people with stroke and aphasia. 	<ul style="list-style-type: none"> - Discuss the importance of friends - Map who is in their support network - Provide ideas for staying in touch with friends - Discuss meeting other people with aphasia. <p>Example Homework:</p> <ul style="list-style-type: none"> - Plan leisure time. - Track activities in a diary. - Invite a friend. - Attend an aphasia group. - Become a member of the AAA. 	<p>Details for the closest AAA coffee groups, Stroke Association support groups and/or hospital aphasia group to provide participant.</p> <p>-Video camera to film session</p>

Module name	Overarching Aim of Module	Subsequent Aims of Module	Activities/Resources	What you need to prepare for this module
<p>Your story</p> 	<p>To develop a shared understanding of the participants and family's experience of stroke and aphasia and family rehabilitation needs</p>	<p>For the person with aphasia and their family member to talk about:</p> <ul style="list-style-type: none"> - Their experience of having a stroke and aphasia. - How stroke has changed things. - Them as a person. - Their rehabilitation needs - Their strengths and how this will facilitate rehabilitation. 	<ul style="list-style-type: none"> - "Your story" questions - "My strengths" checklist <p>Example Homework:</p> <ul style="list-style-type: none"> - Tell story with someone else on ward - Videorecord/write down key information learnt from "my story" - Develop a story resource (PowerPoint) for others. 	<p>Encourage the participant and their family to bring personally relevant information to use as communication tools to help share their story (e.g. family member photographs)</p> <p>-Video camera to film session</p>
<p>Summing up *this is a compulsory module for everyone completing the program</p> 	<p>To review goal attainment progress, review goals for the future and follow up on any gaps.</p>	<p>For the person with aphasia and their family to:</p> <ul style="list-style-type: none"> - Review their goals. - Have time to reflect on the program. - Have any remaining questions answered. - Be provided with resources (if they don't have already). 	<ul style="list-style-type: none"> - Review goals from 'Goal Booklet' - Check resources 	<p>Ensure the 'Goal Booklet' is bought to the session or provide a photocopy of the goals.</p> <p>-Video camera to film session</p>

Components in each module

The ASK intervention modules should promote behaviour change in participants by:

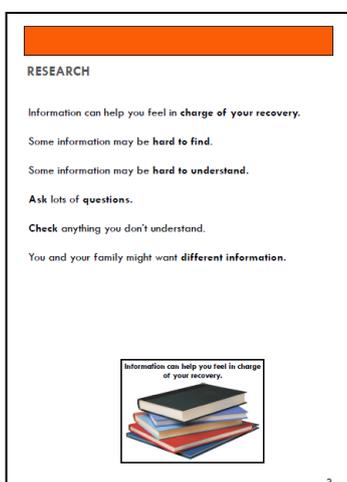
1. Setting objectives for behaviour between sessions (e.g., homework tasks)
2. Considering and/or identifying barriers and enablers to achievement in advance.
3. Revisiting goals and/or homework tasks if not completed.

Each module follows a similar format and includes some of the same elements. Each module should contain:

- Objectives for the session
- Structured learning content
- Action items, discussion items, and/or practical exercises.
- Homework task(s) that are agreed upon by the participant and their family member that follows on from what has been discussed during the session.

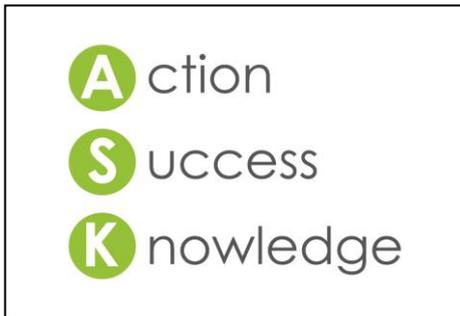


The objectives of the session are provided at the beginning of each module in the format of a ‘This session’ and ‘By the end of the session’ statement. By commencing the session in this way, both the participants and therapist have a shared understanding of the session purpose.



