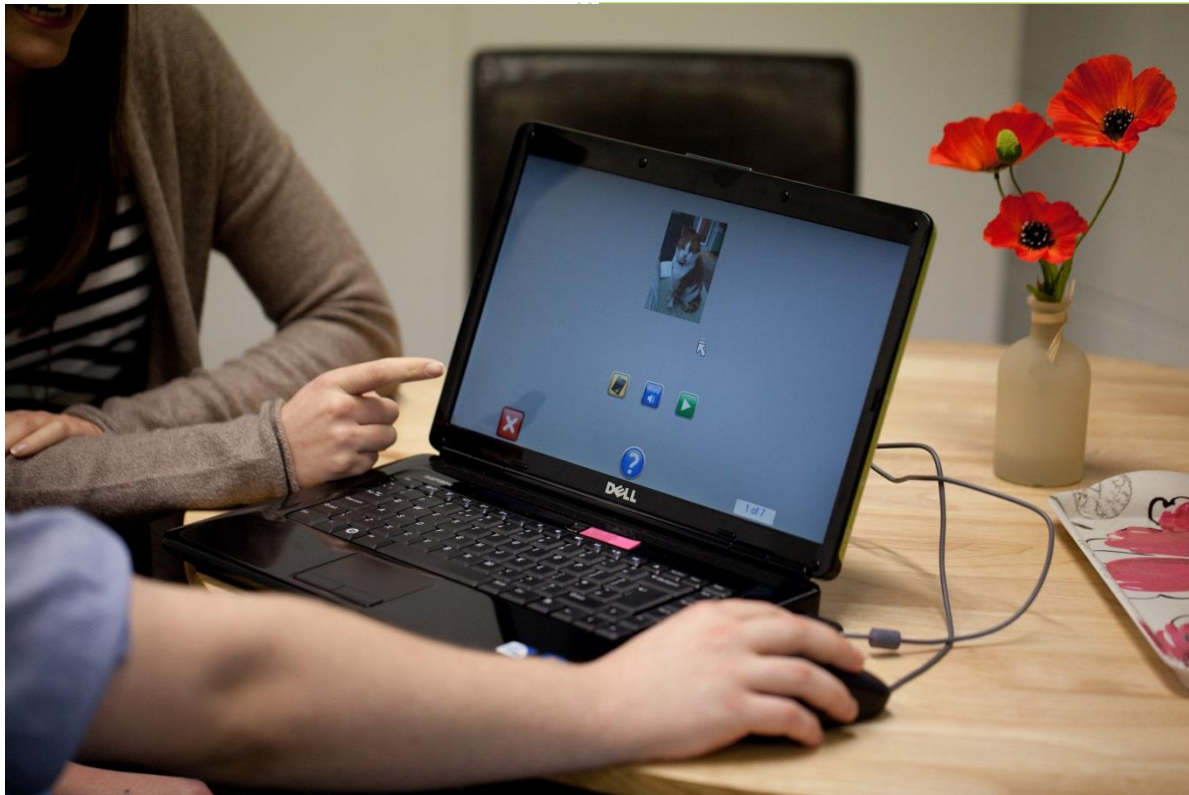




The
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Therapy manual: StepByStep computer therapy approach for the NHS



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Appendix A - Volunteer/Assistant Handbook

Appendix B - User Guide for StepByStep v5

Background to the StepByStep approach to long term aphasia therapy

Speech and language therapy (SLT) is often received regularly in the first few weeks and months after stroke. Medical instability, fatigue and confusion may reduce full engagement with language therapy in the early weeks post stroke, reducing the opportunity for people to participate in treatment. There is evidence that people can continue to improve their language skills for several years [1] and The National Stroke Strategy (2007) [2] recommends people receive rehabilitation for as long as they benefit from it. Treatment of aphasia that persists beyond the first few months post stroke is often not available through NHS services in the UK as ongoing therapy is costly through face-to-face SLT and places greater demands on limited resources. To provide opportunities for people with aphasia to achieve their recovery potential, it is therefore necessary to provide efficient, affordable treatment options.

Targeted therapies with good preliminary evidence to date

Constraint Induced Aphasia Therapy (CIAT), also known as Intensive Language Action Therapy (ILAT), is based on the principle 'use it or lose it' from the observation that use of a skill encourages neuroplastic changes in the brain post injury, and avoids learned non-use. The CIAT makes use of language in games to make, reject or clarify requests for targeted items for 30 hours over 2 weeks [3, 4, 5]. A systematic review of 10 studies conducted over the decade concluded that evidence for this technique is favourable [6].

Model Oriented Aphasia Therapy (MOAT), which tailors treatment according to a patient's individual symptoms, was found to be comparable to CIAT when delivered with similar intensity [7]. Raymer et al (2008) found personal relevance or 'salience' of the language material being practiced to be important when targeting therapy [8].

While the optimum intensity remains unclear, it is generally acknowledged that for stroke rehabilitation regular, repetitive therapy practice is a factor in treatment success.

The resources required to achieve intensive therapy in the long term is prohibitive in the current financial climate and lower cost options for the support of repetitive, intensive practice are needed. Non speech and language therapy professionals have been employed successfully to support therapy activity [9, 10, 11]. Computer therapy, developed for the treatment of aphasia, has also been reported to be useful in the provision of targeted language practice and provides opportunities for independent home practice as part of a self-management approach to maximise practice intensity, improving outcomes for reading, spelling and expressive language [11, 12, 13, 14, 15]. The Department of Health report, 'Our Health, Our Care, Our Say' (2006) recommends self-management for long term conditions supported through technological innovation [16].

The StepByStep© computerised approach to long term aphasia therapy

The StepByStep computerised approach to long term aphasia therapy combines current evidence underpinning language therapy with practical considerations of treatment delivery. Skills of a qualified speech and language therapist are used to select individually targeted therapy exercises, computer software is provided for regular self-managed practice of therapy exercises, and volunteers or therapy assistant support language practice and computer use [17]. To encourage motivation for self-managed practice and reduce the likelihood of negative feedback leading to non-use of language, the StepByStep programme is designed using an errorless learning approach, whereby the patient begins to use exercises in which they experience some success before moving on to a harder exercise once the first exercise becomes easily achievable.

Key principles underpinning the StepByStep approach:

- Focus on using expressive language
- Tailoring exercises according to the patients symptoms

- Providing salient language practice material
- Intensity/regular practice of exercises
- Errorless learning (success with each exercise before progressing to a harder one)

Mode of delivery:

- Self-managed therapy practice using computer software (StepByStep v5)
- Support from non-speech and language therapy professionals

Preliminary evidence for this approach:

A pilot study evaluating this approach was carried out with 34 people with persistent aphasia. They were randomly assigned to the StepByStep approach, or usual long term care (most frequently this was social support). On average people with aphasia practiced their speech exercises on the computer independently for 25 hours over 5 months. The therapy showed statistically significant improvement in the ability to use spoken words when compared to usual care ($P=0.014$). The results indicated that self-managed computer therapy supported by volunteers (total of 4 hours on average) could help people with aphasia to continue to practise, improving their vocabulary and confidence talking [11]. Patients and carers found it an acceptable alternative to face-to-face therapy [18]. Self-managed computer therapy could therefore improve the quality of life of people with persistent aphasia, at relatively low cost and exploratory economic analysis has suggested considerable potential for the intervention to prove cost-effective [11, 19].

Summary of self-managed computerised therapy intervention

The StepByStep therapy approach targets word retrieval as it is one of the challenges most frequently experienced by people with aphasia, restricting their communication. The intervention was designed by speech and language therapists specialising in aphasia intervention and use of computer software for treatment. The StepByStep approach has been used for several years in independent practice and has been adapted in this manual for use within the NHS based on learning from the pilot study and from implementing the intervention into one NHS trust.

Key components

The three key components of the intervention were designed to incorporate key factors that research suggests positively influence aphasia therapy outcomes combined with practical considerations:

1. Qualified SLT assessment of patient's language profile to tailor computer exercises using the StepByStep© software so that they target the specific language deficit identified. Creation of exercises using target words of personal relevance to the patient.
2. Daily independent word finding practice with the tailored computer exercises by the patient over a 6 month period.
3. Volunteer/therapy assistant support to enhance adherence to the computer exercises and to encourage transfer of new words into functional daily situations.

