Supported communication for access and participation

Dr Simon Horton
Supported Communication to Improve Participation in Rehabilitation of people with moderate-severe aphasia after a first stroke: a pilot study (SCIP-R)
Overview

• Communication / conversation in day-to-day life
• Doing speaking & listening: the speech chain
• Speech, language and communication impairments after stroke
• Supporting communication for people with aphasia
  – Key issues, impact & strategies
    • All about the person
    • The environment
    • Supporting understanding
    • Supporting expression
• Supported communication: resources & skills
• Putting it into practice
Learning outcomes

• After the *preparatory session* and *practical skills training* you will have
  – Furthered your understanding of the role of communication/conversation in daily life
  – Updated your knowledge of post stroke communication impairments
  – An understanding of the principles & practice of supported communication
  – Developed insights into your own supported communication skills & implementation in practice
Communication / conversation in day-to-day life

• Central to our lives as social beings
• Making and sustaining relationships
• Expressing and sustaining social identity
  – Language group / dialect / accent
  – Emotional expression, attitude etc
  – Role & identity
  – Status & ‘life history’
• Informing others and being informed: messages in / out
The speech chain...or from here to ear...and back

• Messages out
  – Selecting words to express meaning
  – Sentences – putting words in order
  – Producing speech – respiration, voice, resonance, articulation

• Sound waves travel through the air

• Messages in
  – Hearing
  – Auditory perception
  – Comprehension – decoding the speaker’s message
  – Interpreting meaning
Conversations are collaborations

• Co-operation in two-party conversations
  – Speaker speaks
  – Listener listens & shows s/he is listening
    • The two take turns

• Establishing common ground / mutual understanding
  – Speaker makes sure listener understands
    A: “I was there a week ago – I mean a week ago this Wednesday...”
    B: “aha”
  – Listener makes sure s/he has understood
    A: “I took the dog out for a walk”
    B: “You mean that old collie of yours?”
    A: “that’s the one”
‘Speech’ vs ‘language’

• ‘Speech’
  – Articulating words – co-ordinated efforts of breathing, voice, tongue, lips etc

• ‘Language’
  – Symbols representing objects, actions, ideas, emotions, qualities etc
  – Includes all modalities: speaking, listening, writing, reading, gesture (i.e. sign languages)
Speech, language and communication impairments after stroke

• Impact of nervous system pathology on
  – Language
  – Motor control (e.g. voice, articulation, breathing)
  – Cognition, including attention, memory etc
  – Special senses (i.e. vision, hearing)
  – Social communication
Speech, language and communication impairments after stroke (cont)

• **Aphasia**
  – Many different forms; may affect any modality (i.e. spoken language, writing etc)
  – Certain types may co-occur with apraxia of speech

• **Dysarthria**
  – Different forms according to site of lesion(s) and organs involved

• **Dyspraxia**
  – Oral dyspraxia; apraxia of speech

• **Pragmatic or cognitive communication disorders**
  – Use of speech/language in conversation
Aphasia: impairments

Different types according to site/s of lesion

• **Expressive** e.g. Broca’s aphasia
  – Word-finding difficulties, but preserved understanding
  – ‘Struggles’ with forming words e.g. apraxia of speech

• **Receptive** e.g. Wernicke’s aphasia
  – Fluent but ‘empty’ speech; comprehension difficulties; self-monitoring may be poor
  – Severe comprehension difficulties and no / reduced speech output

• **Mixed aphasia**, including difficulties with reading, writing, gesture etc
People with aphasia may “communicate better than they speak” (Holland, 1977)

• Social ‘rules’ of communication preserved e.g. turn-taking; ‘repairing’ problems; being informative etc
  – Question-Answer; Offer-Acceptance etc
  – Invites completion (of word; of turn etc)
  – Use of word + gesture + intonation

• Use of non-verbal communication e.g.
  – Facial expression
  – (Symbolic) gesture
  – Intonation
  – Vocal non-verbal expression
Why ‘supported communication’?

