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# EVOLUTION OF THE CONCEPTS AND METHODS ASSOCIATED WITH EXPLORING AND MEASURING THE IMPACT OF APHASIA

by

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A thesis submitted in partial fulfilment of the

requirements for the degree of

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Table 1.1
Examples of measures of function

| **Measure used** | **Type of instrument** | **Domains rated*** | **Method used to obtaining rating** | **Rater** |
|---|---|---|---|---|
| Barthel Index (Mahoney and Barthel 1965). | Domain specific | Functional status of daily activities: feeding, washing, dressing, continence, and transferring | Observed abilities (what a person can do) | Clinician or other observer |
| Index of Activities of Daily Life (ADL) (Katz and Akpom 1976) | Domain specific | Functional status of daily activities: feeding, washing, dressing, continence, and transferring | Observed abilities (what a person can do) | Clinician or other observer |
| Crichton Royal Behaviour Rating Scale (CRBRS) (Robinson 1968) | Domain specific | Functional status of daily activities: mobility, feeding, etc and mental disturbance (e.g. memory, orientation) | Observed performance (what a person actually does) | Clinician or other observer |
| Functional Independence Measure and Functional Assessment Measure (FIM/FAM) (Stineman et al 1994). | Domain specific | Personal care, mobility and walking, communication and cognition. | Observed abilities (what a person can do) | Clinician or other observer |

* = the nomenclature is that used by the authors of the tests.

Table 1.2
Examples of measures of activity and participation

| Measure used | Type of instrument | Domains rated* | Method used to obtain rating | Rater |
|---|---|---|---|---|
| Sickness Impact Profile (SIP) (Bergner 1993) | Generic | Work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication, social interaction. | Questionnaire | Subject of measurement |
| Nottingham Health Profile (NHP) (Hunt 1986) | Generic | Physical mobility, pain, sleep, energy, emotional reactions, social isolation. Effects of above on work, home, social life, sex life, interests, hobbies, holidays | Questionnaire | Subject of measurement |
| Short form-36 health survey questionnaire (SF-36) (Ware et al 1993) | Generic | Physical, role, and social functioning, mental health, energy, health perceptions & pain. | Questionnaire | Subject of measurement |
| McMaster Health Index Questionnaire (MHIQ) (Chambers 1976) | Generic | Social function Physical functions and behaviours | Questionnaire | Subject of measurement |
| Dartmouth COOP/WONCA function charts (Nelson 1983, Scholten & van Weel 1992) | Generic | Physical fitness, feelings, daily activities, social activities, changes in health and overall health. | Questionnaire | Subject of measurement |
| Impact on Participation and Autonomy (IPA) (Cardol et al 1999) | Generic | Self-care/ appearance, mobility, leisure, social relations, work, education, family role, financial independence. | Questionnaire | Subject of measurement |

* = the nomenclature is that used by the authors of the tests.

Table 1.3

Examples of measures of psychological well being

| **Measure used** | **Type of measure** | **Domains rated*** | **Method used to obtaining rating** | **Rater** |
|---|---|---|---|---|
| Self Rating Depression Scale (Zung 1965) | Disease specific | Depression | Questionnaire | Subject of measurement |
| Hamilton Depression Scale (Hamilton 1960) | Disease specific | Diagnosis of severity of depression | Observer scale | Trained clinician |
| Beck Depression Inventory (BDI) (Beck et al 1961) | Disease specific | Diagnosis of severity of depression | Questionnaire | Subject of measurement |
| Hospital Anxiety and Depression Scale (HAD) (Zigmond & Snaith 1983) | Disease specific | Frequency of experiencing symptoms of anxiety and depression | Questionnaire | Subject of measurement |
| Goldberg's General Health Questionnaire (GHQ) (Goldberg 1978, Goldberg and Williams 1988). | Disease specific | Use in General Practice. Screens for recent onset psychiatric illness | Questionnaire | Subject of measurement |

* = the nomenclature is that used by the authors of the tests.

Table 1.4

Examples of instruments that have been described as HRQoL measures

| **Measure used** | **Type of measure** | **Domains rated*** | **Method used to obtaining rating** | **Rater** |
|---|---|---|---|---|
| Sickness Impact Profile (SIP) (Deyo et al 1982 and Bergner 1993) | Generic | Work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication, social interaction. | Questionnaire | Subject of measurement |
| Nottingham Health Profile (NHP) (Hunt 1986) | Generic | Physical mobility, pain, sleep, energy, emotional reactions, social isolation.<br>Effects of the above on work, home, social life, home life, sex life, interests, hobbies, holidays | Questionnaire | Subject of measurement |
| Short form-36 health survey questionnaire (SF-36) (Ware et al 1993) | Generic | Physical, role, and social functioning, mental health, energy, health perceptions and pain. | Questionnaire | Subject of measurement |
| McMaster Health Index Questionnaire (MHIQ) (Chambers 1976) | Generic | Social function<br>Physical functions and behaviours | Questionnaire | Subject of measurement |
| EQ-5D (EuroQol Group 1990) | Generic | Mobility, self care, usual activities, pain/discomfort, anxiety/depression | Questionnaire | Subject of measurement |
| WHOQoL and WHOQOL-BREF (WHOQOL group 1998a+b) | Generic | Physical health, psychological health, level of independence, social relationships and environment. | Questionnaire | Subject of measurement |

* = the nomenclature is that used by the authors of the tests.

Table 1.5
Examples of individualised measures

| Measure used | Type of instrument | Domains rated* | Method used to obtaining rating | Rater |
|---|---|---|---|---|
| Schedule for Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle et al 1992)<br><br>and<br><br>Schedule for Evaluation of Individual Quality of Life-direct weighting (SEIQoL-DW) (Hickey et al 1996) | Generic | Domain and relative weighting selected by subject of measurement | Structured interview to elicit important areas of life, rating of current status in each area and relative importance of each of the areas. | Subject of measurement |
| Patient Generated Index (PGI) (Ruta et al 1994) | Generic | Health-related domains and relative weighting selected by subject of measurement | Structured interview to elicit activities limited by health condition, rate degree of disability, give relative importance | Subject of measurement |
| Measure Yourself Medical Outcomes Profile (MYMOP) (Patterson 1996) | Generic | Medical symptom, activity limitation and well-being (selected by subject of measurement) | Questionnaire | Subject of measurement |

* = the nomenclature is that used by the authors of the tests.

Table 1.6

Examples of measures of impairment for people with aphasia

| **Assessment** | **Type of assessment** | **Domains rated*** | **Method used to obtaining rating** | **Rater** |
|---|---|---|---|---|
| Minnesota Test for Differential Diagnosis of Aphasia (the MTDDA) (Schuell 1965) | Language battery | Auditory disturbances, visual & reading disturbances, speech & language disturbances, visuo-motor & writing disturbances, numerical relations | Pen, paper, and spoken tests | Clinician |
| Boston Diagnostic Aphasia Examination (the BDAE) (Goodglass & Kaplan 1983), | Language battery | Fluency, auditory comprehension, spatial and computational skills, oral reading, repetition, music, reading comprehension, naming, writing, automatic speech | Pen, paper and spoken tests | Clinician |
| Western Aphasia Battery (the WAB) (Kertesz 1983) | Language battery | Content, fluency, auditory comprehension, repetition, naming, reading, writing, calculation | Pen, paper and spoken tests | Clinician |
| Porch Index of Communicative Abilities (the PICA) (Porch 1967) | Language battery | Verbal responsiveness, gestural responsiveness, graphic responsiveness, visual matching Notably does not assess auditory comprehension | Pen, paper and spoken tests | Clinician |
| †Comprehensive Aphasia Test (the CAT) (Swinburn, Porter & Howard - in press) | Language Battery | 1.Cognitive screening test, 2. Language comprehension, repetition, spoken naming, reading aloud, writing, 3. Disability Questionnaire | Pen, paper and spoken test | Clinician (cognitive and language section) Person with aphasia (Disability impact section) |

| | | | | |
|---|---|---|---|---|
| Frenchay Aphasia Screening Test (Enderby 1987) | Screening Test | Auditory comprehension, verbal expression, reading, writing | Pen, paper and spoken tests | Clinician |
| Whurr Aphasia Screening Test (Whurr 1996) | Screening Test | Matching, selecting to auditory commands, repeating, reading aloud, naming, oral description, copying, writing, calculation | Pen, paper and spoken tests | Clinician |
| Boston Naming Test (Kaplan et al 1983) | Domain specific test | Picture naming | Pen, paper and spoken tests | Clinician |
| Graded Naming Test (McKenna & Warrington 1983) | Domain specific test | Picture naming | Pen, paper and spoken tests | Clinician |
| Reading Comprehension Battery for Aphasia (LaPointe & Horner 1979) | Domain specific test | Reading | Pen, paper and spoken tests | Clinician |
| Psycholinguistic Assessment of Language Processing in Aphasia (the PALPA) (Kay, Lesser & Coltheart, 1997) | Domain specific test (sub tests that measure discrete components within each domain) | Auditory processing, picture and word semantics, spoken sentence comprehension, written sentence comprehension, reading, spelling | Pen, paper and spoken tests | Clinician |

* = the nomenclature is that used by the authors of the tests themselves.

† = The CAT is not widely used as it is not yet published. It has been used in research projects (e.g. Bruce et al 2003) and will be referred to in the text of the thesis.