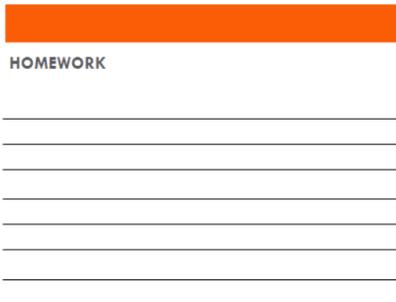
Each module contains research boxes at the start. These boxes provide the scientific background and rationale for the different activities. The amount of time spent focusing on these boxes will be dependent on the needs of the individual and their friends and family. You may want to direct the family and friends to additional information if they wish. These boxes have been deliberately left “Aphasia Friendly” however; some people with aphasia and their

family members may want to be directed to further research information and more in-depth resources such as journal articles.



The “ASK” symbol is used whenever the participants are required to answer a question, or complete an action item. Often this is followed by space to write an answer. It is important to again reiterate that the person with aphasia is not required to write their own answers if they are unable to or feel uncomfortable to do so. All activities can be

adjusted to accommodate the language skills of the person with aphasia and family and friends are also important supports and can write the response if needed. Any space for the completion of activities is designed as a guide only. The person with aphasia and their family and friends should be encouraged to use a variety of modalities (drawing, pictures, music, photos, gesture, words, card sorting) to assist in comprehension of tasks and expression of views.



Independent or ‘homework’ tasks are encouraged to be set for both the person with aphasia and their caregiver to complete together in their own time after each module. This provides an opportunity for active learning. The homework task should be documented for the participant to refer to.



Before commencing each new module please check that all the participants are ready to move on to new material and have completed their homework.

Homework should:

- arise from discussion within the session

- be personally important to the individual and their problems
- be manageable and time-limited
- be clear and specific
- be realistic
- provide more information (be part of the learning process)

Homework guidelines are from Laidlaw, Thompson, Dick-Siskin, Gallagher-Thompson (2003).

An activity described by (Janis & Mann 1977), is to talk about the pros and cons of both completing homework and not completing homework. This will help ensure participants have fully considered a possible change. You may wish to revisit what led the participant to choosing this topic. Consider why they chose the topic and what they were hoping to gain from the module.

Overview of modules

Introductory Booklet - "Before We Begin"

The introductory booklet prepares the patient and their family and friends for the program. It covers aphasia friendly information on; aphasia, what the program will be about, who is invited to participate and a quiz to prepare for the first session. ***You should provide the participants with the 'Before you begin' module after the pre-assessment and consent process but before beginning the program.*** We suggest that prior to giving the patient and their family the introductory booklet, the speech pathologist needs to:

- Be familiar with the booklet and the program in case the participants ask any questions.
- Have arranged a place and time for the first Aphasia ASK sessions and write this down for the participant.

When providing the patient and their family and friends with the 'Before you begin' booklet it may be good to reiterate that The Aphasia ASK Program:

- Is aphasia-focused
- Will be run by a speech pathologist
- Will be different to their normal speech pathology sessions

- Will not include language-tasks or speech practice
- Is about enabling the patient and their family to drive aphasia rehabilitation and ongoing recovery
- Is open to any family or friends that wish to undertake the program with the patient
- Will require that they do some activities independently, outside of the therapy times

Discussion of the treatment rationale with participants is an important component of the treatment that sets the framework for all sessions. It is necessary that all participants have a clear understanding of what the Aphasia ASK intervention is aiming to achieve.

“Your Needs” Quiz

To increase understanding of the participant’s current needs and what they wish to obtain from the Aphasia ASK Program, a pre-program quiz has been developed. This quiz is also designed to prepare the participants for the goal setting session. The participants will need to complete this quiz and bring it with them to the first Aphasia ASK session.

Compulsory Module- “Your Goals”

After welcoming and introducing yourself to all the participants (including family members), the first session should commence by addressing any questions the participants may still have about the program. Take this opportunity to ask the person with aphasia and their family and friends if they have any questions or concerns about the program so far. By flagging these questions early in the session sufficient attention can be given to discussing the answers throughout the module. Every question and concern is important and every participant has valuable knowledge and experience.