• Many barriers to access and participation

• Aphasia may mask ‘competence’
  – May be hard to see ‘the person’ / the active mind / the capacity
  – Importance of “I know that you know”
  – A person’s decision-making capacity may be questioned / person may be ‘excluded’ from discussions or decisions
  – A person may be treated as a child

• Competence can be revealed by
  – Awareness of barriers
  – Skilled communication partners
Communication in context: rehabilitation activities

• Therapy / care activities
  – Case history; assessment; doing therapy etc
• Understanding instructions / explanations
  – What has happened; what this means etc
• Day-to-day choices
  – Menus; comfort (e.g. bed / chair); pain relief etc
• Keeping in touch with people: reducing social isolation
  – Family; friends; staff; other patients
• Key decisions
  – Discharge destination; medication etc
• Family meetings: being meaningfully involved
# All about the person

## Key issues

<table>
<thead>
<tr>
<th></th>
<th>Impact</th>
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<tbody>
<tr>
<td>The lived experience not acknowledged: lack of awareness and focus on the person</td>
<td>Feels isolated</td>
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<tr>
<td></td>
<td>Validity of experience not acknowledged</td>
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<td>May not feel valued</td>
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<tr>
<td>Having to re-learn many things</td>
<td>Low confidence &amp; self-esteem</td>
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<tr>
<td>Abilities not known</td>
<td>May feel ‘useless’: own competence in doubt / unacknowledged</td>
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<tr>
<td>Not known as a person</td>
<td>May feel disorientated &amp; uncertain</td>
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<td></td>
<td>May feel unsupported / left out</td>
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<tr>
<td>Feels anxious / frightened</td>
<td>Withdraws / does not want to engage or try things</td>
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<tr>
<td>Depression / emotional reactions</td>
<td>Barrier to participation &amp; progress</td>
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<tr>
<td>Low mood</td>
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## All about the person (cont.)

<table>
<thead>
<tr>
<th>Key issues</th>
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<tbody>
<tr>
<td>Feels embarrassed / shy about communication</td>
<td>Doesn’t want to communicate / participate in activities</td>
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<td>Gives up</td>
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<td>Becomes withdrawn</td>
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<tr>
<td>Cannot communicate feelings, needs, wishes, decisions</td>
<td>Frustration and emotional upset</td>
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<tr>
<td>Not ready to take things ‘on board’</td>
<td>Barrier to participation &amp; fulfilling potential</td>
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<td></td>
<td>May restrict rehabilitation progress</td>
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<tr>
<td>Individual personal factors e.g. variability in health / well-being;</td>
<td>Time and effort for staff to accommodate individual needs</td>
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<td>effects of time of day etc</td>
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The lived experience not acknowledged: lack of awareness and focus on the person
Acknowledging the person’s lived experience
All about the person: strategies for staff

• “imagine being...”
• Treat the person as trustworthy, interesting and sincere
• Acknowledge the person’s lived experience
  – Empathise: be open to the person’s point of view & show you understand; help people feel included
    • “I understand it must be very confusing / frightening / frustrating etc”
• Take an interest in the person (‘This is me’)
  – Get to know them (bit-by-bit) & build a relationship
  – Find out about their abilities / difficulties
  – Learn from the person, colleagues, family etc
All about the person: strategies for staff (cont.)

• Accommodate individual needs
  – Give people a sense of importance and a feeling of being looked after
  – Attend to the person’s environment – be flexible (e.g. 1:1 rather than group; take time out etc)

• Help lift their mood
  – Encourage appropriately: help people to know how to try
  – Help them cope with the present

• Hard for staff “but ten times harder for the person with aphasia”
  – Share the work of communication
# The environment