Table 1.7

Examples of measures of function in stroke and rehabilitation medicine

| **Measure used** | **Domains rated*** | **Method used to obtaining rating** | **Rater** |
|---|---|---|---|
| Barthel Index (Mahoney & Barthel 1965). | Functional status of daily activities: feeding, washing, dressing, continence, and transferring | Observed abilities (what a person can do) | Clinician or other observer |
| Index of Activities of Daily Life (ADL) (Katz & Akpom 1976) | Functional status of daily activities: feeding, washing, dressing, continence, and transferring | Observed abilities (what a person can do) | Clinician or other observer |
| Functional Independence Measure and Functional Assessment Measure (FIM/FAM) (Stineman et al 1994). | Functional status of daily activities: personal care, mobility and walking, communication and cognition. | Observed abilities (what a person can do) | Clinician or other observer |
| National Institute of Health Stroke Scale (Brott et al 1989) | Neurological function: vision, consciousness, arm, leg, facial movement, ataxia, sensory loss, neglect, dysarthria, language change. | Observed abilities (what a person can do) | Clinician |
| Scandinavian Stroke Scale (Scandinavian Stroke Group 1985) | Neurological Function: eye, arm, leg, hand, facial movement, gait, consciousness, orientation, speech. | Observed abilities (what a person can do) | Clinician |
| Rankin Handicap Scale (Rankin 1957) | Stroke specific. Assign grade on basis of mobility and self care/usual duties. | Subjective (I-V) rating | Clinician |
| Oxford Handicap Scale (Bamford et al 1988, 1989) | Stroke specific. Assign grade on basis of degree of handicap and independence. | Subjective (0-5) rating | Clinician |

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.8
Examples of measures of function in aphasiology

| **Assessment** | **Domains rated*** | **Method used to obtaining rating** | **Rater** |
|---|---|---|---|
| Functional Communication Profile (FCP) (Sarno 1969) | Movement, speaking, understanding, reading, writing | Estimates of ability based on informal interaction/ knowledge of the person with aphasia | Clinician |
| Edinburgh Functional Communication Profile (EFCP) (Skinner et al 1984) | Speech<br>Gesture<br>Writing | Observed ability everyday communication behaviours | Significant other/relative |
| Communication Activities of Daily Living (the CADL/CADL-2) (Holland, Frattali & Fromm, 1999) | Reading, writing, using numbers, social interaction, divergent/contextual/non-verbal communication, sequential relationships, humour/ metaphor | Ability ratings in simulation of everyday situations | Clinician |
| American Speech-Language-Hearing Association Functional Assessment of Communication Skills (ASHA FACS) (1990) | Communication independence:<br>Social communication, communication of basic needs, daily planning, reading writing & number concepts. | Observational scale | Clinician ratings plus judgements made by significant others/relatives |
| Amsterdam-Nijmegan Everyday Language Test (ANELT) (Blomert et al 1994) | Verbal communicative effectiveness only | Effectiveness ratings of monologues elicited from 20 role play scenarios. | Clinician |
| Communicative Effectiveness Index (the CETI) (Lomas et al 1989) | Verbal communicative effectiveness<br>Social participation | Estimates of change to pre-stroke performance based on knowledge of the person with aphasia | Significant other/relative |

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.9

Examples of measures of participation in stroke and rehabilitation medicine

| Measure used | Domains rated* | Method used to obtaining rating | Rater |
|---|---|---|---|
| Sickness Impact Profile (SIP) (Bergner 1993) | Work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication, social interaction. | Questionnaire | Subject of measurement or proxy |
| Nottingham Health Profile (NHP) (Hunt 1986) | Physical mobility, pain, sleep, energy, emotional reactions, social isolation. Effects of the above on work, home, social life, home life, sex life, interests, hobbies, holidays. | Questionnaire | Subject of measurement |
| Short form-36 health survey questionnaire (SF-36) (Ware et al 1993) | Physical, role, and social functioning, mental health, energy, health perceptions and pain. | Questionnaire | Subject of measurement |
| Impact on Participation and Autonomy (IPA) (Cardol et al 1999) | Self care/appearance, mobility, leisure, socials relationships, work, education, family role, financial independence. | Questionnaire | Subject of measurement |
| Reintegration into Normal Living Index (Wood-Dauphinee et al 1988) | Participation in daily, recreational, social activities, family roles, personal relationships, mobility, self-care, coping skills. | Questionnaire | Subject of measurement |
| Therapy Outcomes Measures (TOMs) (Enderby et al 1998) | Impairment, disability, 'handicap' and well-being/distress. | Subjective rating based on knowledge of the person who is the subject of measurement. | Clinician |
| Unnamed (Laman & Lankhorst 1994) | Activities derived from the ICIDH-1 disability codes, with impairments of pain, disfigurement and incontinence added. | Questionnaire | Subject of measurement |

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.10

Examples of tools used to measure activity and participation in aphasiology

| **Assessment** | **Domains rated*** | **Method used to obtaining rating** | **Rater** |
|---|---|---|---|
| Communicative Effectiveness Index (the CETI) (Lomas et al 1989) | Verbal communicative effectiveness Social participation | Estimates of change to pre-stroke performance based on knowledge of the person with aphasia | Significant other/relative |
| Therapy Outcomes Measures (TOMs) (Enderby et al 1998) | Impairment, disability, handicap, well-being/distress. | Subjective rating based on knowledge of the person who is the subject of measurement. | Clinician |
| Functional Communication Therapy Planner (Worrall 1999) | Social networks, interests and activities, communication activity and styles | Questionnaire/interviews, plus observational rating, | Clinician and person who is subject of measurement |

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.11

Examples of measures of well-being in stroke and rehabilitation medicine

| **Instrument** | **Domains rated*** | **Method used to obtaining rating** | **Rater** |
|---|---|---|---|
| General Health Questionnaire (GHQ) (Goldberg & Williams 1988) | Use in General Practice. Screens for recent onset psychiatric illness | Questionnaire | Subject of measurement |
| Beck Depression Inventory (BDI) (Beck et al 1961) | Depression | Questionnaire | Subject of measurement |
| Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith 1983) | Depression and Anxiety | Questionnaire | Subject of measurement |
| Philadelphia Geriatric Centre Morale Scale (Lawton 1975). | Well being and depression | Questionnaire | Subject of measurement |
| Zung Self Rating Depression Scale (Zung 1965) | Depression | Questionnaire | Subject of measurement |
| Hamilton Depression Scale (Hamilton 1960) | Diagnosis of severity of depression | Observer scale | Trained clinician |
| Self-Esteem Scale (Heatherton & Polivy 1991) | Self Esteem | Questionnaire | Subject of measurement |
| Self Esteem Scale (Rosenberg, 1965) | Self Esteem | Questionnaire | Subject of measurement |
| Therapy Outcomes Measures (Enderby et al 1998) | Impairment, disability, handicap, well-being/ distress. | Subjective Rating by clinician based on knowledge of the user | Clinician |

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.12
Examples of measures of psychological well-being in aphasiology

| **Measure used** | **Domains rated*** | **Method used to obtaining rating** | **Rater** |
|---|---|---|---|
| Zung Self Rating Depression Scale (Zung 1965) | Depression | Questionnaire | Subject of measurement |
| Hamilton Depression Scale (Hamilton 1960) | Diagnosis of severity of depression | Observer scale | Trained clinician |
| Beck Depression Inventory (BDI) (Beck et al 1961) | Depression | Questionnaire | Subject of measurement |
| Comprehensive Psychopathological Scale (Asberg et al 1978) | Psychopathological symptoms and their effects | Semi-structured interview | Clinician |
| Visual Analogue Mood Scale (the VAMS ) (Aitkins 1969) | Depression in those with neurological illness | Visual Analogue Scale | Subject of measurement |
| Code-Müller Protocols (Code & Müller 1992) | Psychosocial adjustment | Questionnaire | Subject of measurement, relative and clinician (comparisons made between the ratings) |
| Personal Relations Index (PRI) (Mulhall 1977) | Relationship features between user and spouse: Attitudes, feelings and behavioural states | Semi-structured interview | Subject of measurement or spouse |
| Affect Balance Scale (Bradburn 1969) | General psychological well-being; equally weighted for positive and negative feelings. | Questionnaire | Subject of measurement |
| Stroke Aphasic Depression | Depression | Rating scale of | Carer |

| | | | |
|---|---|---|---|
| Questionnaire<br>(Sutcliffe & Lincoln 1998) | | observed behaviours | |
| Psychosocial Well being Index (PWI)<br><br>(Lyon et al 1997) | Pleasure, meaning &<br>direction in daily life; degree of involvement in chosen daily activities; comfort<br>with/around others | Visual analogue scales | Person with aphasia and caregiver |
| How I Feel About Myself<br><br>(cited in Thelander et al 1994) | Well-being.<br>Domains include autonomy, environmental mastery, personal growth, positive relations, purpose in life, self-acceptance. | Questionnaire | Person with aphasia |
| Visual Analogue Self Esteen Scales (VASES)<br>(Brumfitt & Sheeran 1999b) | Self Esteem | Visual analogue rating scales | Person with aphasia |