Qualified speech and language therapist assessment and tailoring of exercises

A speech and language therapist should tailor computer exercises to the individual using 100 words of personal relevance chosen by the patient. There is a large bank of photographs within the computer software and if something extra is required (e.g. picture of a family pet, grandchild or favourite football team) it can easily be photographed digitally and added by the SLT.

The computer software enables the SLT to select exercises using these words that follow steps in the therapy process that the therapist would take if delivering it face-to-face. The SLTs delivering this intervention should receive training on how to set up appropriate exercise steps. The SLTs should base the selection of exercises on language skills demonstrated in initial language assessments. The steps can then be applied to all sets of vocabulary.

The SLT should provide initial face-to-face demonstration of the software exercises and spend up to 2 hours (spread over 1-3 sessions) checking that the individual is able to use the software and monitoring the appropriateness of the tailored exercises. The SLT should also review the need for additional pieces of hardware such as tracker balls in order to make it physically possible for patients to use the computer.

If a speech and language therapy department has access to the StepByStep telehealth module, therapists or therapy assistants could use this as a source of monitoring progress and updating exercises. Therapists should limit this method of monitoring to once every two weeks.

Regular self-managed practice

The patient should be asked to work through the exercises on the computer aiming to practice each day for 20-30 minutes. Patients should be given a 6 month period to work through the therapy material on the computer and practice using the new vocabulary in their daily lives. Due to holidays and bouts of illness during a six month period of time, breaks from using the software should not be unexpected but regular use over at

least four of the six months should be encouraged. The amount of practice will be captured automatically by the computer programme.

The software is designed for life long use should the patient wish. The initial six months of tailoring by a speech and language therapist and support from a volunteer/ assistant is intended to assist with learning to self-manage. In the Big CACTUS study those patients who have the software installed on their own computers will not be prevented from continuing to practice if they wish following the 6 month supported intervention time. If computers were loaned, they may be taken back after 6 months to give to a new patient (as permanent loan of equipment would be unusual in practice).

Volunteer/assistant support to assist with treatment adherence and carry over into daily activity

To enhance treatment compliance, the SLT should provide training to local volunteers who already have a working relationship with the SLT department (based in NHS trusts, local voluntary organisations, or student SLTs) or therapy assistants based in the department. They should use the training programme and volunteer/assistant handbook developed and evaluated during the CACTUS pilot study. The volunteer/assistant should follow the instructions set out in the handbook (see Appendix A).

The volunteer/assistant should be asked to visit the patient once a month for an hour, or every two weeks for half an hour (to suit the patient). It may be that more frequent visits are required initially, followed by less frequent visits as the patient becomes better able to use the software.

The volunteer/assistant should carry out the following tasks:

- provide technical assistance
- observe and encourage use of computer exercises
- check results and discuss difficulties
- assist patient to move on to harder tasks in the therapy process pre-programmed by the SLT
- encourage the use of new words in everyday situations through word games, conversation and discussions with family about how to encourage use
- set up new vocabulary sets if all 100 words have been completed

The patients should be able to contact the volunteer/assistant by telephone for technical advice on computer use between planned visits if necessary.

The volunteer/assistant should complete a feedback form after each visit and send it to the SLT. The SLT should use this to monitor the volunteer/assistant support and the progress of the patient and provide guidance to the volunteer/assistant on how to proceed. Volunteers/assistants may be invited to meet together with their peers and the SLT for an hour every few months for support and discussion of issues arising and new practice material required by their patient. The volunteer/assistant may contact the SLT by e-mail, telephone or face to face between support sessions to report any concerns/difficulties.

Resources required for the intervention:

Speech and language therapist

The speech and language therapist providing this intervention should hold a speech and language therapy qualification from an institution recognised by the Royal College of Speech and Language Therapists. The therapist should have experience of providing therapy to people with aphasia as a consequence of stroke. They should have received training on how to use the software and provide the StepByStep intervention.

Therapy assistant / volunteer

A therapy assistant should work for the same NHS trust as the therapist and be part of the team supporting speech and language therapy interventions. The assistant may be a specific speech and language therapy assistant or a more generic rehabilitation/therapy assistant.

A volunteer should hold appropriate DBS checks from the NHS trust from which they are supporting patients or from local voluntary organisations with existing relationships with the speech and language therapy department.

All assistants and volunteers should undergo the same training to support the intervention as provided in this manual.

Support should not be provided by any staff or volunteers who have not undergone the training provided in this manual. Additional informal support may be provided by a relative or carer however.

Software

This intervention uses the StepByStep v5.0 software from Steps Consulting Ltd [20].

Hardware

The software should be installed on either the patient's home computer if they have one, or on an NHS computer available to loan for a six month period.

StepByStep v5 works on Windows 7 and Windows 8 on a laptop, desk top or tablet. It does not work on Windows XP, a Mac or on an iPad at the time of writing this manual.

The computer should have good speakers from which the words spoken can be heard clearly. For recording purposes, the computer either needs to have a good internal microphone, or, if recordings from this are quiet or distorted, an external microphone should be provided.

Screen size and resolution should be considered so that the pictures and words are large enough for the individual patient to see clearly.

Some patients may require tracker balls or external mice in order to gain physical access to the computer.

Assessment of the patient's language, tailoring of the computer software and provision of support (Speech and language therapist role)

Assessment of the word finding deficit

As a minimum, patients should have their naming ability assessed with a standardised naming test. In the Big CACTUS project, the Naming objects test in the Comprehensive Aphasia Therapy test (CAT) should be used. The results of this assessment should guide the clinician to understand the severity of the word finding deficit and the types of error made e.g.

- semantic paraphasias (chair → table)
- phonemic paraphasias (brollie → broccoli)
- literal paraphasias (umbrella → umblerela)
- neologisms (chair → wibble)
- perseveration (saying a previous word again)

The performance on the assessment along with observation through conversation should indicate the types of cue which best assist the patient to find the correct words e.g.

- a phonemic cue ('tel'... → television)
- a semantic cue ('you wear this on your head' → hat, 'its an animal you might have as a pet' → cat)
- a written cue (first letter or whole word, provided by the therapist, or written on paper/sky writing by the patient)
- visual cues (can the patient copy the word from hearing it, or do they need to see your lips?)
- how aware is the patient of his/her errors on assessment? Do they need to be encouraged to listen to their own production?

Assessment of the patient's interests and areas of their life where increased vocabulary may improve participation.

The therapist should discuss what vocabulary would be meaningful for the patient to learn. This can be conducted with the patient and with input from friends and relatives. Pictures can be used to assist patients in indicating topics that are of importance to them. Once the patient has been added in the clinician version of the StepByStep programme, the therapist should show the pictures/words available within each of the topics the patient indicated are of importance. Further topics and words should be added as necessary to make the therapy material as personalised as the individual requires. For example,

- If a patient wishes to learn family names, the therapist should input photos of family members
- If a patient doesn't recognise the picture on StepByStep the therapist should change it for a picture more familiar to the patient, using either google images, or photographs of the patient's own version, the patient's own cat for example.
- If a patient uses a different but acceptable word for an object, the therapist should change this within the StepByStep programme to reflect the patient's variant of that word (this might be a regional variation)

In the Big CACTUS study 100 words should be selected for practice over the following six months. Vocabulary sets should be grouped according to topic.

Refer to the Big CACTUS training slides, or the StepByStep website for instructions on how to select personalised vocabulary sets.

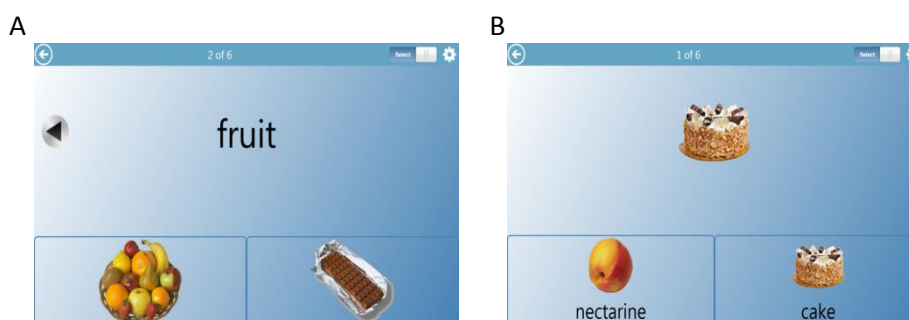
Tailoring the computer therapy exercises

The therapist should set up therapy steps to assist the patient learn their chosen vocabulary. There are seven steps that will automatically be applied to each set of vocabulary.