<table>
<thead>
<tr>
<th>Key issues</th>
<th>Impact</th>
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</thead>
<tbody>
<tr>
<td><strong>Noise</strong></td>
<td>Trouble concentrating</td>
</tr>
<tr>
<td>• People talking (too loud)</td>
<td>Trouble understanding / making oneself understood</td>
</tr>
<tr>
<td>• Noise of TV, radio, music, Hoovers etc</td>
<td>Feeling disorientated</td>
</tr>
<tr>
<td>• Feeling disrespected</td>
<td>Feeling disrespected</td>
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<tr>
<td>• Feeling angry</td>
<td>Feeling angry</td>
</tr>
<tr>
<td><strong>Being in a 4 – 6 bedded bay</strong></td>
<td>Staff / patient / relatives chatter</td>
</tr>
<tr>
<td><strong>Being in a side room</strong></td>
<td>Isolation</td>
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</tbody>
</table>

*Staff / patient / relatives chatter:
Talking about others within earshot
Companship, mutual support, ‘modelling’
*
Noise, interruption & the mobile
The environment: strategies for staff

• Be aware; be respectful
• Think about confidentiality
• Turn down the volume / turn it off
• Ask people to be quiet(er)
• Create quiet conditions e.g. 2-3 people in a group
• Go elsewhere e.g. side room; outside etc
• Mutually supportive (group) vs privacy
<table>
<thead>
<tr>
<th>Key issues</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff do not know person’s level of understanding</td>
<td>Disempowerment</td>
</tr>
<tr>
<td>Trouble understanding</td>
<td>• Not able to take an active role</td>
</tr>
<tr>
<td>• Activity / questions / statements etc not contextualised</td>
<td>• Not included in decision-making</td>
</tr>
<tr>
<td>Does not benefit; progress slowed</td>
<td>Frustration, disorientation, anxiety</td>
</tr>
<tr>
<td>Frustration, disorientation, anxiety</td>
<td>Staff unable to help / support – feel</td>
</tr>
<tr>
<td>Frustration, disorientation, anxiety</td>
<td>frustrated and helpless</td>
</tr>
<tr>
<td>Lack of focus on the person</td>
<td>Person feels excluded / not valued</td>
</tr>
<tr>
<td>Talking to others &amp; not the person</td>
<td>Important issues / information may be missed</td>
</tr>
<tr>
<td>• Other staff</td>
<td></td>
</tr>
<tr>
<td>• Family members</td>
<td></td>
</tr>
<tr>
<td>Environmental barriers</td>
<td>Distraction for person and staff</td>
</tr>
<tr>
<td>• Noise, lighting etc</td>
<td></td>
</tr>
<tr>
<td>Personal barriers</td>
<td>Person cannot concentrate / engage</td>
</tr>
<tr>
<td>• Pain, discomfort etc</td>
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</table>
Supporting understanding: strategies for staff

• Get to know the person’s strengths and difficulties
  – Ask colleagues; listen / observe; find out what works best

• Use environmental / contextual clues
  – Who are you?
    • Name and role
  – Objects; familiar photos etc
  – Demonstrate / model activity / gesture etc
  – Put into context: “You remember the other day...”
Supporting understanding: strategies for staff (cont.)

• Concentrate on / address the person
  – Remove / avoid distractions; check source of distraction (e.g. pain, discomfort etc)
  – Eye contact: focus and watch the signs

• Quiet
  – Cut out noise
  – Go to side room; leave the group; 1:1 etc
  – Reduce ‘overload’

• Information in manageable chunks
• Always check understanding
Supporting explanations
## Supporting expression

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<tr>
<th>Key issues</th>
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</thead>
<tbody>
<tr>
<td>Cannot find words / ways to express self</td>
<td>Person is disempowered / excluded</td>
</tr>
<tr>
<td>Message is not understood / not clear</td>
<td>Frustration</td>
</tr>
<tr>
<td></td>
<td>Staff are anxious / uncertain</td>
</tr>
<tr>
<td>Not supported</td>
<td>Frustration</td>
</tr>
<tr>
<td>• Unable to finish the message</td>
<td>Lack of participation</td>
</tr>
<tr>
<td>• Unable to make use of resources (e.g. pictures; symbols; ABC s etc)</td>
<td>Distressing for staff and person with aphasia; pictures etc can seem childish</td>
</tr>
<tr>
<td>Variability / uncertainty</td>
<td>Staff uncertainty</td>
</tr>
<tr>
<td>• Yes / no confusion</td>
<td>Person is unable to convey needs, feelings, decisions etc</td>
</tr>
<tr>
<td>• Abilities change from time-to-time</td>
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Disempowered and excluded
Supporting expression: strategies for staff