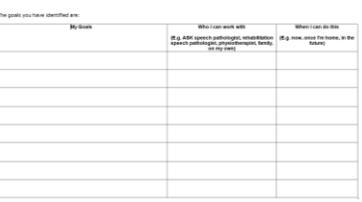
Goal setting is critical to the process of directing rehabilitation efforts towards the achievement of personally relevant goals. This module will focus primarily on establishing goals for the ASK program. This process will use the ‘SMARTER’ goal setting approach; a process that is **Shared, Monitored, Accessible, Relevant, Transparent, Evolving and Relationship-centred** (Hersh et al, 2011). By the end of the session, all parties should be

clear on the participant's goals and these documented in the goal attainment scaling (GAS) format. The resources you will need are explained in table 2.

The 'Your Needs Quiz' has been developed to prepare the participants for this goals setting process. Begin by looking through the completed quiz with the participants. Discuss the areas the participants feel confident in and areas they wish to know more about. Write these down on the first page of the 'Goal Development' handout. Explain that together you will use the information they have given and turn them into goals. The term 'goal' is used throughout this module, however, it is understood that the use of this term may cause confusion for some participants. Please clarify or adapt the use of this term if required.

To help set goals, you may find it helpful to decide what modules the participants are most interested in. Use the decision aid table titled 'Choose your topics' to help the participants select the areas which interest them most. You should identify areas of interest both, for the person with aphasia and for family members. Once they have both chosen areas they both wish to know more about, discuss those that overlap and those that are different. Discuss if each of the different modules are still something they both wish to learn more about it. If so, these modules become the priorities. Discuss the order of them together and come up with a joint decision. ***Family members are targets of the intervention too, so if they wish to know about a topic the person with aphasia does not, this should be respected and addressed in a session specifically for them as family members.***

Table 2 Goal setting resources

Resource name	What it looks like...	Use this to....
The 'Your Needs Quiz'		Prepare the participants for the goal setting process; have an initial understanding of the participants needs.
Choose your topics		Help the participants select the modules that interest them most.
"Goal Development Handout"		<p>Develop goals into the GAS format</p> <p>Keep a record of participants goals during the program</p> <p>Prioritise the order of the modules completed</p> <p>Goals should be documented in a way that is appropriate for the participant with aphasia to understand</p>
My Other Goals		Acknowledge and record goals that may not necessarily be able to be addressed during the program or need to be achieved by seeing a different health professional.

If the participants come up with goals such “Be able to walk on my own”, this is fine but needs to be clarified that they will work towards this with the physiotherapist. You can acknowledge such goals by using the ‘My Other Goals’ handout, and discussion about, who

they want to work on it with and when they want to work on these goals. Encourage the participants to show the 'My Other Goals' handout to their other appropriate rehabilitation clinicians. The "My Other Goals" process is optional and is designed to help distinguish the goals appropriate for the ASK program from other rehabilitation goals the participants may have.

The goals that are appropriate for the ASK program are written down on the 'Goal Development Handout'. ***Goals should be generated for both the person with aphasia and their family/friends. Some goals may be applicable to both the person with aphasia and their family and thus are shared goals; others might simply relate to one party.*** Goals that are chosen may be activities or strategies the participants might be doing already but would perhaps like to increase how regularly they are doing it. Examples goals that were generated from participants during the pilot study included:

- To learn what aphasia is.
- To learn ways to stay positive.
- To develop/use strategies to communicate better/improve interactions with others.
- To find appropriate information about aphasia and support groups (online resources).
- To learn how to participate in aphasia research.
- To find out information about support available once home (including speech therapy).
- To learn about how to stay positive.
- To learn about how to stay connected with friends and colleagues.
- To learn more about aphasia recovery "timelines".
- To learn/use strategies to cope when feeling low.
- To learn/use strategies to manage fatigue/stress (family member goal).
- How to improve my communication/interactions with my young children.
- To be able to explain what aphasia is to my children.
- To access relevant information about returning to work.
- To learn strategies to improve confidence to interact/communicate with friends.
- To develop a realistic view of recovery and what it means for my life and work.

- To identify a support person to help if needed when return home (family member goal).

When developing goals it is important to:

Think about whether this goal forming process has been **Shared**:

- ✓ Have the participants been able to prepare for the session?
- ✓ Have families and significant others been involved?
- ✓ Has the information been presented in way that is understood?
- ✓ Is the information relevant?
- ✓ Is the working relationship a trusting and collaborative one?
- ✓ Have all participants understood the purpose of goal setting?