Picture recognition

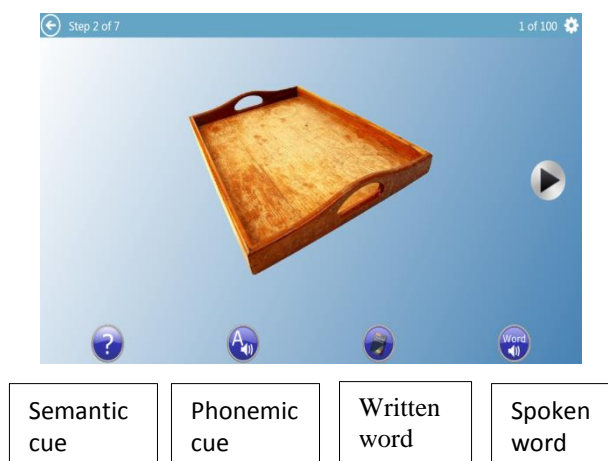
This step is designed for familiarisation of the vocabulary by using simple matching tasks.

As standard, this step is set up as a written word to picture match from a choice of two pictures (A). In Big CACTUS we request that therapists change this standard step to show the picture for the patient to match with the picture and written word below, so they focus on the picture that will be presented in later steps, and hear the target word spoken and see it written (B)



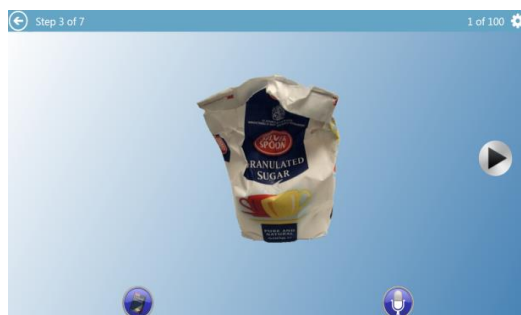
Confrontation naming

This step provides the patient with a target word with cues at the bottom of the screen. The patient should be encouraged to click on the clues from left to right to help prompt retrieval of the word.



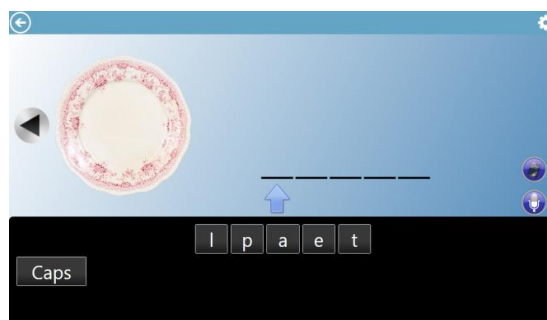
Confrontation naming with feedback

The exercise in this step is designed to encourage the patient to name the word with feedback on whether the correct word has been retrieved. If the patient needs a clue, the written word can be presented on pressing the dictionary icon. If the microphone button is pressed, once the patient records the spoken word, speech recognition is used to determine whether it is the correct word.



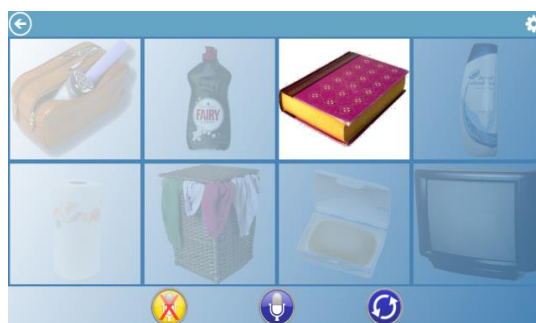
Using writing to cue naming

This step shows an anagram for the patient to unscramble and name the word. Once the patient knows what the word is he/she can press the microphone button, record the spoken word and receive feedback.



Naming from a grid

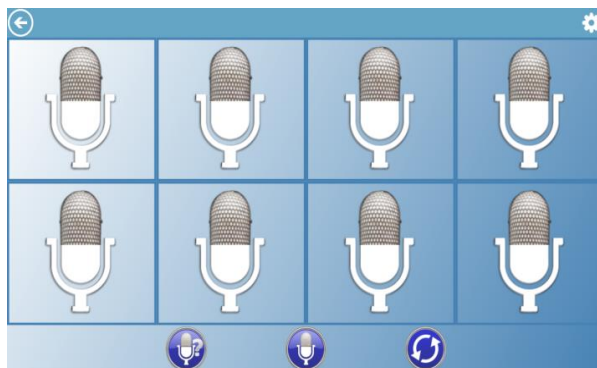
This step requires the patient to name pictures without cues. The patient should be instructed to press the microphone button to record the spoken word. The computer will indicate whether the word was correct.



Eight pictures are shown in the grid as standard. This should be changed if this is too many for the patient. See Big CACTUS training slides or StepByStep website for instructions on how to change this presentation.

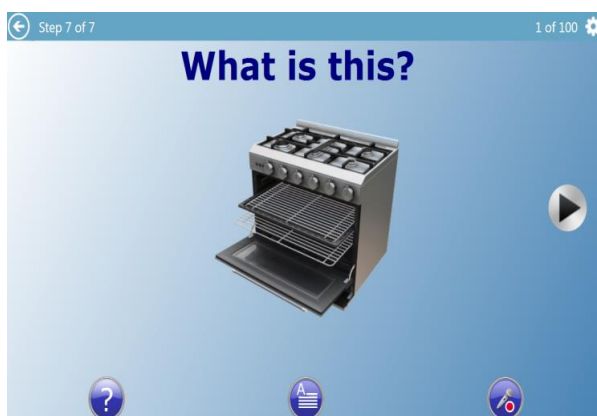
Naming from memory

This step requires the patient to remember what was in the grid in the previous step. They should be instructed to click on the microphone icon and say a word they can remember. If they produced one of the words, the picture will be revealed. If they need a reminder the patient can chose to flash all of the pictures up with the microphone? button. This step is linked to the previous step, so if eight pictures are too many for the patient to remember, changes should be made to the previous step.



Using words in functional sentences

This step asks a question and requires that the patient answers the question using the target word in a sentence.



There are two sentence steps to provide the patient with practice using the target words in different sentences

Therapy steps should be tailored according to the needs of the individual patient. The therapist should consider two issues when tailoring:

- 1) The steps should be of incremental difficulty to enable progression to achieve unaided word retrieval through an errorless learning approach.**

If one type of step is particularly difficult for the patient, the therapist should copy the step and tailor it to make it more achievable before the patient tries the original step.

Example 1:

















If presentation of lots of cues on the same page is confusing for the patient, the confrontation naming task should be copied and adapted to show different cues in different steps.

Example 2:

If unravelling an anagram is too difficult, this step should be copied and adapted to enable the patient to practice copying the word with the letters presented in the correct order before moving on to try the anagrams again.

This intervention is designed to improve word finding using the principles of ‘language action’ therapy. Practising production of words should be the target of the majority of therapy exercise steps set up.

- 2) The steps should present cues that are most likely to be useful as informed by the naming assessment and conversation with the patient.**

<u>Definitions of prompts available</u>		
		This is a semantic prompt providing a video of someone describing the meaning of the word.
		Click here to see a video showing the mouth movements when saying the whole word.
		Click here to see a video giving the first sound of the word.
		Click on the dictionary button to display the written word for the picture.
		Click here to see the first letter of the word in the picture.
		Click once to see the sentence shown on the screen. Click again to hear the sentence spoken.
		Click here to record your attempt and hear it played back
		Voice recognition – say the word and the computer provides feedback of accuracy.

Example 1:

Use semantic cues on confrontation exercises if semantic prompts helped the patient to find the words during the naming assessment.

Example 2:

If on assessment the patient was able to repeat words, but only when watching your lips, provide a whole word repetition cue with a video. As a second step or second cue, provide the sound cue with a video.

Example 3:

If the patient is able to repeat words easily and phonemic cues helped word retrieval on assessment, the therapist should provide phonemic cues in the confrontation naming exercise, followed by the whole spoken word cue in case it is needed. If phonemic cues help the patient on assessment without the need to look at lips, there is no need to record videos to accompany these sound prompts.