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.13

Examples of measures of HRQoL in stroke and rehabilitation medicine

| **Measure used** | **Domains rated*** | **Method used to obtaining rating** | **Rater** |
|---|---|---|---|
| Sickness Impact Profile (SIP) (Bergner 1993) | Work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication, social interaction. | Questionnaire | Subject of measurement |
| Reintegration into Normal Living Index (Wood-Dauphinee et al 1988) | Participation in daily/ recreational/social activities, family roles, personal relationships, mobility, self-care, coping skills. | Questionnaire | Subject of measurement |
| Quality of life Index-Stroke Version (Ferrans & Powers 1985) | Stroke specific version. Measures firstly satisfaction and then importance of various domains of health and functioning, socio-economic, psychological/spiritual and family life. | Questionnaire | Subject of measurement |
| EQ-5D (EuroQol group 1990) | Mobility, self care, usual activities, pain/discomfort, anxiety/depression | Questionnaire | Subject of measurement |
| WHOQoL and WHOQOL-BREF (WHOQOL group 1998a+b) | Wide ranging but include activities of daily life, pain, energy, family life, sex life, finance, satisfaction levels | Questionnaire | Person with aphasia |
| Burden of Stroke Scale (the BOSS) (Doyle et al 2002) | Domains of functioning, psychological distress associated with specific functional limitations, and ,general well-being in stroke survivors | | Subject of measurement |
| SS-QOL (Williams et al 1999) | Stroke specific. Measures energy, family/social role, language, mobility, mood, personality, self-care, thinking, vision, arm function, work. | Interview | Subject of measurement |

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.14
Measures of HRQoL used with people with communication disability

| Instruments | Study population | Domains rated* | Method used to obtaining rating | Rater/whose perspective |
|---|---|---|---|---|
| Sickness Impact Profile (SIP) (Deyo et al 1982, Bergner 1993) | People with stroke | Work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication, social interaction. | Questionnaire | Subject of measurement |
| Reintegration into Normal Life Measure (Wood-Dauphinee et al 1988) | People with stroke | Participation in daily/ recreational,/social activities, family roles, personal relationships, mobility, self-care, coping skills. | Questionnaire | Subject of measurement |
| Quality of life Index-Stroke Version Stroke (Ferrans & Powers 1985) | People with stroke | Stroke specific version.<br>Measures satisfaction and importance of various domains of health and functioning, socio-economic, psychological/spiritual and family life. | Questionnaire | Subject of measurement |
| Short Form 36 (SF36) (Ware and Sherbourne 1992) | People with Head and Neck Cancer | Physical, role, and social functioning, mental health, energy, health perceptions and pain. | Questionnaire | Subject of measurement |
| General Health Questionnaire (12 item version) (Goldberg and Hillier 1979) | People with Head and Neck Cancer | Use in General Practice.<br>Screens for recent onset psychiatric illness | Questionnaire | Subject of measurement |
| Psychosocial Adjustment to Illness Scale (PAIS) (Derogatis 1975, 1983) | People with Head and Neck Cancer | Generic measure of psychological and social adjustment to illness in medical patients and/or relatives. | Semi-structured interview | Subject of measurement |
| Functional Assessment of Cancer Therapy – General head and neck (FACT-G) (Cella 1993) | People with Head and Neck Cancer | Disease specific instrument measuring quality of life:<br>Physical symptoms and functional status, spiritual well-being | Questionnaire | Subject of measurement |
| Voice Handicap Index | Head and Neck | Functional, physical and emotional consequences of | Questionnaire | Subject of |

| | | | | |
|---|---|---|---|---|
| (Jacobsen et al 1997) | Cancer | voice impairment | | measurement |
| LSI-A (Life Satisfaction Index) (Neugarten et al 1961) | People with traumatic brain injury | Psychological well-being: zest of living, mood tone and congruence between desired and achieved goals | Questionnaire | Subject of measurement |
| Functional Independence Measure (FIM/) (Stineman et al 1994). | People with traumatic brain injury | Functional status of daily activities: personal care, mobility and walking, communication and cognition. | Observed abilities (what a person can do) | Clinician or other observer |

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.15

Examples of measures of HRQoL used with people who have aphasia

| **Measure used** | **Domains rated*** | **Method used to obtaining rating** | **Rater** |
|---|---|---|---|
| Geriatric Evaluation of Relative's Rating Instrument (GERRI) (Schwartz 1983) | Cognitive, mood and social functioning. | Questionnaire | Relative or caregiver. |
| Functional Life Scale (Sarno et al 1973) | Activities of daily living, cognition, home/outside activity, social interaction. | Observed abilities (what person can do) | Clinician. |
| Caregivers Burden Interview (Zarit et al 1980) | Sense of burden | Questionnaire | Relative or caregiver. |
| Dartmouth COOP/WONCA function charts (Nelson 1990, Scholten and van Weel 1992) | Physical fitness, feelings, daily activities, social activities, changes in health and overall health. | Questionnaire | Person with aphasia |
| Short form-36 health survey questionnaire (SF-36) (Ware et al 1993) | Physical, role, and social functioning, mental health, energy, health perceptions and pain. | Questionnaire | Person with aphasia or clinician |
| Sickness Impact Profile (SIP) (Bergner 1993) | Work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication, social interaction. | Questionnaire | Person with aphasia or clinician |
| Behaviour, Emotion, Attitude Communication Questionnaire (Thelander et al 1993), | Behaviour, Emotion, Attitude Communication | Questionnaire | Person with aphasia |
| Affect Balance Scale (Bradburn 1969) | General psychological well-being; equally weighted for positive and negative feelings. | Questionnaire | Subject of measurement |
| How I Feel About Myself (cited in Thelander et al 1994) | Well-being. Domains include autonomy, environmental mastery, personal growth, positive relations, purpose in life, self-acceptance. | Questionnaire | Person with aphasia |

Table 2.1

Procedures undertaken during the development of the DQ

| **Stages and phases** | **Process** | **Iteration** | **No. of PWA involved** | **Nature of involvement of PWA** | **Purpose** | **Where details are shown** |
|---|---|---|---|---|---|---|
| **Stage 1 Indirect user involvement** Phase 1 | Write original instrument based on clinical experience | Original DQ **draft 1** | | | Construct instrument | Appendix 2.2 |
| | Administer DQ | DQ **draft 1** | 15 | Participants in administration plus offering unsolicited comment | Pre-test items | |
| | Modify tool | DQ **draft 2** | | | | Table 2.3 |
| Phase 2 | Administer DQ | DQ **draft 2** | 15 | Participants in administration plus offering unsolicited comment | Pre-test items | |
| | Seek expert colleague advice | | 1 (4 SLTs) | Expert advisor | Obtain expert opinion | |
| | Modify tool | DQ **draft 3** | | | | Table 2.4 |
| Phase 3 | Administer DQ | DQ **draft 3** | 10 | Participants in administration plus offering unsolicited comment | Pilot instrument | |
| | Modify tool | DQ **draft 4** | | | | Table 2.5 |
| | Administer DQ | DQ **draft 4** | 40 | Participants in administration plus offering unsolicited comment | Field test instrument | |
| | Modify tool | DQ **draft 5** | | | | Table 2.6 |
| | Administer DQ | DQ **draft 5** | 47 | Participants in administration plus offering unsolicited comment | Field test instrument | |
| **Stage 2** | Conduct focus | DQ **draft 5** | 7 | Expert advisors | Obtain expert | |

| | | | | | | |
|---|---|---|---|---|---|---|
| **Direct user involvement** | groups with DQ users (SLTs & people with aphasia) | | (plus 9 SLTs) | | opinion | |
| | Modify tool | CDP **draft 1** | | | | Table 2.11 |
| **<u>Stage 3</u> Direct user consultation** | Group interviews | | 13<br><br>(7+6) | Expert informants | Include users - ensure content validity | |
| | Individual in depth interviews | | 13 | Expert informants | Include users - ensure content validity | |
| | Convene advisory group | | 3 (plus one non-aphasic family counsellor) | Expert advisors | Include users - ensure content validity | |
| | Modify tool | CDP **draft 2** | | | | Table 5.3 |
| **<u>Stage 4</u> Clinical usability** | Field testing | CDP **draft 2** | 23 (15 SLTs) | Participants in administration plus solicited comment | | |
| | Modify tool | CDP **draft 3** | | | | Table 5.12 and Appendix 5.26 |

Table 2.2

Rationale for DQ item inclusion

| Question | Original rationale |
|---|---|
| | All items are rated by the person with aphasia and therefore represent that person's perception of the situation. |
| Q 1-4 | Situations and people who commonly facilitate or hinder *comprehension* for someone who has aphasia. The items focus on varying degrees of intimacy and familiarity between speakers, and the number of people taking part in the exchange. |
| Q 5-8 | Situations and people who commonly facilitate or hinder *talking* for someone who has aphasia. The items focus on varying degrees of intimacy and familiarity between speakers, the physical situation and the number of people taking part in the exchange. |
| Q 9-12 | Common literacy-based activities, which vary in the amount and accessibility of the text to be *read*. |
| Q 13-16 | Common literacy-based activities, which vary in the amount and complexity of the text to be *written*. |
| Q 17-19 | The acknowledgement, anxiety and functional relevance of the reported challenges in everyday life. |
| Q 20-23 | The extent to which the difficulties reported above had an impact have on everyday life. |
| Q 24-31 | Emotional states commonly reported as being associated with having aphasia. |
| Q 32-33 | Levels of satisfaction with current and future life. |