Think about whether these goals can be **Monitored**:

- ✓ Have the goals been written in a way that allows for continuous evaluation?
- ✓ Have the goals been written in a way that allows for small changes to be measured?
- ✓ Can these goals be used to regularly discuss improvements or lack of improvements?

Think about whether these goals are **Accessible**:

- ✓ Are they written in an aphasia-friendly format?
- ✓ Does extra time or support need to be provided to allow the participants to understand?
- ✓ Do the participants understand that they can add to their goals if they think of new ones

Think about whether the goal setting process has been **Transparent**:

- ✓ Are the participants clear about which goals can be achieved through the Aphasia ASK Program?
- ✓ Has a clear link be established between the goals the participants selected and how these goals can be achieved?
- ✓ Have the participants been able to influence what they will learn about during the Aphasia ASK Program based on their current needs and goals?

Think about whether the participants are aware that this process is **Evolving**:

- ✓ Are the participants aware that they can revisit and revise the goals?
- ✓ Are the participants aware that they can change which modules they would like to do during the Aphasia ASK Program if they like?

Think about whether the goal setting process has been **Relationship-centred**:

- ✓ Have the goals been client-centred?
- ✓ Has rapport and trust been developed between the participants and speech pathologist?

The identified goals are then prioritised as to their level of importance and written in a GAS format. There is space provided for 5 goals. A participant can do more or less depending on what is achievable for them. Encourage the participants to add to their goals as they think of new ones. Examples of goals and how they might be put into the GAS format are provided in figure 2 and figure 3. It is acknowledged that sometimes the goal setting process may be more difficult with some participants than others. Often participants report that they don't know what to expect. In the early stages of recovery, and where clients are unfamiliar with their goal needs, therapists may need to lead the goals that are chosen for the ASK program. However, goals should always be relevant to individual needs and based on the priorities of the participants. People with aphasia and their families may need to hear the importance of setting goals several times and at several stages in recovery before they are able to identify with the goal setting process. Goals can be revisited throughout the duration of the Aphasia ASK program. A reason it may be difficult to complete goal setting is that the participants may feel that it would not be useful to set or write goals down. It is important to reiterate that having goals recorded will be helpful for everyone to make sure you stay on track and once finished identify what you have achieved. It might be helpful to discuss what other people with aphasia and their families have said about goals. Many people are surprised about how valuable the goal setting component was once the program is concluded.

Comments made by family members from the pilot ASK trial about goal setting included:

'I think it was good to have the goals and concentrate on those goals as you went through. I think without them we'd be at a loss, so it was good because we had the conversations with people and up top and – what was next?.. No. I would think it was quick and they – the conversations we had about each of the goals was important and relevant.'

“The goals are excellent...at the beginning it seemed a bit stupid to us, but when you get to the final one and you actually compare where you are now to the goals and things that you set and where you thought you would be, that was very beneficial because you actually understand better the advances that you did make.”



Goals should be documented in a way that is appropriate for the participant with aphasia to understand. Keep a photocopy of the written goals to revisit during the summing up module.

Figure 1 Example Goal breakdown: “Learn ways to stay positive”

Aphasia **ASK**

<p>Fantastic outcome</p> 	<p>I will have used two staying positive strategy by the completion of the ASK intervention.</p>
<p>Better than expected</p> 	<p>I will have used one staying positive strategy by the completion of the ASK intervention.</p>
<p>Expected outcome</p> 	<p>I will have completed the staying positive module and identified one strategy I would like to implement to stay positive.</p>
<p>Less than expected</p> 	<p>I can't identify a strategy to help me stay positive.</p>
<p>Much less than expected</p> 	<p>I can't identify a strategy to help me stay positive and I have started feeling low.</p>

Figure 2. Example Goal breakdown: “Meet other people with aphasia”