Example 4:

If patients appear unaware of their errors on assessment, recording and playback button can be added to the exercises to promote self- monitoring of word production.

Example 5:

Some patients cue themselves in with written word, first letter, or sky writing. If the patient uses this strategy during assessment, or if their writing is better than their spoken language, the therapist should provide a written letter cue, followed by a whole written word cue if the written letter cue doesn't always work.

Patients will require different sets of cues depending on what is shown to assist them during the formal assessment and informal conversation.

Although StepByStep provides a range of cues for each word in the library, the therapist should check that the cues needed for the patient are present for each chosen word in the vocabulary sets. Therapists should add any missing cues that are indicated from the assessment. (There is no need to record spoken sound, words and sentences, written letters, words and sentences, semantic or sound videos for all vocabulary items if not required by the patient).

If additional cues need to be recorded, the therapist should ensure that the recordings are clearly audible and/or visible.

Cues should be ordered from minimum to maximum assistance from left to right.

The exercise configuration should be applied in the same way to all of the vocabulary sets.

Please see Big CACTUS training slides or StepByStep website for details of how to record cues, and how to modify the exercise steps.

Training the patient to use the StepByStep programme

Once the therapy programme has been tailored for the patient, the therapist should show them how to use the exercises.

The therapist should show the patient the following

- How to switch on the computer and open the StepByStep programme
- The calendar and how this shows how much practice has been carried out
- How to select the vocabulary they want to practice
- How to carry out each of the steps (one or two examples from each step can be shown)
- How to move up to a harder task if the current was feels too easy.

The therapist should leave the patient (and carer if available) with the user guide/instruction booklet (see appendix A) which provides reminders of how to use the programme and what is required for each type of step. The therapist should annotate the instruction book with any additional instructions.

The booklet recommends that the patient tries to practice for 20-30 minutes each day. The therapist should discuss this with the patient and help to identify times of day when the patient can fit practice into their daily routine.

The therapist should leave their contact details and arrange a further visit to introduce the volunteer/assistant if not present at the training visit. If a further visit is made to introduce the volunteer/assistant, the therapist can check the appropriateness of the tailored steps, make alterations if necessary, and sort out any initial difficulties the patient has experienced since the previous visit.

Training and support of volunteers

The therapist should deliver training to volunteers and/or assistants either as a group or on a one-to-one basis. The therapist should take the volunteer/assistant through the volunteer/assistant handbook and familiarise them with their responsibilities and how to carry them out (see appendix A for handbook).

When a patient has been identified for the volunteer/assistant to support, the therapist should meet with them to explain the way the patient communicates and provide advice on any specific communication strategies required for the individual patient before their first visit (a brief meeting immediately prior to the visit or a discussion in the car on the way to the visit is often most practical). The therapist should accompany the volunteer/assistant on their first visit to introduce them to the patient. The therapist should go through the patient's tailored exercises on the computer and refer them to the user guide given to the patient (see appendix B). The volunteer/assistant may accompany the therapist to familiarise themselves with the individual patient's exercises and support required either at the time the therapist provides the exercises to the patient, or at a further visit 1-2 weeks later. Before leaving the patient's house the therapist should ensure the patient and volunteer/assistant exchange best contact details. Following the visit, the therapist should provide a short debrief (often in the car, or outside the patient's home) to summarise what they need to assist this particular patient to try and achieve and to check that the volunteer/assistant feels comfortable and confident to visit independently on future occasions. The therapist should remind the volunteer/assistant to contact them with feedback forms after their next visit.

The therapist should ensure that the volunteer/assistant has copies of the feedback form (see volunteer/assistant handbook and printable copy of the form in appendix A) and ensure they know that they must return a completed copy to the therapist after each patient visit.

The therapist should review the feedback forms and respond to the volunteer/assistant by phone, e-mail or in person for support and recommendations. Changes to the exercise set up and additional vocabulary can be made by the volunteer/assistant under the guidance of the therapist.

If there is more than one volunteer/assistant performing the support role, peer support meeting can be arranged with everyone by the therapist as a chance to discuss ideas and issues occurring.

Volunteer/assistant role

The volunteers/assistants should refer to their handbook for supporting the intervention. Please see appendix A.

Amendment 1 (18th May 2015)

StepByStep computer therapy – tips

Selecting cues

StepbyStep gives you the option to record a range of cues that might help a patient to retrieve each of the words they have chosen to practise.

You do not need to record all cue options for every word. Rather, you need to decide which cues are most likely to help your patient and make sure they have been recorded e.g.

Videos of single sounds or whole words (mouth movements)	Required if repetition of words is particularly difficult, but not required if patient can repeat words from an auditory example
Audio recording of single sounds	Required if sound cues help patient to retrieve the word (now all included in the latest update)
Audio recording of whole words	Required for repetition/hearing target words
Video/audio recordings of semantic cues	Only required if semantic information helps the patient to retrieve words.

If you need to record a lot of new audio/video material, consider whether your volunteer/assistant has the time and skills to help you with this.

If unsure whether a particular cue will be helpful from initial assessment, but think that it could be, record the cue just for a subset of the 100 words initially.

You could ask the volunteer/assistant to check how the patient responds to this cue in their feedback form. If it seems to be helpful, consider visiting to add it in for other words, or explaining how to add the cues in to the volunteer/assistant.

Selecting/changing steps

For many people, the existing steps may be appropriate.

You may need to consider changing the existing steps to change the types of cues available e.g. hiding the semantic cue button if they are not of any help to the patient.

Occasionally, you may wish to add in a step e.g. if more work on spelling is required and you think a greater range of spelling exercises would be beneficial.

Hide/Show words

Not all of the 100 words need to be displayed to the patient at once. If a patient is more severe and you think they would benefit from concentrating on 10 or 20 words to start with, consider hiding the others, and making sure the volunteer/assistant 'shows' more sets of words as the patient progresses with their therapy.

NB. If you are having difficulties ensuring your patients have regular visits from a competent volunteer/assistant, it may be better to leave all words available for practice so as not to disadvantage patients from continuing to practice more words.

Feedback

Where remote access to the patient's computer exercises is not possible, feedback to and from the volunteer/assistant is important to enable you to know how the patient is doing and to recommend any adjustments to the exercises being practised or to the cues used, and also for making suggestions regarding ways to practise the new words in everyday settings, away from the computer.

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Volunteer/Assistant Handbook



Name of therapist:

Contact details:

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Appendix 1 – Expenses form

Appendix 2 – Feedback form and checklist

Welcome to Big CACTUS

Thank you for getting involved in the Big CACTUS project. Your enthusiasm and skills are vital to enable us to provide valuable support to people with aphasia who are learning to say more by practising important words with computerised language exercises. These patients will be using computer speech therapy in their own homes, so we ask you to visit them at home at least once a month to help with this.

This handbook provides you with information about *Big CACTUS* and your important role within it.

Thank You



THE TAVISTOCK TRUST FOR APHASIA



Big CACTUS study

Aphasia is a language disorder affecting understanding, talking, reading and writing, often as a result of a stroke. People with aphasia rarely receive speech and language therapy for more than a few months after a stroke. They may receive continued support from stroke groups and carers/relatives. There is evidence that people can continue to improve their language skills for several years.

There is also evidence that people with aphasia can use computer software independently for structured language practice. This research study asks:

- Can people improve their ability to find words using the StepByStep approach using computers for practice?
- Does the StepByStep approach affect how well people with aphasia talk about their interests in conversation?
- Do people with aphasia and their carers perceive any improvements in communication and daily life?
- Is this approach cost-effective?

We need 285 people with aphasia to take part in this study across the whole of the UK. Participants will be randomly allocated to either

- continuing with usual activities/therapy only OR
- using the computer therapy exercises in addition to usual care OR
- carrying out daily puzzle book activities in addition to usual care

Usual care will involve a range of activities as this varies across the country, for example face-to-face speech and language therapy support, or attendance at support groups. The **computer therapy** will be tailored to the individuals' needs by an SLT, using a computer program specifically designed to help people with aphasia improve their word finding ability, called StepByStep. Participants will be encouraged to practice daily for 6 months, and *trained volunteers or therapy assistants will provide support with language practice and computer use.*

Participants allocated to do **puzzle book activities** will be provided with books of standard puzzles to be carried out each day. A member of the research team will contact the participants or carers once a month to mimic the attention provided by volunteers/ therapy assistants in the computer therapy arm.