• Acknowledge the difficulty
  – Take / share responsibility – “sorry I’m being so thick...”
  – Take time to keep trying
  – Stay calm / relaxed
  – Persevere: be prepared for trial & error; be prepared to ‘park’ the issue and come back later
  – Importance of arriving at an understanding (rather than ‘correct’ talk)
  – Use humour appropriately

• Don’t make assumptions
  – Establish clear Yes / No
  – Check (but don’t bombard with questions – ask one question at a time)
Supporting expression: strategies for staff (cont.)

• Create time & space
  – Check for environmental / personal barriers

• Get to know the person’s strengths and difficulties
  – Ask colleagues; listen / observe; find out what works best
  – Be responsive to the person’s skills

• Provide resources and encourage to use alternative means
  – Always have pen / paper to hand
Attending, exploring, supporting
## Resources for supported communication

<table>
<thead>
<tr>
<th>Issue</th>
<th>Resources</th>
</tr>
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<tbody>
<tr>
<td>People with aphasia cannot be rushed</td>
<td>Take time – reassure him / her you will take time to listen</td>
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<td></td>
<td>Come back later</td>
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<td></td>
<td>Build a trusting relationship: the person feels valued</td>
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<tr>
<td>Words are fleeting / inaccessible</td>
<td>Pen &amp; paper – make a record; share use of resources if you can</td>
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<tr>
<td>Aphasia is unseen / unacknowledged</td>
<td>Stroke &amp; aphasia card</td>
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<tr>
<td>Not knowing the person or their abilities / difficulties</td>
<td>Family members / colleagues (‘champions’)</td>
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<td></td>
<td>• Information on biography</td>
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<td></td>
<td>• Communicative approaches – learn from each other’s expertise</td>
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<tr>
<td></td>
<td>Interpret/reassure but not talking for</td>
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## Resources for supported communication (cont.)

<table>
<thead>
<tr>
<th>Issue</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barriers to verbal communication</td>
<td>Objects / photos etc in the immediate environment</td>
</tr>
<tr>
<td></td>
<td>Pen / paper – writing / drawing</td>
</tr>
<tr>
<td></td>
<td>Alphabets</td>
</tr>
<tr>
<td></td>
<td>Pictures; symbols</td>
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<tr>
<td></td>
<td>Newspapers, magazines etc</td>
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<td></td>
<td>Calendars</td>
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<tr>
<td></td>
<td>Maps; diagrams</td>
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<tr>
<td></td>
<td>Personal items; ‘This is me’ – meaningful resources</td>
</tr>
<tr>
<td></td>
<td>Gesture</td>
</tr>
<tr>
<td>Environmental barriers</td>
<td>Plan for interactions / meetings</td>
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<td></td>
<td>Attend to physical spaces</td>
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</table>
## Skills for supported communication

<table>
<thead>
<tr>
<th>Issue</th>
<th>Skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gaining and focussing attention</td>
<td>Remove distractions (noise etc)</td>
</tr>
<tr>
<td>• Ensure you fully capitalise on the</td>
<td>Be well positioned</td>
</tr>
<tr>
<td>person’s abilities</td>
<td>Use focussing talk (“OK, now we were going to talk about ....”)</td>
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<tr>
<td></td>
<td>Signals (facial expression; gesture etc)</td>
</tr>
<tr>
<td>Quality of your talk</td>
<td>Slow down your talk</td>
</tr>
<tr>
<td>• Speed of your talk / delivery: too</td>
<td>Introduce gaps (chunking)</td>
</tr>
<tr>
<td>fast for the person to follow</td>
<td>One question / statement at a time</td>
</tr>
<tr>
<td>• Inappropriately loud voice</td>
<td>Give time</td>
</tr>
<tr>
<td>• Talks too quickly / mumbles</td>
<td>Focus on the most important thing</td>
</tr>
<tr>
<td>• Chatters (distracting)</td>
<td>Don’t distract with ‘asides’</td>
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</table>
# Skills for supported communication (cont.)