Table 2.3

Changes made between the DQ drafts 1 & 2

(following administration of DQ with 15 people with aphasia)

| Type of change | Changes made. | Question/ headings | DQ draft 1 | DQ draft 2 | Rationale for changes |
|---|---|---|---|---|---|
| Inclusion & accessibility. | Mode of administration | Whole tool | (self completion) | (therapist-administered) | To ensure ratings are by the person with aphasia (not caregiver). Ease of administration |
| Acceptability. | Reworded | Q1 | understand YOUR WIFE/ HUSBAND | your FAMILY | To be relevant to those not married. |
| Accessibility. | Reworded | Q2 | understand ONE OTHER PERSON | A STRANGER | To specify which other person. |
| Accessibility. | Reworded | Q3 | understand A SMALL GROUP of people who are NOT YOUR FAMILY | A SMALL GROUP | Simplification of language. |
| Acceptability & accessibility. | Reworded after re-conceptualisation | Q4 | understand TV or RADIO | TV | Elimination of double question (...or...), as ability may vary between the two options. |
| Accessibility. | Reworded | Q6 | find the right words/put sentences together when talking to SOMEONE YOU DON'T KNOW | A STRANGER | Simplification of language. |
| Acceptability & accessibility. | Reworded after re-conceptualisation | Q7 | find the right words/put sentences together when talking to CLOSE FRIENDS | A SMALL GROUP | Reduction of ambiguity. Focusing on number of people rather than intimacy of relationship. |
| Accessibility. | Reworded | Q14 | spell/write OTHER SINGLE | other single words (EG. | Use of exemplar. |

| | | | | | |
|---|---|---|---|---|---|
| | | | WORDS | A SHOPPING LIST) | |
| Accessibility. | Reworded | Q15 | spell/write A LETTER OR CARD | A LETTER | Deletion of double questions (…or…). |
| Acceptability & accessibility. | Reworded after re-conceptualisation | Q16 | spell/write AN OFFICIAL FORM (e.g. a household bill) | an official LETTER (e.g. a letter or complaint of enquiry) | Reduction of ambiguity. Forms do not necessarily require any writing, can be ticked/crossed. |
| Acceptability & accessibility. | Reworded after re-conceptualisation | *Q19 | Does your communication AFFECT YOUR DAILY LIFE | Deleted | Repetitive given Q20-23 which are 'Which aspects of the difficulty affect your daily life ...' |
| Acceptability | Reworded after re-conceptualisation | Heading | **EMOTIONS:** | **DISTRESS:** | New title intended to convey the negative emotions associated with aphasia (will be revisited). |
| Acceptability | New rating introduced: | Emotion section | none – a little – a lot | 5 (Always, a lot)<br>4 (sometimes, a lot)<br>3 (always, a little)<br>2 (sometimes, a little)<br>1 (never) | Dissatisfaction with rating based solely on intensity of emotion. Needed temporal element to convey consistency of emotional state. |
| Acceptability | Reworded after re-conceptualisation | *Q30 | ACCEPTING | HOPELESS | Seen as patronising/ superficial. More commonly expressed emotion introduced. |
| Acceptability | Reworded after re-conceptualisation | *Q31 | PLEASED | PESSIMISTIC | Seen as patronising/ superficial. More commonly expressed emotion introduced. |
| Acceptability | Reworded after re-conceptualisation | Q33 | NEGATIVE | DISSATISFIED WITH LIFE | Seen as superficial. More commonly expressed emotion introduced. |

Questions or items that are not mentioned were not changed between iterations.

* the numbers on this table for draft 1 do NOT correspond to the numbering on the original DQ draft 1 shown in figure 2.1. The numbering has been changed from the original in this table to increase clarity of this table. The item content and wording does not vary between figure 2.1 and this table.

Table 2.4

Changes made between drafts 2 & 3 of the DQ

(after 'expert' colleague consultation and administration with 15 people with aphasia)

| **Type of change** | **Changes made.** | **Question/ headings** | **DQ draft 2** | **DQ draft 3** | **Rationale for changes** |
|---|---|---|---|---|---|
| Accessibility & acceptability | Mode of administration | Whole tool | Spoken administration only | Help-sheets introduced | Reduce barrier that comprehension impairment might present. |
| Accessibility & acceptability | Method of scoring | Whole tool | 5 (unable) to 1 (no problem) | 4 (Unable) to 0 (no problem) | Felt that 0 (rather than 1) denoting 'no problem' was clearer . |
| Acceptability | Rewording after re-conceptualisation | Q1 | Understand your FAMILY | THE PERSON YOU ARE CLOSEST TO | Reducing ambiguity. Main focus is degree of intimacy. |
| Accessibility | Rewording | Q2 | Understand A STRANGER | SOMEONE YOU DON'T KNOW AT ALL | Simplification of language. |
| Accessibility | Rewording | Q3 | Understand A SMALL GROUP | IN A SMALL GROUP OF PEOPLE | Reducing ambiguity. |
| Acceptability | Rewording after re-conceptualisation | Q4 | Understand the TV | SOMEONE IN AUTHORITY E.G. A DOCTOR OR BENEFITS OFFICER | Elimination of ambiguous item dependent on the programme. Introduction of new concept. Strengthen notion of hierarchy within each section. |
| Accessibility | Rewording after re-conceptualisation | Q5 | find the right words/put sentences together when talking to YOUR FAMILY | THE PERSON YOU ARE CLOSEST TO | Reducing ambiguity. |

| | | | | | |
|---|---|---|---|---|---|
| Accessibility | Rewording | Q6 | find the right words/put sentences together when talking to A STRANGER | SOMEONE YOU DON'T KNOW AT ALL | Simplification of language. |
| Accessibility | Rewording after re-conceptualisation | Q8 | find the right words/put sentences together when talking to ON THE PHONE OR BEHIND A GLASS BARRIER e.g. post office/ticket office | UNDER PRESSURE OR IN A STRESSFUL SITUATION | Reducing ambiguity (these situations may lack relevance for an individual PWA). |
| Acceptability | Rewording after re-conceptualisation | Heading | **HANDICAP:** | **EMOTIONAL IMPACT:** | Rejection of the assumption of negative emotions relating to aphasia |
| Acceptability & accessibility | Rewording after re-conceptualisation | Q19 | Have you LOST CONFIDENCE in yourself as a result of your communication | Have you lost confidence as a result of your communication? | Simplification of language. |
| Acceptability. | New concept introduced. | | | Do you feel other people understand what's wrong? | Lack or presence of empathy seen as relevant to explore. |
| Acceptability. | New concept introduced. | | | Have you lost any self esteem as a result of your communication difficulty? | Expansion of the self-image concept. |
| Acceptability. | New concept introduced. | | | Do you feel isolated as a result of your communication difficulty? | Expansion of the self-image concept. |
| Acceptability & accessibility | Rewording after re-conceptualisation | Q25 | DEPRESSED | SAD | Felt depressed had unhelpful connotations. |
| Acceptability. | New concept introduced. | | | Lonely | Suggested as a relevant concept to include. |

Questions or items that are not mentioned were not changed between iterations.

Table 2.5

Changes between the DQ drafts 3 & 4

(following after 10 administrations of the DQ with people with aphasia,)

| **Type of change** | **Changes made.** | **Question/ heading** | **DQ draft 3** | **DQ draft 4** | **Rationale for changes** |
|---|---|---|---|---|---|
| Acceptability | Rewording | 'Activities' questions i.e.Q1-16 | 'how DIFFICULT is it for you to…' | 'how EASY is it for you to…' | Attempt to reduce the causal connection between impairment and disability. |
| Accessibility | Rewording | Q2 | Understand SOMEONE YOU DON'T KNOW AT ALL | Understand SOMEONE YOU DON'T KNOW | Simplification of language. |
| Acceptability & accessibility | Rewording after re-conceptualisation | Q3 | Understand IN A SMALL GROUP of people | Small group of FRIENDS | Comments by PWA* that ease of communication dependent on *who* was in the group/degree of intimacy. |
| Acceptability & accessibility | Rewording after re-conceptualisation | Q7 | find the right words/put sentences together when talking to A SMALL GROUP | Small group of FRIENDS | Comments by PWA* that ease of communication dependent on *who* was in the group/degree of intimacy. |

| | | | | | |
|---|---|---|---|---|---|
| Acceptability & accessibility | Rewording after re-conceptualisation | Q11 | read and understand AN OFFICIAL FORM (eg a bill) | an official LETTER | Reduction of ambiguity. Forms thought variable more in amount of *reading* necessary. |
| Acceptability & accessibility | Rewording after re-conceptualisation | Q15 | spell/write A LETTER | spell/write a letter TO A FRIEND | Increased specificity as ease of writing dependent on *who* was being written to. |
| Acceptability & accessibility | Rewording after re-conceptualisation | Q17 to Q20 | Which aspects of the difficulty affect your daily life ... | I want to find out how the communication difficulties you've just told me about affect your daily life, (*reiterate an example of where they have difficulty*) how much does that affect you on a day to day basis? | Clarification of issue. Need to highlight focus PWA on the activities they had previously described, and how they were barriers to daily life. |
| Accessibility | Rewording | Q21 | Do you feel you have any DIFFICULTIES WITH COMMUNICATION since your stroke | HOW WOULD YOU RATE your communication difficulties since the stroke? | Simplification of language in an attempt to establish if PWA perceived aphasia as a disability |
| Accessibility | Rewording | Q22 | If you have any difficulties - do they WORRY YOU | DO THESE difficulties worry you? | Simplification of language. |
| Acceptability | Item deleted | Q23 | Do you feel OTHER PEOPLE UNDERSTAND what's wrong? | | Degree of understanding by others dependent on many factors. Very variable. Rating therefore felt invalid. |

| | | | | | |
|---|---|---|---|---|---|
| Accessibility | Rewording | All emotions questions | Could you indicate which words describe how you feel about your communication since your stroke? | We're going to look at how that makes you feel. I'm going to suggest some feelings and I want you to indicate if you ever feel this emotion. If you do, how much? | Attempt to reduce the formality of the style of questioning.<br>Attempt to break the assumption of negative emotions associated with aphasia. |
| Acceptability | Item deleted | Q30 | LONELY | | Repetitious.<br>Too close to isolated. |

PWA* = people with aphasia

Questions or items that are not mentioned were not changed between iterations.