About Stroke

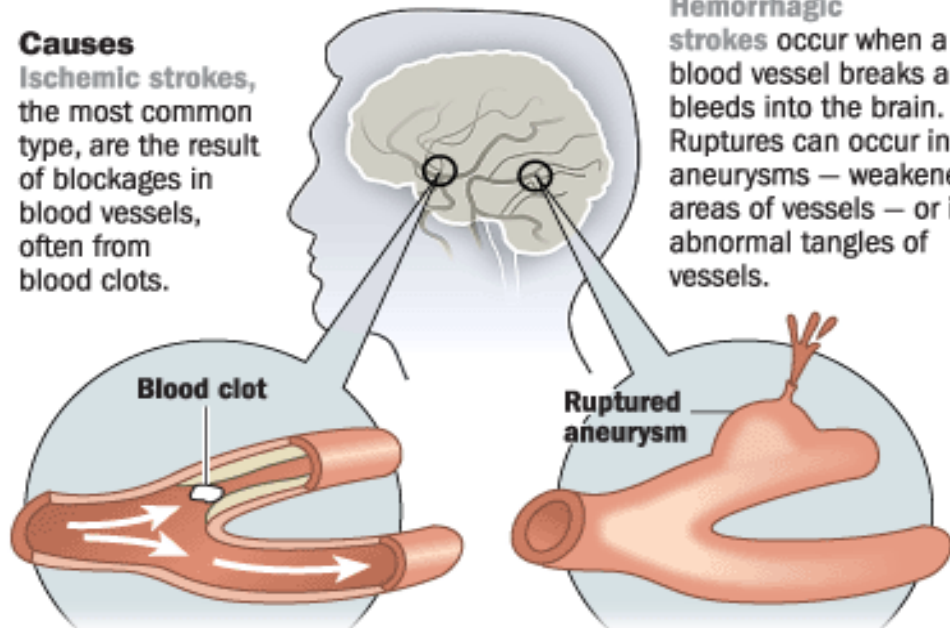
A stroke occurs when the blood supply to part of the brain is suddenly interrupted. Brain cells die when they are deprived of oxygen and nutrients.

Causes

Ischemic strokes, the most common type, are the result of blockages in blood vessels, often from blood clots.

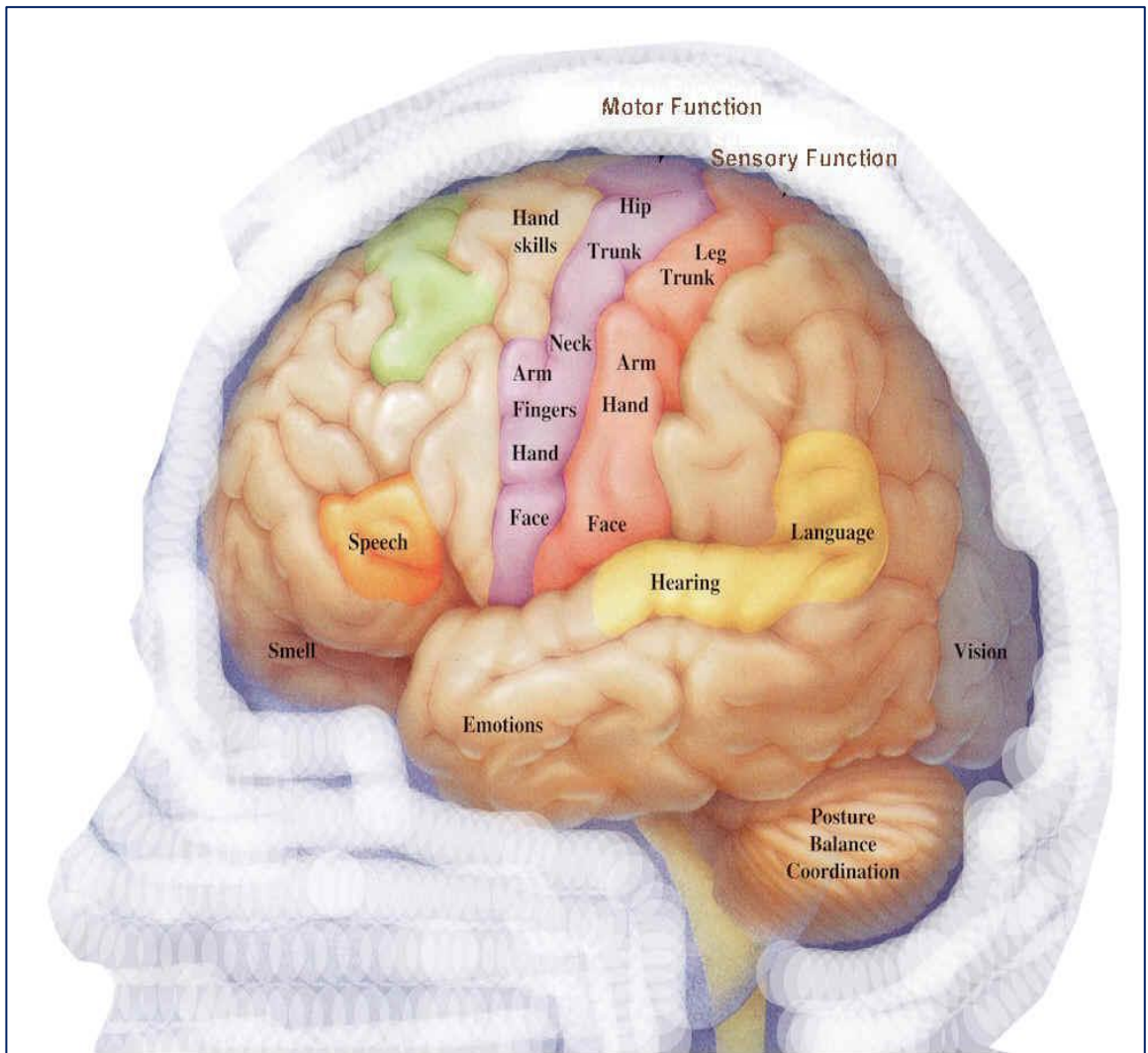
Hemorrhagic

strokes occur when a blood vessel breaks and bleeds into the brain. Ruptures can occur in aneurysms – weakened areas of vessels – or in abnormal tangles of vessels.



- ▶ **Infarct** - an area of tissue that has recently died as a result of the sudden loss of its blood supply, e.g. following blockage of an artery by a blood clot
- ▶ **Haemorrhage** - the loss of blood from a ruptured blood vessel

Area of brain damaged & what it may affect



What is aphasia?

Aphasia is a life-disabling condition caused by damage to the parts of the brain that are responsible for understanding and using language.

The communication difficulties that result from this brain damage will generally mean that the person with Aphasia will find it very hard or impossible to undertake many everyday activities such as shopping, making a telephone call, reading, following a film or joining in a conversation.

Someone with Aphasia may have problems with any one, or more, of the following:

- talking
- listening
- understanding
- writing
- using numbers

Aphasia is a complex condition. It affects each person differently and may be hardly noticeable or very severe. A person with Aphasia may find that their communication difficulties can change from day-to-day or even hour-to-hour. They are likely to be worse when tired, unwell or under pressure.

Having Aphasia is often isolating and extremely frustrating.

It usually results in loss of work for people under retirement age, with loss of status, social contact and financial security.

Roles within the family may change, and friendships and close relationships come under great strain.

Types of aphasia

The three most common types of aphasia are:

- Broca's aphasia
- Wernicke's aphasia
- global aphasia

Broca's aphasia

Broca's aphasia, also known as non-fluent aphasia, is where a person has great difficulty speaking and can only manage to string a small number of words together in short, halting sentences. However, it is usually possible to understand the meaning of their speech. For example, a person with Broca's Aphasia might say, "Want...coffee... no...milk".

Wernicke's aphasia

Wernicke's aphasia, also known as fluent aphasia, is where a person is able to speak normally and use long, complex sentences, but the actual words that they use do not make sense, or they include nonsense words in their speech.

One example of speech recorded by a researcher was, "Mother is away here working her work out of here to get her better, but when she's looking, the two boys looking in other part".