Aphasia **ASK**

<p>Fantastic outcome</p> 	<p>I will have attended a stroke/aphasia group on a regular weekly basis when I returned home from hospital.</p>
<p>Better than expected</p> 	<p>I will have attended a stroke/aphasia group on a regular monthly basis when I returned home from hospital.</p>
<p>Expected outcome</p> 	<p>I will have completed the staying connected module and attended one aphasia group session when I returned home from hospital.</p>
<p>Less than expected</p> 	<p>I do not attend a stroke/aphasia group session after I left hospital but still understand connecting with others is important.</p>
<p>Much less than expected</p> 	<p>I do not attend a stroke/aphasia group session after I left hospital and have started to feel low.</p>

Living the Learning

The objective of the living the learning module is to increase the participants knowledge of aphasia/stroke information and where to access more information if needed. Providing health information has been shown to improve patient and carer knowledge, satisfaction and reduce the occurrence of depression. Providing information in ways that patients and their families are actively involved has the greatest impact on mood (smith et al 2008). This module allows participants to select topics that they are interested in learning more about. It is important to also brainstorm other topics relevant to the participants that they may wish to have more information about and write them down in the space provided. This module also considers different information provision options (e.g., factsheets, meeting other people, watching DVD). Discuss the options with all the participants and see which form/s they prefer to receive information in. Discuss the feasibility of meeting another person with aphasia or their family member within your health setting. **The Aphasia and YOU DVD the “Australian Aphasia Guide” have been included in the program to provide to the participants.** The DVD links are also available on YouTube and the link for this is provided in the Aphasia Resource section of this booklet. You may wish to also provide the participants with the aphasia friendly ‘AAA Video Handout’ to accompany the video and assist with understanding. **It is important to give the participants opportunity to watch the DVD over the course of the intervention and discuss what they have learnt and whether they have any questions.**

This module also contains a list of stroke, aphasia, rehabilitation and family and caregiver resources. This list is by no means exhaustive. Additional Health fact sheets usually provided by your facility and those published by the National Stroke Foundation information may be needed to support the participants learning about stroke and aphasia. Also, some liaising with the research team may be needed if the participant’s questions are outside of your scope of practice.

Topic selection	Potential Resources
What is stroke?	Australian Aphasia Guide http://strokefoundation.com.au/what-is-a-stroke/types-of-stroke/
Causes of stroke	Australian Aphasia Guide
Stroke recovery	NSF Fact Sheet https://enableme.org.au/resources/rehabilitation
What is aphasia	"About Aphasia" Video Set- 'Living with aphasia' - a guide for carers- Sir Charles Gardiner Hospital
Causes of aphasia	'Living with aphasia' - a guide for carers- Sir Charles Gardiner Hospital
Aphasia recovery	About Aphasia" Video Set- Australian Aphasia Guide NSF Fact sheet - Communication after stroke Australian Aphasia Rehabilitation Pathway http://www.aphasiapathway.com.au/?name=0-Pathway-Overview
Approaches to aphasia therapy	Aphasia Rehabilitation Best Practice Statements 2014 http://www.aphasiapathway.com.au/?name=About-the-statements
How to keep improving after therapy ends	Better Conversations with Aphasia website is a free e-learning resource. "PWA and their families will find out what conversation therapy is, what other PWA think of it, and be able to reflect on whether it is right for them." Therapy apps relevant to the person with aphasia AAA- Aphasia coffee groups QLD STEPS program http://www.health.qld.gov.au/abios/steps/documents/what_is_steps/steps_brochure.pdf
Driving after stroke	NSF Fact Sheet- Driving after stroke NSF website: http://strokefoundation.com.au/afterstroke/stroke-rehab-recovery/stroke-recovery/driving-after-stroke/
Work after stroke	NSF Fact sheet - Returning to work after stroke

	How to volunteer - A guide for people with aphasia - Advice, tips and guidance for people with aphasia who would like to volunteer Connect Press (2007)
Support groups	AAA- Aphasia coffee groups NSF stroke groups https://enableme.org.au/about-enableme http://strokefoundation.com.au/afterstroke/get-help/state-stroke-associations/
Carer services and information	About Aphasia" Video Set Aphasia– a guide for spouses and older children 'Living with aphasia' - a guide for carers- Sir Charles Gardiner Hospital https://enableme.org.au/resources
Depression after stroke	NSF- Depression after stroke DVD NSF Fact sheet – Depression after stroke NSF Fact sheet - Emotional and personality changes after stroke
Information for children	NSF Fact sheet - Supporting children after a family member's stroke About Aphasia" Video Set Aphasia–. The treasure hunt Video https://www.youtube.com/watch?v=3qZmO1iKASg https://kidstrokemotion.wordpress.com/
Information for friends	Talking about friends booklet- talkback association.