Table 2.6

Changes made between the DQ drafts 4 & 5

(after extensive piloting with 47 people)

| Type of change | Changes made | Question | DQ draft 4 | DQ draft 5 | Rationale for changes |
|---|---|---|---|---|---|
| Acceptability | Rewording after re-conceptualisation | Q3 | Understand a small group of FRIENDS | Understand 3 or 4 friends OR FAMILY | Specifying the number involved to reduce ambiguity. Highlighting that either social group could be equally intimate. |
| Acceptability | Rewording after re-conceptualisation | Q7 | Find the right words/put sentences together when talking with a small group of FRIENDS | Find the right words/put sentences together when talking with 3 or 4 friends OR FAMILY | Specifying the number involved to reduce ambiguity. Highlighting that either social group could be equally intimate. |
| Acceptability | Rewording after re-conceptualisation | Q9 | Read and understand SINGLE WORDS | Read and understand A SINGLE WORD | Reduce ambiguity. Attempt to highlight that focus is reading a word in isolation. |
| Acceptability | Item deleted | Q33 | Optimistic | | Confusion by both poles of same concept being asked. |

PWA* = people with aphasia

Questions or items that are not mentioned were not changed between iterations.

Table 2.7
Target sampling characteristics for user field trial

focus group of people with aphasia

| **Criteria** | **Groupings** | **Target** |
|---|---|---|
| Number of people | | 8 |
| Gender | Male | 4 |
| | Female | 4 |
| Race | White | |
| | Non-white | At least one |
| Age | AP in their 40s | At least one |
| | AP in their 50s | At least one |
| | AP in their 60s | At least one |
| | AP in their 70s | At least one |
| Duration of living with aphasia | Less than one year | 4 |
| | More than 18months | 4 |
| Living Status | Living alone | 4 |
| | Living with family/partner | 4 |
| Severity of impairment of expression | Severe | At least one |
| | Mild | At least one |
| Type of impairment of expression | Fluent | At least one |
| | Non-fluent | At least one |
| Severity of impairment of comprehension | Moderate | At least one |
| | Mild | At least one |

Table 2.8
Sampling characteristics for the SLT user field trial focus group

| **Criteria** | **Groupings** | **Target** |
|---|---|---|
| | | |
| Number of therapists | | 9 |
| | | |
| Gender: | Male | At least one man |
| | Female | |
| | | |
| Age | > 40 | At least one |
| | <40 | |
| | | |
| Experience | Under 2 years | 3 |
| | 2-5 years | 3 |
| | Over 5 years | 3 |
| | | |
| Type of work | Acute | 3 |
| | Rehabilitation | 3 |
| | Community | 3 |
| | | |
| Location of work | Metropolitan | |
| | Non-metropolitan | At least one |

Table 2.9

Sampling success for user field trial focus group of people with aphasia

| Criteria | Characteristics | Target | Actual | Achieved |
|---|---|---|---|---|
| Number of people | | 8 | 7 | √ |
| Gender | Male | 4 | 4 | √ |
| | Female | 4 | 3 | √ |
| Race | White | | 6 | √ |
| | Non-white | At least one | 1 | √ |
| Age | AP in their 40s | At least one | 1 | √ |
| | AP in their 50s | At least one | 2 | √ |
| | AP in their 60s | At least one | 1 | √ |
| | AP in their 70s | At least one | 3 | √ |
| Duration of living with aphasia | Less than one year | 4 | 2 | √ |
| | More than 18months | 4 | 5 | √ |
| Living Status | Living alone | 4 | 4 | √ |
| | Living with family/partner | 4 | 3 | √ |
| Severity of impairment of expression | Severe | At least one | 1 | √ |
| | Mild | At least one | 2 | √ |
| Type of impairment of expression | Fluent | At least one | 2 | √ |
| | Non-fluent | At least one | 5 | √ |
| Severity of impairment of comprehension | Moderate | At least one | 4 | √ |
| | Mild | At least one | 3 | √ |

Table 2.10

Sampling characteristics for the user field trial

focus group of SLT

| Criteria | Characteristics | Target | Actual | Achieved |
|---|---|---|---|---|
| Number of therapists | | 9 | 9 | √ |
| Gender | Male | At least one man | 1 | √ |
| | Female | | 8 | √ |
| Age | > 40 | At least one | 0 | X |
| | <40 | | 9 | √ |
| Experience | Under 2 years | 3 | 3 | √ |
| | 2-5 years | 3 | 4 | √ |
| | Over 5 years | 3 | 2 | √ |
| Type of work | Acute | 3 | 2 | √ |
| | Rehabilitation | 3 | 4 | √ |
| | Community | 3 | 3 | √ |
| Location of work | Metropolitan | | 8 | √ |
| | Non-metropolitan | At least one | 1 | √ |

Table 2.11

Changes between the DQ (draft 5) & the Communication Disability Profile[1] (draft 1)

(after administration of DQ draft 5 with 47 people with aphasia and consultation with user focus groups)

| Type of change | Changes made. | Question/ headings | DQ draft 5 | CDP draft 1 | Rationale for changes |
|---|---|---|---|---|---|
| Acceptability and accessibility | Rewording after re-conceptualisation | Q1 to Q16 | Compared with before your stroke, how easy is it for you to... | Since your stroke how easy is it for you to.. | Phrasing questions positively. Simplifying the language. |
| Acceptability and accessibility | Reordered | Q1-4 | 'Talking' section now comes first | | Talking felt to be the most pertinent area and the one that PWA* were anticipating talking about. |
| Accessibility | Reworded. | Q1 | Find the right words/put sentences together when talking to THE PERSON YOU ARE CLOSEST TO | TALK to the person YOU ARE closest to | Simplify the language. |
| Acceptability and accessibility | Reordered to come after question relating to person closest to them. | Q2 | Find the right words/put sentences together when talking to SOMEONE YOU DON'T KNOW | TALK with 3 OR 4 FAMILY OR FRIENDS | Keeping questions relating to familiar people together. |
| Accessibility | Reworded. | Q3 | Find the right words/put sentences together when talking to SOMEONE YOU DON'T KNOW | TALK to someone you don't know | Simplify the language. |
| Acceptability and accessibility | Reworded. | Q4 | Find the right words/put sentences together when talking UNDER PRESSURE OR IN A | TALK IF YOU ARE STRESSED | Simplify the language. Reduce ambiguity by deletion of double question (or). |

[1] The term Communication Disability Profile (or CDP) relates to the DQ in its next stage of its development. These changes are detailed in chapter 5.

| | | | | | |
|---|---|---|---|---|---|
| | | | STRESSFUL SITUATION | | |
| Acceptability | New item for each communication activity section | Q5, 12, 19, 26. | This question appears at the end of each communication activities section (talking, understanding, reading, writing). | Any other situations or things that make *TALKING (etc.)* difficult? | Reduce the prescriptive nature of the tool.<br>Allows PWA to bring own experiences to the dialogue. |
| Acceptability | Reordered (as above), also reworded and rescaled. | Q6, 13, 20, 27. | This question appears at the end of the communication activities within each section (talking, understanding, reading, writing). | So you've told me that its most difficult for you when...but that ... is easier, is that right? What's that like on a DAY TO DAY basis? | Wording was simplified. Wording changed to enable rating by use of one scale only as suggested by PWA & clinicians. |
| Acceptability and accessibility | Reordered to be included in each communication activity section. | Q7, 14, 21, 28. | This question appears at the end of the communication activities within each section (talking, understanding, reading, writing). | Does that WORRY YOU? | Enable rating using one scale |
| Acceptability and accessibility | Reordered to come after question relating to person closest to them. | Q9 | Understand SOMEONE YOU DON'T KNOW | 3 OR 4 FAMILY OR FRIENDS | Keeping questions relating to familiar people together |
| Acceptability and accessibility | Rewording after re-conceptualisation | Q11 | Understand the SOMEONE IN AUTHORITY e.g. a doctor or a benefits officer | Understand WHEN YOU'RE UNDER PRESSURE | Reducing ambiguity (the exemplar situations may lack relevance for PWA).<br>Reducing prescriptive nature. |
| Accessibility | Reworded. | Q15 | read and understand A SINGLE WORD | Read and understand a single word LIKE A WORD ON A LIST | Addition of real life exemplar. |
| Accessibility | Reworded. | Q16 | read and understand SHORT PHRASES (e.g. a newspaper headline) | Read and FOLLOW a newspaper headline | Simplified language. |
| Acceptability and accessibility | Reworded and reordered | Q17 | read and understand AN OFFICIAL LETTER | Read and follow A PIECE IN A PAPER | Simplified language.<br>PWA suggested hierarchy was different. |
| Acceptability | Reworded and | Q18 | read and understand AN | Read and FOLLOW AN | Simplified language. |