Many people with Wernicke's aphasia are often unaware that their spoken language makes no sense to others and they can become angry or frustrated by the lack of understanding that is shown by others.

Global aphasia

Global aphasia is the most severe form of aphasia. Someone with the condition has difficulty with all forms of communication, including speaking, reading, writing, correctly naming objects or people and understanding other people's speech.

Guidelines for volunteers/assistants

Frequency of contact

Visit the person using the computer for 1 hour once a month or for 30 minutes every 2 weeks (depending on need)

Be available on the telephone or through email for interim support

At these visits you should:

Check results and discuss difficulties

Supported practice

Direct participant to a more appropriate level of difficulty

Change words in 'grid' steps

Set up new vocabulary (if they work through all vocab quickly)

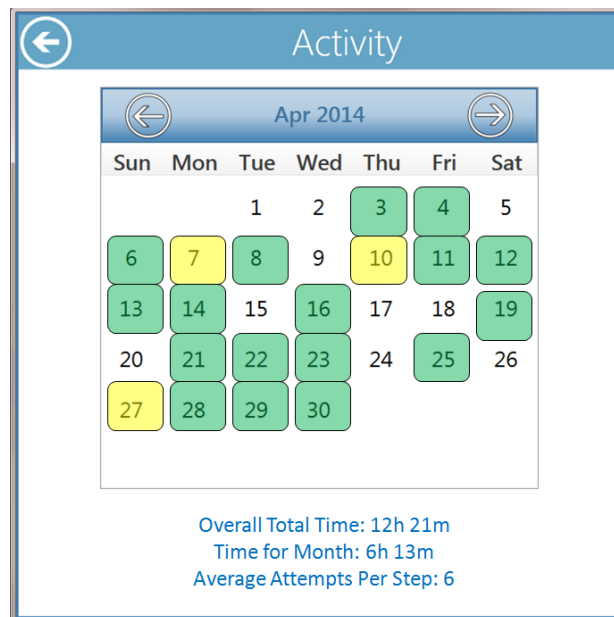
Encourage the use of new words in everyday situations

Check results and discuss difficulties

Look at how often the exercises (vocabulary topics) have been practiced on the calendar which appears when you load up each exercise. If some topics are not being used, ask why

Yellow shows it has been used but for less than 20 minutes on that day and green shows it has been used for more than 20 minutes on the marked day

If being used less than every other day and less than 20 minutes usually, remind them that the best progress is likely to be made if practice is carried out for 20-30 minutes every day, like going to the gym!



Supported practice

Watch the person using the exercises

Be patient while they think about the answer

Offer clues

Use the icons in each step from left to right to provide clues

Get them to listen to the word if they can't find it/trying gets very frustrating for them (can usually click on the picture to hear the word)

Praise any progress/achievement you see

Don't say 'well done' when they clearly got it wrong

StepByStep prompts and advice

		This is a semantic prompt providing a video of someone describing the meaning of the word.
		Click here to see a video showing the mouth movements when saying the whole word.
		Click here to see a video giving the first sound of the word.
		Click on the dictionary button to display the written word for the picture.
		Click here to see the first letter of the word in the picture.
		Click to hear the sentence spoken and to see it appear on the screen
		Click here to record your attempt and hear it played back
		Voice recognition – say the word and the computer provides feedback of accuracy.
		Click here to pass if unable to name picture (on Steps with grid)
		Start again (on Steps with grid)
		Show all/flash all pictures as a reminder (on memory grid Step)

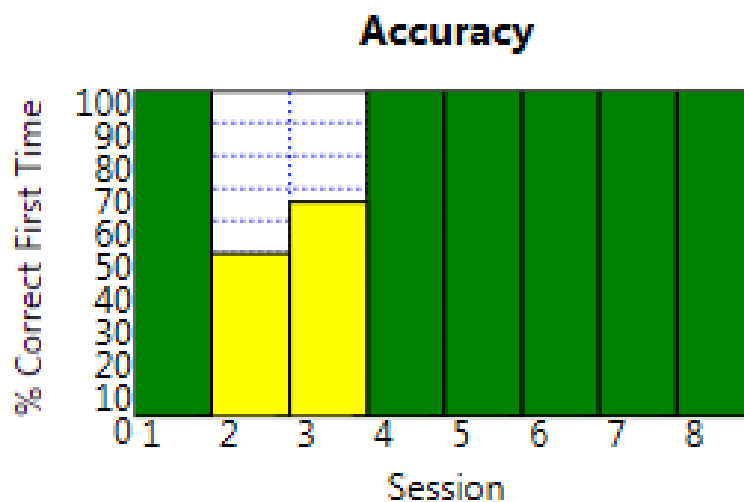
- Prompt participant to **scroll down** to see all of their vocabulary topics
- Prompt participant to **scroll across** through all the steps
- Encourage them to click through the prompts if needed from **left to right**
- If scoring >90% on a step, prompt to move onto the next step
- If consistently scoring <50% on a step, encourage them to work on a more appropriate step

Direct participant to an appropriate level of difficulty

Scroll across through the steps and look at the accuracy table for the percentage accuracy score for each step that has been completed

If scoring >90% accuracy on a step, suggest they move up to work on the next step

If the person is working at a step where they are constantly achieving <50%, suggest a more achievable step to work on.



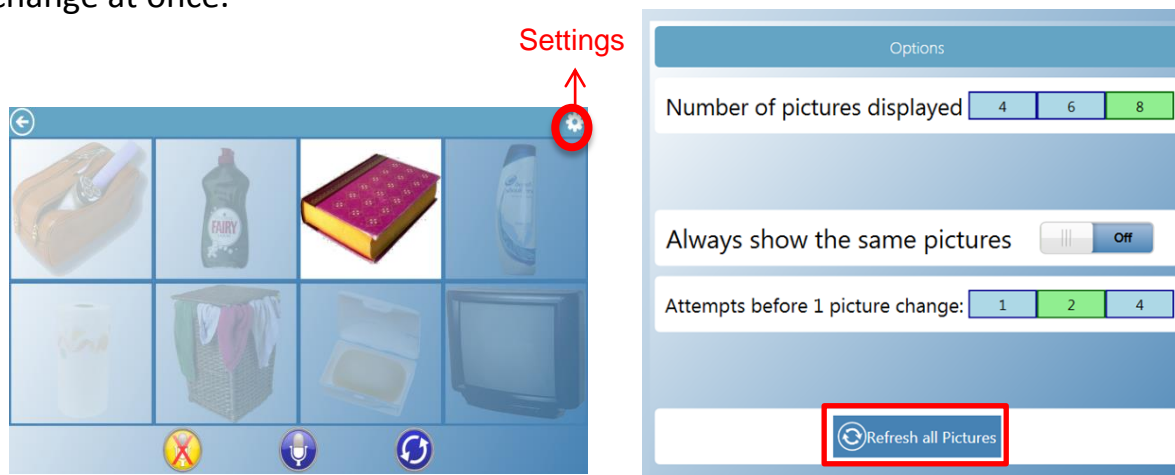
Change words in 'grid' steps

There are two different steps which use a grid to help the participant learn the words ('naming from grid' and 'naming from memory')



The pictures shown on the 'naming from grid' step change one picture at a time after each step has been attempted either once, twice or four times (which will be done by the therapist).

If the participant has been practicing this step for the vocabulary set you are looking at, click on **settings** and then click to '**refresh all pictures**' so that all the pictures change at once.



The changes made to this step are automatically duplicated to the 'naming from memory' step so the pictures shown will match.

Encourage use of the new words in conversation

Brainstorm ways of getting words used functionally everyday (can do this with family and friends if present as well as the person with aphasia)

Have conversations with person with aphasia about their interests (shown by their chosen vocabulary).

Add new word sets

If the person has worked through the words in all of the vocabulary topics set up for this project, ask them if they want to choose some more words and set up some new vocabulary for them to practice. If this is the case, speak to the therapist for advice.

Maintain use

So that the person maintains the ability to retrieve words, encourage them to practice all vocabulary on the computer each month.

Re-visit steps of confrontation naming from grid, naming from memory, sentence level naming of vocabulary for which all steps have been completed previously.