Not Just Words

The aim of this module is to talk about what makes a good conversation and specific strategies that can help both people with aphasia and their family members communicate better. It might be good to remind participants, that as social people, we often accompany our interactions with a number of non-verbal and verbal additions to enhance our conversations (e.g. maintain eye contact, use humour, ensure understanding etc).

Communication involves much more than words. In one way or another, people are always communicating. The different strategies each communication partner uses will vary. It is important to reiterate that communication can be adjusted to accommodate the language skills of the person with aphasia and family and friends are important supports. The person with aphasia and their family and friends should be encouraged to use a variety of modalities (drawing, pictures, music, photos, gesture, words) to assist in comprehension of tasks and expression of views. It is important for partners to be aware that aphasia can be variable. A person with aphasia may need different levels of support at different times of the day and in different situations.

The strategies provided in this module are based on Aura Kagan's work at the Aphasia Institute in Canada. The institute offers a specialised training program called Supported Conversation for Adults with Aphasia (SCA™).

For more information see:

Kagan, A. (1998). Supported conversation for adults with aphasia: methods and resources for training conversation partners. Aphasiology, 12(9), 816-830

Simmons-mackie, N. (1998). In support of supported conversation for adults with aphasia. Aphasiology, 12(9), 831-838

Work through the strategies of SCA and determine those that may be appropriate for each person to use. Currently, little is known about the impact of partner training on persons with acute aphasia. Interventions such as this are therefore an important contribution to the literature gap (Simmons-Mackie et al, 2010). However, research on chronic aphasia has

concluded that communication partner training (either with the communication partner alone or with both the person with aphasia and their partner) has positive outcomes for communication. Furthermore, while interventions may often include elements of counselling and education it is the direct training of partners that has the highest level of evidence to date. Direct interventions often include therapeutic feedback on interactions between people with aphasia and their partners (Simmons-Mackie et al, 2010). The practice scenarios in the module should be completed so that the person with aphasia and their partner are given direct feedback regarding their interactions and how things may be improved.

Staying Connected

This module allows the participants to identify the key supports they have. Both participants with aphasia and their family are also encouraged to reflect upon the support systems they have around them. The theme of support is a key component of living successfully with aphasia. The important role of support has been consistently highlighted in studies of people with chronic aphasia (Brown, et al., 2010; Cruice, Worrall, & Hickson, 2006; Hinckley, 2006; Holland, 2006) with the value of practical support, emotional support, and social companionship being emphasised (Brown, et al., 2010). This module also allows the participants to create a visualisation of their friendship networks. Whether a person wants to tell their friends about their stroke and aphasia and how and when they wish to do this is entirely individual. Discussing how they would or wouldn't like this to occur allows an opportunity for the person with aphasia's wishes to be known and respected. This module provides an opportunity for the person with aphasia to express how they would like their friends to communicate with them. You may like to photocopy their responses so they can put their ideas in a place where their friends can see when they come and visit. Whether someone wishes to also meet other people with aphasia is also individual and is explored in this module.

Your Story

Reflection and storytelling helps to create meaning and structure during times of change.

Aphasia can impact on people's lives in different ways. Common understanding of a person's experience is an important part of building their identity. The purpose of this module is for participant and their family member to share their experiences of having stroke and aphasia. While questions to help prompt this module are provided, they can be adapted to suit individual needs. It is important for all participants are able to share their account of their story (wether facts recalled are correct or not). In the pilot Aphasia ASK trial simply having time set aside to talk about things as a family was seen as valuable. One participant commented:

Even just things like the session where (we) got to talk about his – we both talked about our story. I thought that was one of the really great sessions because a couple of – the first days “L” was quite blurry on what actually happened to him, so just actually being able to go through the story of what actually happened to him and work through that.