| | | | | | |
|---|---|---|---|---|---|
| and accessibility | reordered | | ARTICLE IN A PAPER OR A PAGE IN A BOOK | OFFICIAL LETTER | PWA suggested hierarchy was different. |
| Accessibility | Reworded | Q22 | spell/write OTHER SINGLE WORDS (e.g. a shopping list) | Spell other single words LIKE a shopping list | Simplified language. |
| Acceptability and accessibility | Reworded | Q16 | spell/write AN OFFICIAL LETTER (e.g. a letter or complaint of enquiry) | write an official letter | Deleted exemplar to simplify question and reduce prescriptive nature of the tool. |
| Acceptability and accessibility | Deleted item | | HOW WOULD YOU RATE your communication difficulties since the stroke? | | Seen as redundant. Previously a lead-in question for the impact on daily life section. This section has now been spread over rest of tool. |
| Acceptability | | Heading | DISTRESS | EMOTIONAL CONSEQUENCES | Attempt to move away from negative assumptions. |
| Accessibility | Rubric reworded | Emotions section | We're going to look at how that makes you feel. I'm going to suggest some feelings and I want you to indicate if you ever feel this emotion. If you do, how much? | | |
| Acceptability and accessibility | | Q29 | Have you LOST CONFIDENCE as a result of your communication? | Are you confident about your communication? | Moved to be with other 'emotion' questions.<br>Positive pole used. |
| Accessibility | Reworded. | Q30, 31, 32 | FRUSTRATED, SAD, ANGRY | Does your communication make you *frustrated, sad, angry?* | |
| Acceptability and accessibility | Rewording after re-conceptualisation | Q33 | | Do you feel in control of your communication? | Positive pole used in attempt to reduce the negativity of this section. |
| Acceptability | Item deleted | | HELPLESS and HOPELESS | | Reduce the negativity of the questioning.<br>Neutral version added in Q35. |
| Acceptability | Item deleted | | UNFAIR | | Reduce the negativity of the |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | questioning. In contrast to other emotions Qs, recognition that little action could be taken if PWA did feel it was unfair. |
| Acceptability | Reworded. | Q34 | STUPID | Some people feel stupid because their communication has changed, do you ever feel stupid? | Enable acknowledgement of masked competence. |
| | | | PESSIMISTIC | | Reduce the negativity of the questioning.<br>Neutrally worded in Q35. |
| Acceptability and accessibility | Rewording after re-conceptualisation | Q35 | | When you look to the future how do things look? | Reduce the negativity of the questioning.<br>Neutral wording used. |
| Acceptability and accessibility | Rewording after re-conceptualisation | Q36 | DISSATISFIED WITH LIFE | How do things look today? | Reduce the negativity of the questioning.<br>Neutral wording used. |
| Acceptability | Un-rated item added | Q37 | | Do you have people who are important to you? | Reduce the negativity of the tool. |
| Acceptability | Un-rated item added | Q38 | | Are there things you enjoy at the moment? | Possibility of ending on a positive theme. |

PWA* = people with aphasia

Questions or items that are not mentioned were not changed between iterations.

Table 4.1

Sampling characteristics of group interview SLT participants

| Criteria | Characteristics | Achieved |
|---|---|---|
| Number of people with aphasia | | 13 |
| Gender | Male | 9 |
| | Female | 4 |
| Ethnicity | White | 11 |
| | Non-white | 2 |
| Age | AP in their 40s | 1 |
| | AP in their 50s | 2 |
| | AP in their 60s | 8 |
| | AP in their 70s | 2 |
| Duration of having aphasia | Less than one year | 3 |
| | More than 18months | 10 |
| Living Status | Living alone | 5 |
| | Living with family/partner | 8 |
| Expressive impairment | Severe | 2 |
| | Mild | 6 |
| Expressive type | Fluent | 3 |
| | Non-fluent | 10 |
| Receptive ability | Moderate | 3 |
| | Mild | 10 |

Table 4.2

Sampling characteristics of the individual in-depth interview participants

| **Criteria** | **Characteristics** | **Target** | **Actual** | **Achieved** |
|---|---|---|---|---|
| Number of people with aphasia | | 20 | 13 | X |
| Gender | Male | 50% | 6 | √ |
| | Female | 50% | 7 | √ |
| Ethnicity | White | | 12 | √ |
| | Non-white | At least one | 1 | √ |
| Age | AP in their 40s | At least one | 1 | √ |
| | AP in their 50s | At least one | 4 | √ |
| | AP in their 60s | At least one | 7 | √ |
| | AP in their 70s | At least one | 1 | √ |
| Duration of having aphasia | Less than one year | 50% | 11 | X |
| | More than 18months | 50% | 2 | X |
| Living Status | Living alone | At least one | 9 | √ |
| | Living with family/partner | At least one | 4 | √ |
| Expressive impairment | Severe | At least one | 4 | √ |
| | Mild | At least one | 5 | √ |
| Expressive type | Fluent | At least one | 3 | √ |
| | Non-fluent | At least one | 10 | √ |
| Receptive ability | Moderate | At least one | 3 | √ |
| | Mild | At least one | 10 | √ |

Table 4.3
Biographical details of the expert advisory group

| | **Harry** | **Sue** | **John** | **Gwen** |
|---|---|---|---|---|
| **Age** | 48 | 47 | 68 | 48 |
| **Sex** | Male | Female | Male | Female |
| **Ethnic background** | White | White | White | White |
| **Duration of aphasia** | 14 years | 13 years | 7 years | N/a |
| **Type of aphasia** | Non fluent (mild word finding & comprehension difficulties) | Non fluent (mild word finding & comprehension difficulties) | Fluent (significant difficulty with comprehension & expression) | N/a |
| **Current job** | Counselling | Counselling | Not employed | Family support worker |
| **Duration of working with PWA* (described in their own words)** | 10 years counselling/support | On & off since 1993, doing workshop with Chris Ireland - counsellor since 1999 | Learning the internet, pushing for Bristol (second Connect site), talk a lot, try to help people, teaching at groups | At Connect, 1 year Stroke Assoc., Family Support Worker (1 year) Dysphasia Support Organiser (2 and 1/2 years) |

* PWA denotes people with aphasia

Table 5.1

Changes to the participation section as a result of direct user consultation (stage 3)

| **Artist's Version** | **Original wording** | **Advisory panel comments relating to the *picture*** | **Advisory panel comments relating to *wording*** | **Advisory panel comments relating to *concept*** | **Outcome** |
|---|---|---|---|---|---|
| Version 1 | How does that get in the way for you in everyday life? (appendix 5.1) | Inaccessible | Unacceptably negative. | Ill-defined | Redraw.<br>Rethink concept of participation.<br>Expand section.<br>Reword. |
| Version 2 | How is talking in everyday life? (appendix 5.2) | Inaccessible and obscure | Inaccessible, obscure. | Ill-defined | Reconsider procedure for this section.<br>Delete picture. |
| | What makes talking worse? (appendix 5.3) | Inaccessible | Conceptually inadequate. | Ill-defined | Redraw.<br>Rethink concept of participation.<br>Expand section.<br>Reword. |
| | What makes talking easier? (appendix 5.4) | Accessible and acceptable | Conceptually inadequate. | Ill-defined | **Picture-final version**<br>Rethink concept of participation.<br>Expand section.<br>Reword. |
| | Are there people who make talking easier? (appendix 5.5) | Too difficult to identify specific people, non-family not represented. | Conceptually inadequate. | Ill-defined | Redraw.<br>Rethink concept of participation.<br>Expand section.<br>Reword. |
| Version 3 | How are things you WANT to do? | Minor amendments to details. | Needed discussion to refine wording. | Acceptable and accessible. | Minor changes to increase accessibility/acceptability of picture.<br>**(appendix 5.6)**<br>Minor changes to perfect wording. |

| | | | | | |
|---|---|---|---|---|---|
| | How are things you HAVE to do? | Acceptable and accessible | Needed discussion to refine wording. | Acceptable and accessible | **Picture-final version.** (appendix 5.7) Minor changes to perfect wording |
| | How are things at HOME? | Acceptable and accessible. | Needed discussion | Needed minor amendments to details | Minor changes to increase accessibility/acceptability. **(appendix 5.8)** |
| | What HELPS? (introducing the concept) | Already finalised | | | (appendix 5.4) |
| | WHO helps? (identifying specific facilitators) | Acceptable and accessible. | Needed discussion to refine wording. | Needed discussion around issue of race. | **Picture-final version. (appendix 5.9)** Minor changes to perfect wording |
| | What THINGS help? (identifying specific facilitators) | Minor amendments to details. | Needed discussion to refine wording. | Needed minor amendments to details | Minor changes to increase accessibility/acceptability. (produced **appendix 5.10 – final version).** Minor changes to perfect wording. |
| | What makes it HARDER? (introducing the concept) | Minor amendments to details. | Needed discussion to refine domains | Needed minor amendments to identify domains to be included. | Minor changes to increase accessibility/acceptability of picture. (produced **appendix 5.11 – final version).** Minor changes to perfect wording. |
| | Who makes it harder? | Acceptable and accessible. | Needed discussion. | **Acceptable and accessible.** | **Picture-final version. (appendix 5.12)** Minor changes to perfect wording |
| | What makes it harder? (identifying | Minor amendments to details. Need for additional | Needed discussion. | Highlighted insufficiency of barriers. | Redraw picture, add more barriers to original drawing. (produced appendix 5.13 then **final** |

| | | | | | |
|---|---|---|---|---|---|
| | specific barriers) | picture. | | | **version appendix 5.14)**<br>Add new picture (with several amendments) depicting behaviours that act as barriers in conversation<br>**(final version appendix 5.15)** |