Feedback

Complete feedback form after each visit with:

What you have done

Amount of time spent

What went well

What didn't go so well

Questions to therapist

Email/send feedback form and completed visit checklist to therapist after your visit

The therapist will reply to you with advice and support by email or phone:

- recommendations of things to try
- modification of steps (e.g. adding a prompt or reducing the number of pictures to name on the grid)
- recommend adding vocabulary and explain how to do this

Record additional activity

Record dates interacted with person

Face-face, telephone or telehealth

Activity carried out

Your Health and Safety

We ask that you:

1. Take reasonable care for your own health and safety and that of others who may be affected by what you do or do not do.

In practical terms this means:

- *Always keep your mobile phone switched on*
 - *Ensure that someone always knows where you are & what time you expect to be back*
 - *Email your therapist or delegated person with all appointment times & addresses at least 24 hours before the appointment.*
 - *Park your car as close to the location as possible and in a well-lit area when dark*
 - *Reverse park for easy exit*
 - *Conceal all valuable equipment e.g. lap-top computers etc. in your vehicle*
 - *Trust your gut feeling - if you not happy about the place/situation or people hanging around etc. don't go in*
2. Do not carry out any of your voluntary duties while under the influence of alcohol or illegal drugs. Please inform your supervisor if any prescribed medication you are taking may affect your health and safety or that of others.
 3. When working with computers adjust the furniture and computer so you are comfortable, ensure the light is not shining on the screen, clean the screen when necessary, take regular breaks and work at a comfortable pace.
 4. Never give medication or assist a client to take any medication during a visit. If someone asks for your opinion on a medical matter always recommend that they consult their GP. NEVER give advice.

Confidentiality

You **should**:

1. Regard all information you have access to or have been given in this role as confidential unless advised otherwise.
2. Keep only factual and objective notes about individuals.
3. Be mindful of discussions that involve confidential information and ensure that these are not overheard or carried out in front of people who do not need this information.
4. Be mindful that confidential information included in e-mails is not necessarily completely secure (take advice from your therapist about acceptable e-mail content in line with local NHS trust policies)

You **must not**:

1. Leave confidential information lying around, ensure that it is locked away or shredded. This includes any documents that contain names or addresses of any kind.
2. Disclose information given to you to third parties without consent.

HOWEVER

If the person you are supporting makes a disclosure to you that may put themselves or others at serious risk you must inform them that you are obliged to share the information with your supervisor and a decision will be made to report to relevant others in authority (let the therapist know).

Volunteer/Assistant Agreement

Volunteers and assistants are an important and valued part of **Big CACTUS**. This agreement tells you what you can expect from us and what we hope for from you.

We will do our best to:

- assist volunteers/ assistants in carrying out their roles by providing information, support and training
- reimburse monthly, any agreed out of pocket expenses (supported by receipts & mileage travelled forms) incurred due to your involvement in **Big CACTUS**
- ensure adequate insurance cover for volunteers undertaking these duties
- consult with you and keep you informed of possible changes
- respect your skills, dignity and individual wishes and do our best to meet them
- endeavour to resolve any problems, grievances and difficulties which may occur during your involvement in **Big CACTUS**

I, _____ will do my best to:

- commit to 6 months of volunteering or assisting, to support at least one participant through their computer intervention period
- help **Big CACTUS** work with people with aphasia
- work reliably to the best of my ability
- give as much warning as possible if I cannot work when expected
- follow the local NHS trust procedures and standards, including confidentiality, equal opportunity and Health & safety
- maintain confidential information of participants
- provide receipts & expenses sheets for all agreed out of pocket expenses monthly

This agreement is binding in honour only and is not a legally binding contract of employment.

Volunteer/ assistant name

Signature

Big CACTUS lead therapist name


Signature

Date: _____

Useful Websites

<i>Speak with IT</i>	http://speakwithit.org/
<i>Step by Step</i>	http://www.aphasia-software.com/
<i>Propeller Software</i>	http://www.propeller.net/
<i>Aphasia Now</i>	http://www.aphasianow.org/
<i>Speakability</i>	www.speakability.org.uk
<i>Rehab UK</i>	www.rehabuk.org.uk
<i>Stroke Association</i>	www.stroke.org.uk

Appendix 2: Feedback form and checklist



Feedback form (for volunteers or therapy assistants)

Supporting computer therapy practice

R	/	/	/	/
---	---	---	---	---

For lead therapist use only

For communication between therapist and volunteers/therapy assistants.
Please send this back to your Big CACTUS lead therapist or hand over in person
[Note to therapists: Do not return to CTRU. Do not attempt to enter onto database]

Participant first name

Name of volunteer/assistant

Designation Therapy assistant Volunteer Other please specify

Date of home visit Distance travelled miles

Mode of transport Car Public transport Other please specify
 Taxi Community transport

Activity type(s) and duration
Please tick ✓ all that apply to indicate what type of activities you carried out and how long you spent on each activity

<input type="checkbox"/> Setting up/adjusting computer or microphone	<input style="width: 30px;" type="text"/> mins
<input type="checkbox"/> Encouraging/motivating use of the computer therapy	<input style="width: 30px;" type="text"/> mins
<input type="checkbox"/> Assistance with using software <small>(e.g. adding new exercises, moving up/down a level)</small>	<input style="width: 30px;" type="text"/> mins
<input type="checkbox"/> Conversations to practice using the words <small>(non-computer based)</small>	<input style="width: 30px;" type="text"/> mins

What did you do?

What went well? / What did not go so well?

Any issues / questions? NB Please note here if you think there is a need to change the exercises


Other contact(s) since last home visit
Please tick ✓ all that apply to indicate any other contact you have had with the participant since the last visit, and the total amount of time spent

<input type="checkbox"/> Email	<input style="width: 30px;" type="text"/> mins	<input type="checkbox"/> Video call	<input style="width: 30px;" type="text"/> mins
<input type="checkbox"/> Telephone	<input style="width: 30px;" type="text"/> mins	<input type="checkbox"/> Face-to-face	<input style="width: 30px;" type="text"/> mins

Distance travelled miles

Version number -Page number-

Complete the feedback form and checklist and return to the lead therapist by email or in person. NB. If you are going to return the pdf form by email, please ensure you download it and save it to your computer prior to starting to complete the form (otherwise it won't save what you've written!)



Volunteer/Assistant Checklist

R	/	/	/	/
---	---	---	---	---

For lead therapist use only

Think about whether you need to do each of these tasks during your visit. It is essential that you check results and discuss any difficulties, support their practice and complete the feedback form each visit

Tick the ones that you do this visit:

- Check results and discuss any difficulties
- Supported practice
- Direct participant to a more appropriate level of difficulty
- Change words showing in 'grid' steps ('naming from grid' and 'naming from memory')
- Encourage use of new words in conversation
- Maintain use (re-visit later steps for vocabulary which has been previously completed)
- Complete feedback form

Now return your completed checklist and feedback form to the lead therapist

Version number -Page number-



Feedback form (for volunteers or therapy assistants)

Supporting computer therapy practice

R			/	
For lead therapist use only				

For communication between therapist and volunteers/therapy assistants.

Please email completed form to

or hand over in person

[Note to therapists: Do not return to CTRU. Do not attempt to enter onto database]

Participant first name

Name of volunteer/assistant

Designation Therapy assistant Volunteer Other please specify

Date of home visit Distance travelled miles

Mode of transport Car Public transport Taxi Community transport Other please specify

Activity type(s) and duration

Please tick ✓ all that apply to indicate what type of activities you carried out and how long you spent on each activity

- Setting up/adjusting computer or microphone mins
- Encouraging/motivating use of the computer therapy mins
- Assistance with using software (e.g. adding new exercises, moving up/down a level) mins
- Conversations to practice using the words (non-computer based) mins

What did you do?

What went well? / What did not go so well?

Any issues / questions? NB Please note here if you think there is a need to change the exercises

Other contact(s) since last home visit

Please tick ✓ all that apply to indicate any other contact you have had with the participant since the last visit, and the total amount of time spent

- Email mins Video call mins
 - Telephone mins Face-to-face mins
- Distance travelled miles



StepByStep v5



User Guide

To open StepByStep

1. Switch the computer on



2. If needed, type in the username and password

3. Double click on the StepByStep icon



To practise your words

1. Click on **My Words**



The calendar then appears and shows the date and amount you have practised. Aim to practice for 20 minutes a day.