<table>
<thead>
<tr>
<th>Issue</th>
<th>Skills</th>
</tr>
</thead>
</table>
| Quantity of your talk: giving information  
  • Too much at a time  
  • Too involved / complex / technical | Chunk talk / information – break up with pauses or ‘markers’  
Check understanding – repeat & rephrase as necessary  
Be aware of word choice (technical terms; acronyms etc)  
Show; demonstrate; model  
Give as many clues as possible  
Support verbal communication  
  • Write down (as appropriate); read out / refer back  
  • Use diagrams / pictures / communication book etc  
  • Use ‘visual punctuation’ |
## Skills for supported communication (cont.)

<table>
<thead>
<tr>
<th>Issue</th>
<th>Skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of your listening</td>
<td>Give time and (create) opportunity</td>
</tr>
<tr>
<td>• Not paying attention or listening carefully – distracted</td>
<td>• Environment</td>
</tr>
<tr>
<td>• Not attending to the message</td>
<td>• Eye contact</td>
</tr>
<tr>
<td>• Not supporting adequately</td>
<td>• Observation (non-verbal behaviour – intonation; facial expression etc)</td>
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<tr>
<td></td>
<td>• Show you are listening</td>
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<tr>
<td></td>
<td>• Offer a range / combination of strategies – share modes</td>
</tr>
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<td></td>
<td>• Summary &amp; suggestions (checks)</td>
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<tr>
<td>Respectful communication</td>
<td>Use empathy / person-centeredness</td>
</tr>
<tr>
<td>• Acknowledge difficulties and competence</td>
<td>Feed back your understanding / interpretation (where there is doubt)</td>
</tr>
<tr>
<td>• Interpret messages as communicative</td>
<td>Avoid a ‘teacherly’ manner – accept, don’t evaluate</td>
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<td></td>
<td>Humour as appropriate</td>
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</tbody>
</table>
Resourceful communication
A asks about ‘type’ of word: Yes / No

M crosses out written attempt

A suggests drawing

A suggests referent too early - rejected

M - essential features enable correct referent to be identified

get seven weeks
get two weeks
June
Practical exercise 1: role play

• In pairs threes, find out / convey biographical information about e.g. yourselves, family, place of birth etc etc

• RULES
  – No speech
  – No writing of words
  – DRAWING
  – NUMBERS
  – GESTURE, NVC only
Practical exercise 2: face-to-face training

- Each person in 1:1 conversation with communication partner trainers e.g.
  - A is with 1st trainer (20 mins) including feedback
  - A is with 2nd trainer (20 mins) including feedback etc etc
- Find out about the person e.g. background, history, family, occupation, interests etc
- Tell them about yourself and your role e.g. provide an explanation about something to do with your job; stroke care etc
Face-to-face training feedback

At the end of the 15 minute session you will be asked to

- **Consider what went well**
  - Use the feedback sheet to discuss Skills and Resources
  - Trainer discusses these points and **emphasises positive aspects**

- **Consider areas to work on**
  - Use the feedback sheet to discuss Skills and Resources
  - Trainer discusses these points and **indicates two key aspects to improve for skills and resources**

- Trainer gives overall score

- Trainee puts ‘aspects to work on’ into practice in second conversation session
Resources for day-to-day practice

• On the ward
  – *Handy pack*: key pointers / reminders / basic symbols etc
  – *Learning logs*
    • A monthly reflective record of your experiences using supported communication e.g.
      – Responding to the person
      – Supporting understanding and expression
      – Supporting participation etc
    • Identifying the need for additional support or training
Bibliography

• London Deanery [http://www.faculty.londondeanery.ac.uk/e-learning/feedback](http://www.faculty.londondeanery.ac.uk/e-learning/feedback)
• The Aphasia Institute [http://www.aphasia.ca/training/tips.html](http://www.aphasia.ca/training/tips.html) (tips on communicating with a person with aphasia)