Table 5.2

Comparison of the *structures* of CDP drafts 1 and 2

| **CDP 1** | **CDP 1** | **CDP 1** | | **CDP 2** | **CDP 2** | **CDP 2** |
|---|---|---|---|---|---|---|
| Domain | Item content | Method of rating | | Domain | Item content | Method of rating |
| **Disability self-rating:** | | | | **Talking** | | |
| 1. **Talking** | 4 communication activity items | One stage | | Activities | 4 communication activity items | One stage |
| | 1 open-ended item | One stage | | | | |
| | 1 participation item | One stage | | | | |
| | 1anxiety item | One stage | | **Expressing yourself** | | |
| 2. **Understanding** | 4 communication activity items | One stage | | Activities | 4 communication activity items | One stage |
| | 1 open-ended item | One stage | | | | |
| | 1 participation item | One stage | | | | |
| | 1 anxiety item | One stage | | **Understanding** | | |
| 3. **Reading** | 4 communication activity items | One stage | | Activities | 4 communication activity items | One stage |
| | 1 open-ended item | One stage | | | | |
| | 1 participation item | One stage | | | | |
| | 1 anxiety item | One stage | | **Reading** | | |
| 4. **Writing** | 4 communication activity items | One stage | | Activities | 4 communication activity items | One stage |
| | 1 open-ended item | One stage | | | | |
| | 1 participation item | One stage | | | | |
| | 1 anxiety item | One stage | | **Writing** | | |
| | | | | Activities | 4 communication activity items | One stage |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | **Participation** | 3 participation items<br>(things have to do, want to do and at home) | One stage |
| | | | | **External influences** | 4 items identifying facilitators & barriers<br>(what helps, what hinders) | Not rated |
| **Emotions** | 8 items | Two stage | | **Emotional consequences** | | |
| | 1 item relating to significant others | Not rated | | 1. Self image | 6 items | Two stage |
| | | | | 2. Feelings | 6 items | Two stage |
| | | | | 3. Satisfaction | 2 items | One stage |
| | Total items | 37 items | | Total items | 41 items | |

Table 5.3
Changes between CDP drafts 1 & 2

| Type of change | Changes made. | CDP draft 1 | CDP draft 2 | Rationale for changes |
|---|---|---|---|---|
| Accessibility and acceptability. | | Written text with written help-sheets | Inclusion of pictures throughout for every question, and every phase of explanation. | |
| | Rewording to increase specificity. | Since your stroke how easy is it for you to: | Q1-4 Since your stroke, during the last week, **(picture)** how easy is it for you to: | Increase psychometric robustness. |
| Accessibility. | Reworded item.<br>Item order changed. | Talk to **someone you don't know?** | Talk with a group of friends? | Reordered on advice of panel, and in line with endorsement frequencies |
| Accessibility. | Reworded item.<br>Item order changed. | Talk to **3 or 4 family or friends?** | Talk to a stranger, someone you don't know? | Reordered on advice of panel, & in line with endorsement frequencies |
| Acceptability. | Reworded item. | Talk **if you** are stressed? | Talk under pressure? | Place emphasis on environment not individual |
| Acceptability.<br>Accessibility. | Items moved to form a new section.<br>Section expanded as detailed below (*) | What's that like on **a day to day** basis? | | Having these items after each section was repetitive. It also erroneously assumed that PWA could distinguish effect of *each* modality (talking, reading etc.) on participation. |
| Acceptability.<br>Accessibility. | Items moved to form a new section.<br>Section expanded as detailed below (○) | Any **other people or situations** that are difficult? | | Having these items after each section was repetitive. Again erroneously assumed that PWA could distinguish effect of different people on *each* modality (talking, reading etc.) |
| Acceptability | New section introduced. | | Express yourself with the person closest to you | Enable people who use non-verbal methods to demonstrate their competence<br>Validate the experience of communicating through nonverbal means. |
| Acceptability.<br>Accessibility. | New section introduced. | | Express yourself with a group of friends | See above |

| | | | | |
|---|---|---|---|---|
| Acceptability.<br>Accessibility. | New section introduced. | | Express yourself with someone you don't know | See above |
| Acceptability.<br>Accessibility. | New section introduced. | | Express yourself if you are under pressure" | See above |
| Accessibility. | Reworded on advice from panel. | Understand **the person closest to you (use person's name)?** | Understand a stranger, someone you don't know | |
| Accessibility | Reworded on advice from panel. | Understand **3 or 4 family or friends?** | Understand in a group | |
| Accessibility. | Reworded on advice from panel. | Read and understand a **single word** like a word on a list? | Read and follow one word | Concept now supported by picture. |
| Accessibility. | Reworded on advice from panel. | Read and follow **a newspaper headline?** | Read and follow a headline | |
| Accessibility. | Reworded on advice from panel. | Read and follow **piece in a paper?** | Read and follow a whole story in a paper | |
| Accessibility. | Reworded on advice from panel. | Spell/write your **name and address?** | Write your name? | |
| Accessibility. | Reworded on advice from panel. | Spell **other single words** like a shopping list | Write other single words like a list? | Concept now supported by picture. |
| Acceptability.<br>Accessibility. | *Expanded participation section.<br>Reworded on advice from panel. | *What's that like on **a day to day** basis? | *How are things you have to do? | Conceptually ill-defined. |
| Acceptability.<br>Accessibility. | Expanded participation section. | | How are things you want to do? | Reworded on advice from panel. |
| Acceptability.<br>Accessibility. | Expanded participation section. | | How are things at home? | Home seen as crucial to well being and identity |
| Acceptability.<br>Accessibility. | ○Expanded external influences section.<br>Reworded on advice from panel. | ○Any **other people or situations** that are difficult? | WHO helps? | Conceptually ill-defined.<br>Redefine components relating to external influences |

| | | | | |
|---|---|---|---|---|
| Acceptability. Accessibility. | Expanded external influences section – new item. | | What THINGS helps? | See above |
| Acceptability. Accessibility. | Expanded external influences section – new item. | | WHO makes it harder?' | See above |
| Acceptability. Accessibility. | Expanded external influences section – new item. | | WHAT makes it harder? | See above |
| Accessibility. | Changes to manner of presentation. Reworded on advice from panel. | | Do any of these show living with aphasia makes you feel? | Giving some element of choice to people with aphasia |
| Accessibility. | Reworded on advice from panel. | Are you **confident** about communicating? | Does living with aphasia make you feel less confident? | Disliked word 'communication'. Attempt to break the causal link between impairment and disability. |
| Acceptability. | Reworded on advice from panel. | Do you feel **in control** of your communication? | Does living with aphasia make you feel less in control? | Stress that control relates to life situations NOT communication ability. |
| Acceptability Accessibility | New concept on advice from panel. | | Do you feel able? | Positive expression of construct of competence. Worded on advice from panel. |
| Acceptability. Accessibility. | Original concept reintroduced. Reworded on advice from panel. | | Does living with aphasia make you isolated? | |
| Acceptability. Accessibility. | Original concept reintroduced. Reworded on advice from panel. | Some people **feel stupid** because their communication has changed, do you ever **feel a bit daft?** | Does living with aphasia make you embarrassed? | Focus on emotional consequence of misperceived competence. |
| | New concept introduced and worded on advice from panel. | | Do you feel valued? | Positive expression of construct of respect |

| | | | | |
|---|---|---|---|---|
| Accessibility. Acceptability. | Reworded on advice from panel. | Does your communication make you **angry?** | Does living with aphasia make you ever feel angry? | Reduce causal link between impairment and disability. |
| Accessibility. Acceptability. | | Does your communication make you **frustrated?** | Does living with aphasia make you frustrated? | Reduce causal link between impairment and disability. |
| Accessibility. Acceptability. | New concept introduced and worded on advice from panel. | | Do you feel determined? | Positive expression of construct of determination |
| Accessibility. Acceptability. | Reworded on advice from panel. | Does your communication make you **sad?** | Does living with aphasia make you unhappy? | |
| Accessibility. | Reordered. Reworded on advice from panel. | Does that **worry you** ? (but added four times at the end of each communication activity section) | Does living with aphasia make you feel worried? (asked once only) | Concept confined to single question only. |
| Acceptability. | New concept introduced and worded on advice from panel. | | Do you feel content? | Positive expression of construct of contentment |
| Acceptability. | New concept introduced and worded on advice from panel. | | What is fun for you? | Enabling expression of positive aspects of current life |
| Acceptability | New concept introduced and worded on advice from panel. | | Is there anything else that is important to you about living with aphasia? Anything you feel we haven't covered? | Reduce prescription. |
| Acceptability. | New concept introduced and worded on advice from panel. | | Is there anything you would like to say about your life now? | Reduce prescription. |

Questions or items that are not mentioned were not changed between iterations.

Question numbers have been omitted. There is significant variation between the drafts in which question numbers relate to items, they were therefore seen to be unhelpful.