2. **Close** the calendar by clicking on the **back arrow**



Yellow

Practised for less than 20 minutes on the day shown

Green

Practised for more than 20 minutes on the day shown

3. **Scroll** up and down to see **all** your word **topics**



4. **Click** in the **middle** of a **box** to practise those words

You will see the last exercise you practiced with those words.
The exercises get a bit harder in each step.

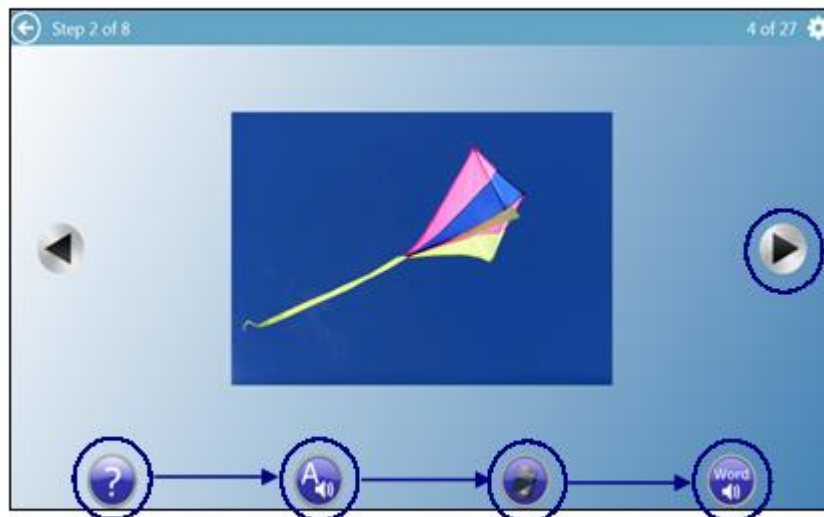
Examples of different steps

This step is to **learn** what each **picture** is **called**



You can click on the big picture to hear the word spoken
Click on the bottom picture that matches the big picture

A step like this is for you to **practise saying the word**



Click here
to move to
the next
picture

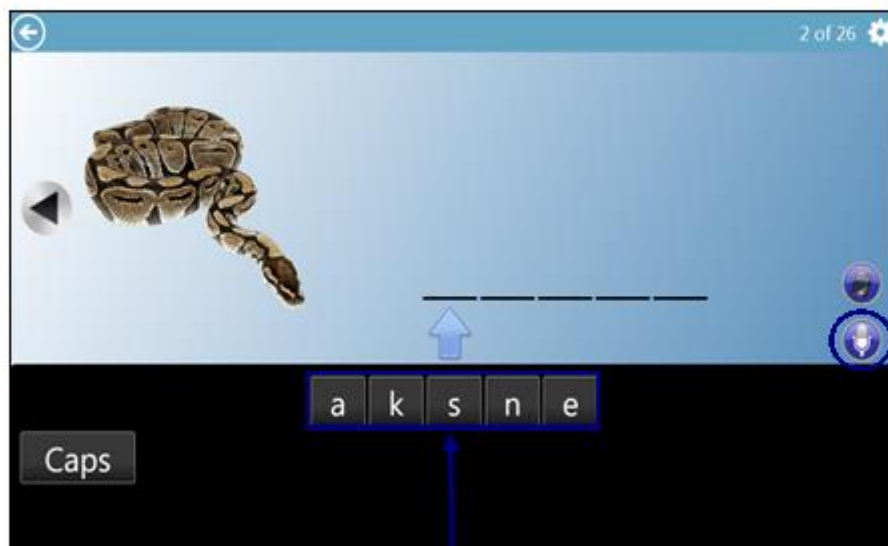
Work from left to right if you need some extra help
to name the picture shown

A step like this is to see if you can **say** the **right word**



Press this button and when it turns green, say the word the computer will tell you if you are right

Steps like this are for you to **practise spelling** the **word**



You can click here to say the word instead of spelling it

Click on the letters in the right order to spell the word

Steps like this are for you to **practise saying** the **words** you have been learning in your **topics**



Pass - click here to move on to try a different picture

Microphone - click here and when it turns green, say the name of the picture shown

Click here to start again with these pictures

This step is for you to **practise saying** the **words** that you were working on in the step before **from memory!**



Show all pictures briefly

Microphone

Start again

A step that looks like this is for you to **practise** using your **words** in **sentences**



Step 8 of 8 6 of 7

Ask me if I need these

Click to listen to and show written sentence

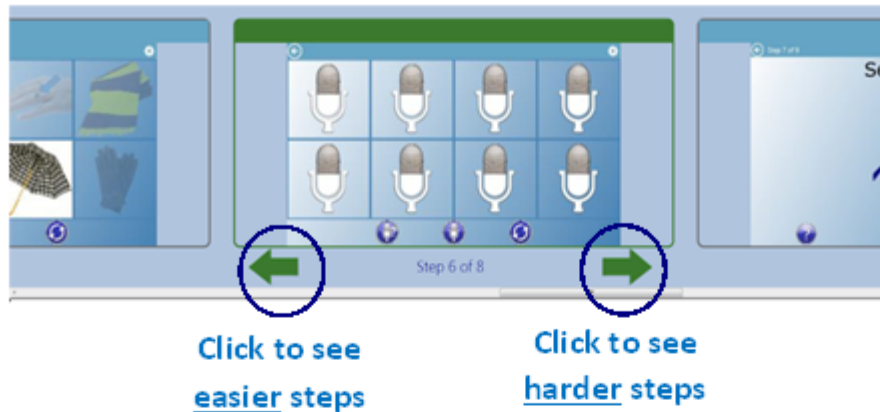
Click to say your word in a sentence as prompted at the top of the screen

Moving between steps

If you want to work on a **different step**, click on the **back arrow** to come out of the current step



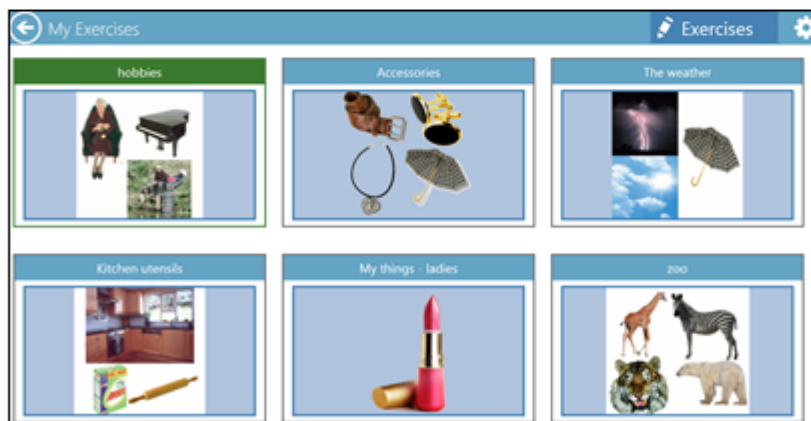
Click on the **green arrows** to choose an **easier** or **harder** step





Click in the **box** of the **step** you want to **work on**

Changing word topic


If you want to practice a **different** set of **words**, keep pressing the **back button** until you see all your word sets. Click on the **topic** you want to **work on** instead.



Closing StepByStep

When you have **finished practising** for the day, press the **back buttons**  until you get to the **first screen**. Then **click** on the  to **exit** the programme.

List of prompt buttons

		This is a semantic prompt providing a video of someone describing the meaning of the word.
		Click here to see a video showing the mouth movements when saying the whole word.
		Click here to see a video giving the first sound of the word.
		Click on the dictionary button to display the written word for the picture.
		Click here to see the first letter of the word in the picture.
		Click to hear the sentence spoken and to see it appear on the screen
		Click here to record your attempt and hear it played back
		Voice recognition – say the word and the computer provides feedback of accuracy
		Click here to pass if unable to name picture (on Steps with grid)
		Start again (on Steps with grid)
		Show all/flash all pictures as a reminder (on memory grid Step)

Extra notes/things to remember

Advice

Try to **practise** your words on StepByStep for **20-30 minutes every day**

Work through **all** your vocabulary **topics**

Start at Step 1 and move onto the **next step** if you are **doing really well** on that step

If you have any **questions** about using the **therapy software** please **contact**:

Volunteer/Assistant: _____



.....



.....

Speech Therapist: _____



.....



.....