For some people with aphasia their experience may be overwhelming negative and it may be a difficult task to share their experiences so far. This module therefore also includes a task to allow participants to identify their strengths. It is optional task that may be completed if time permits. This task is based on the work of Dr. Audrey Holland and “Positive Psychology and Aphasia Treatment”. The purpose of this task is to explore with the participant and their family how they may capitalise on their “strengths” and rather than focusing on “weaknesses”.

Finding the positive

After stroke and aphasia participants are likely to have feelings of loss, sadness and negativity. To experience these feelings are natural and often necessary. It is important to acknowledge that aphasia can have a large impact on everyone. The aim of this therefore is

to acknowledge the emotional needs of each participant (e.g. grief, frustration) and explore that depression is common after stroke and aphasia. However, this module also highlights that it is important to remember that the positives are also there. Hence, one very important aspect of recovery for participants, family and friends is to find these positives and to share in them together. This module includes a number of activities to help to do this including an assessment of coping, a good thing happened, keeping track of progress and planned activities.

Assessment of coping

There are many different ways of coping with a difficult experience. It is important to be aware of which strategies the participants with aphasia and their families are using. Assessment of coping can help to identify participants that are using less adaptive coping strategies and who may benefit from additional support. The coping strategies mentioned in the modules adapted from the 'Brief COPE' (Carver, 1999) and are presented as "positive and negative strategies". Whilst in this context we are using the coping strategies to facilitate discussion rather than for an assessment, it is important to be mindful of which strategies the participants are using. McGurk, Kneebone and Pit ten Cate (2011) report that increased depressive symptoms are seen in carers that primarily use avoidant styles of coping. It therefore may be beneficial at this point to address any concerns about where extra support can be access in the future should it be needed.

A good thing happened

The purpose of this activity is to provide practice in taking responsibility for the good things that happen in life, not just the bad. For this activity, you may wish to provide a personal example of something good that happened in your week and describe how you brought it about. This activity has been evaluated by Seligman (in Evans, 2011). For example, "This week I really enjoyed catching up with an old friend for coffee. We spoke about memories of when we travelled together. In order to bring this about, I organised a time with her and bought her a coffee". Your example will then lead into asking the participants for one good thing that has happened in their week. The study showed that participants that wrote down three good things that went well each day for a week were happier at 1 month, 3 months and 6 months post the intervention (Evans, 2011).

Keeping track of progress

In the early stages post stroke, it is recommended that wherever possible, the therapist illustrates spontaneous recovery to the person with aphasia and their family (Holland, 2007). This can be done in a meaningful way by taking notes of daily changes and drawing attention to them. This allows you to emphasize what the person with aphasia can still do and capitalize on their communication strengths. Furthermore, it provides opportunities to celebrate in their success. Results from Brown et al.'s (2012) study of living successfully with aphasia emphasised how the acknowledgement of improvements early during recovery as well as repeatedly across time provided people with aphasia hope; facilitated self-confidence; and provided positive reinforcement for continued achievement. Furthermore, a key finding from Grohn 2014 et al's study was that participants often described perceived or desired improvement in the context of activities they valued, for example, conversing with family and friends, using the telephone, writing and reading emails and reading for pleasure.

Planned activities

Findings from research in living successfully with aphasia have highlighted the importance of engagement in meaningful activities. Engagement in activities provides people with aphasia a sense of ability, competency, confidence and independence. A behavioural approach (aimed at increasing participation in pleasant activities) to address low mood in people with aphasia (The Communication and Low Mood (CALM) program) has shown significant improvements in reducing depression for patients randomly allocated to the intervention of 3-18 sessions of therapy in their homes over 3 months (refs). It is important therefore to identify ways to facilitate participation in valued activities as rehabilitation and recovery progresses.

Summing Up

The purpose of this module is to discuss how well the Aphasia ASK Program has been able to achieve the participants goals set at the beginning of the program. It allows an opportunity to reflect on the Aphasia ASK experience and discuss any unfilled gaps or remaining questions the participants may have. Progress towards agreed goals should be regularly discussed. Goals often change with time, as recovery occurs and as priorities change. To allow for changes in circumstances, goals should be regularly revisited and revised. (Hersh et al, 2011). As part of the 'SMARTER' goal setting process, it is critical that goal are reflected back upon and discussed with the participants. It is acknowledged that some goals have change or evolved and some skills may have been learnt that were not previously identified as goals. Start by reflecting back on the Aphasia ASK Program with the participants. Use their 'Goal Booklet' as a guide for discussion. For each goal rate on the participants GAS table where they feel they are in relation to achieving their goals. Mark these results on your own copy of their goals. This will need to be kept as a record for outcome measures. If the participants report unmet goals discuss further what they would still like to achieve. Brainstorm with the participants how this can be brought about. It is hoped that achievable options can be presented to the participant's to assist them in continuing to work towards their goals. This may include:

- Having an extra Aphasia ASK session to work on unmet areas of interest for the participants
- Enabling the participants to continue working towards their goals with their family or friends
- Helping the participants locate resources or information that may assist in answering questions
- Encourage the completion of goals during the follow-up telephone sessions.

ASK telephone follow-up

Follow-up monthly phone calls or visits (which ever method is suitable for the participants) will be made until 12 months post stroke. The follow up calls should find out how the participants needs are going, revisit the participant goals set during the program and

provide additional information and resources where necessary. Calls should be made monthly upon completion of the face to face sessions. If there is a crisis or severe symptomology expressed during a telephone call, clinicians are able to call more than once during a month as part of their duty of care and recommendations of further support should be made as appropriate. If a person with aphasia does not have a support person and are not able to be follow-up by phone, they are able to come in for a face to face session but this needs to be documented.

Follow-up Telephone Treatment (optional prompts)

Greeting and Introductions

Hello my name is XX from XX hospital and I'm calling about the Aphasia ASK program that you completed with me.

Hello, its XX calling from XX about the Aphasia ASK program. How are you and XX going?

How have you and XX been since I last saw you?

Overall, how would X (the person with aphasia) rate how they have been going since your last contact?

1 Worse than usual

2 The same as usual

3 Better than usual

If client feels that are not doing well, find out and address the primary area of concern

'I'm sorry to hear that you haven't been doing so well. What are you having the most problems with?'

Why do you think you are having trouble?

"Have you been using any skills you learned in the ASK aphasia program to help you out?"

What strategies have you been using the most?

"Do you feel like you need more support or information?"

"What do you feel you need to work on the most to help?"

Revisiting Goals that have been set

I'm calling to check on the goals that we set at the end of the end of last face to face session

together.

We set these goals:

1) List goal here

2) List goal here

3) List goal here

How many of these did you accomplish/do?

Let's start with X how have you been going with the first goal/activity? How well have you done with this goal?

1) Fantastic

2) Better than expected

3) As expected

4) Less than expected

5) Much less than expected

Last time we spoke on the phone we identified some things you wanted achieve over the past month. They were:

How many of these did you accomplish/do?

How have you been going with this goal/activity?

Achievement of goals/activities

How did you feel about having accomplished x?

How enjoyable did you find x?

Are you finding that you feel better when you x?

Would you like to continue on with this goal for next time?

Non-achievement of goals/activities

Can you tell me a little bit about why you don't think you achieved X

Did you ran out of time and couldn't complete this activity/goal? If so, we can chat about some ways to fit this into your schedule.

Was it because you really do not find the goal/activity to be important? If so, we can select a different activity/goal to achieve instead next time.

Was the goal/activity more difficult to accomplish than what you originally had expected? If so, we can discuss breaking it into smaller steps.

If your goals have just been difficult, we can either select some different ones or we can come up with

some strategies for making this easier for you.

You might find that achieving your goals may become easier with time.

Identifying new goals and actions

Would you like to continue the goals/ activities or select different ones to do for next month?

It is important to select goals/activities that you think you will achieve and that you will find enjoyable.

“What do you feel you need to work on the most?”

Closing the phone call

When would be the best time to call you next month to see how you are going?

Thanks so much for talking to me today. I look forward to hearing from you next month

Thank you for your support with this research program!

For any questions or quires regarding the Aphasia ASK program please contact:

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