Table 5.4

Endorsement frequencies for communication activity items in the DQ (draft 4)

| **Item** | **N at twelve month** | **Mean at twelve months** |
|---|---|---|
| Talk-closest | 35 | 1.61 |
| Talk-stranger | 35 | 2.26 |
| Talk-group | 28 | 2.29 |
| Talk-pressure | 35 | 2.79 |
| Comp-closest | 35 | 0.6 |
| Comp-stranger | 35 | 1.26 |
| Comp-group | 35 | 1.59 |
| Comp-authority | 30 | 1.65 |
| Read-word | 35 | 0.96 |
| Read-headline | 35 | 1.5 |
| Read-official | 35 | 2.31 |
| Read-article | 35 | 2.43 |
| Write-name | 35 | 1.21 |
| Write-word | 35 | 1.76 |
| Write-friend | 35 | 2.86 |
| Write-official | 35 | 3.26 |

Table 5.5

External influences expressed in qualitative interviews

| **Item within the CDP** | **Exemplar from the qualitative in-depth interviews** |
|---|---|
| *PEOPLE that HELP or HINDER – talking/understanding* | |
| Partner | Wife, partner, partner encouraging AP to think for themselves, partner offers clues, husband supplies word |
| Brother/sister | Brother |
| Son and daughter, | Daughter helps, one son good, one son not, difference between sons |
| Granddaughter/son/other children | Grandchildren easy, children better |
| Friend/neighbour | Friends at work, old friend fantastic, neighbour, friends – rejection , friends less relaxed than family, two good friends treat me the same, friends very helpful |
| Other people/health/social care | Nurse wrote letter to the bank, speech therapy, volunteer, surveyor |
| People look away | Try to get away, people don't listen |
| Interrupting | Talk over me, interrupted |
| Looking bored/ attentive | Negative attitudes, interested in conversation, keeping interested |
| Noisy/busy | Too much going on gets in the way |
| Far away | Added/agreed by advisory panel |
| Two talking at once | They talked and not to me |
| Cover face | Added/agreed by advisory panel |
| Speak quickly | Talks quickly |
| Other barriers/facilitators | Picks out one person in a group to talk to when groups problematic, someone speaks for me others filling in words |
| *THINGS that HELP– talking/understanding* | |
| Listen to me | Interested in conversation, friendly and interested, respect, positive attitudes, positive reactions help |
| Telling people (help cards) | Tell people had a stroke, pretence at being non-aphasic, fine telling close friends about aphasia –not others, helped to tell people |

| | |
|---|---|
| Extra time | Talking - extra time, patience, he was impatient |
| Pictures | Added/agreed by advisory panel |
| Writing things down | Someone scribing, writes things down in bank, write instead of speak |
| Other facilitators | Talks one to one, picks out one person in a group, simplifies language, takes deep breaths, rephrasing, thinks before speaking, use of first letter, repetition, talking slow and posh, rabbit on when stuck for word, writing instead of speaking, having a laugh about it |
| *THINGS that HINDER - talking /understanding* | |
| Glass barrier | Added/agreed by advisory panel |
| Queues | Added/agreed by advisory panel |
| Phone | Phone |
| Upset | Agitated, vicious circle, worse if upset, struggling makes it worse |
| Tired | Tiredness, worse when tired |
| Other barriers | Others filling in words, changing topic of conversation |
| *Things that HELP - reading/writing* | |
| Someone helping | Someone scribing at history class, volunteer helps spelling by doing crosswords, neighbour fills in betting slips |
| Speaking books | Listen to radio, listens to taped books |
| Extra time | Extra time, extra time for reading |
| Dictionary | Dictionary |
| Large print | Print better than writing |
| Computer | PC (computer) – can self-correct |
| Other facilitators | Reading to self at night, re-reading, reading out loud, using a piece of paper as a guide, leaving writing and coming back to it |
| *Things that HINDER- reading/writing* | |
| Glass barriers | Added/agreed by advisory panel |
| Queues | Added/agreed by advisory panel |
| Wrong hand | Added/agreed by advisory panel |

| | |
|---|---|
| Upset | Added/agreed by advisory panel |
| Under pressure | Added/agreed by advisory panel |
| Tired | Added/agreed by advisory panel |
| Too much | Multi-tasking |

Table 5.6

Emotional constructs from which to select

| **Emotional construct** | **Origin** | **Other words used to refer to construct *** |
|---|---|---|
| *Less control* | Interviews | Helpless, incapable, dependent, being trapped |
| *Less confidence* | Interviews/DQ | Lost confidence |
| *Embarrassed* | Interviews/?DQ | Embarrassed, (?self esteem) |
| *Isolated* | Interviews/DQ | Isolated, excluded, being ignored, unloved, rejected, neglected |
| *Angry* | Interviews/DQ | Angry, mad |
| *Frustrated* | Interviews/DQ | Frustrated |
| *Sadness* | Interviews/DQ | Sad, depressed, unhappy, down a bit |
| *Anxiety* | Interviews/DQ | Anxious, frightened, worried |
| *Able* | Interviews/?DQ | Can't do things, incompetent, a nutter, not being normal (?self esteem), stupid |
| *Valued* | Interviews/?DQ | Lack of respect, being small, lower down (?self esteem) |
| *Determined* | Interviews | Determined |
| *Contented* | Advisory panel | Sense of loss, being whole |
| Independent | Advisory panel | |
| Uptight | Interviews | Uptight |
| Shocked | Interviews | Shocked |
| Tired | Interviews | Tired, exhausted, knackered |
| Proud | Interviews | Proud |
| Hopeless | Interviews/DQ | Hopeless |
| Unfair | Interviews/DQ | Unfair |
| *Optimistic* | Interviews/DQ | Pessimistic, optimistic |
| *Satisfied with life* | Interviews | Positive attitude, dissatisfied with life |

* = Both positive and negative aspects of the construct are mentioned
*italics* = those ultimately selected
?DQ = emotional constructs that could be subsumed within the self esteem question of the DQ.

Table 5.7

Sampling characteristics for the London field trial SLTs

| **Criteria** | **Groupings** | **Target** | **Actual** |
|---|---|---|---|
| | | | |
| Number of therapists | | 10-15 | 15 |
| | | | |
| Gender | Male | At least one man | 0 |
| | Female | | 15 |
| | | | |
| Age | 20-29 | At least one | 3 |
| | 30-39 | At least one | 5 |
| | 40-49 | At least one | 3 |
| | 50+ | At least one | 4 |
| | | | |
| Experience | Under 2 years | At least one | 1 |
| | 2-5 years | 3 | 4 |
| | Over 5 years | 3 | 10 |
| | | | |
| Type of work | Acute | At least one | 3 |
| | Rehabilitation | 3 | 5 |
| | Community | 3 | 7 |
| | | | |
| Location of work | Metropolitan | | 15 |

Table 5.8

Biographical details of pilot-test participants (people with aphasia)

| **Characteristic** | **Number** |
|---|---|
| Number of administrations: | 23 |
| Age: | |
| Under 40 | 0 |
| 41-50 | 2 |
| 51-60 | 7 |
| 61-70 | 6 |
| over 70 | 8 |
| Sex: | |
| Male | 12 |
| Female | 11 |
| Ethnicity: | |
| White British | 19 |
| Asian | 1 |
| Afro-Caribbean | 3 |

Table 5.9
Reported experiences of pilot testers ( people with aphasia) on CDP administration

| **Views regarding OVERALL PROCEDURE:** | **Number** |
|---|---|
| - Positive<br>(those asterisked rated the content as appropriate but added comments that suggest limitations – see below) | 21 |
| - Negative | 0 |
| - Unable to comment | 2 |

| **Area of interest** | **Comments**<br>**(verbatim transcription taken from the feedback forms)** |
|---|---|
| CONTENT and overall perception: | Content was relevant<br>Found it very helpful<br>Thought it was useful<br>Identified with the emotions illustrated<br>She seemed to enjoy it, in that she was engaged and keen to respond<br>Very thought-provoking – enabled her to discuss concerns re: future, think in structured way about impact of aphasia in different settings (tumour)<br>She liked the fact that it addressed areas of her life that weren't usually addressed<br>Felt it really focussed on her as a person and overtly respected her point of view<br>Put (us) on the right track<br>Commented that some situations were not appropriate to him (didn't ever do the shopping or go to the bank)<br>Some sections were positive using encouragement and feedback e.g. domains 1-20<br>Others were negative e.g. barriers; emotional consequences, lifestyle/particaption (dependent on |

| | |
|---|---|
| | mood - patient's whole performance in therapy changes, depends on whether feeling positive or negative. Overall a mixed picture.<br>Thought was helpful to talk about emotions<br>Both liked the emphasis on THEIR perspective and that it was respectful of them<br>Brought up fact that he did not think his partner always understood the difficulties he experienced (useful)<br>* some situations were variable e.g. talking with a group of friends could be easier but sometimes not |
| FORMAT:<br>- general | Felt pictures were useful – easy to identify with<br>Seemed easy to do<br>Happy to comply but because of expressive difficulties unable to comment about procedure but seemed to find it helpful<br>Both liked the pictures<br>Both liked the no 'right/wrong' aspect<br>Liked the pictures –very helpful<br>Scales useful<br>Commented that some situations the rating varied<br>*Emotional scale – more confusing<br>*Not prepared to be pigeon-holed, especially in the emotions section<br>* emotions scale complicated – took time to accept it<br>She was happy that the procedure was accessible to her. Because it was pictures she did not strain herself trying to produce words to express herself, especially in the emotions section which are more difficult to express at times<br>Found it hard to cope to cope with the 'barriers' section – wanted to rate each one. He also found participation section difficult to score and finally we scored each area separately (NB Patient is single, living on own, no mobility problems but 'relatives' section a bit tricky). |
| - length: | Good<br>* found it exhausting (this person had an untreatable brain tumour)<br>Not too long |

Table 5.10
Reported experiences of therapists during CDP pilot testers

| **Views regarding OVERALL PROCEDURE:** | **Number** |
|---|---|
| No. of SLTS reporting that there was one or more people they chose not to administer the CDP with | 7 |
| CONTENT:<br>- Appropriate<br>(those *ed rated the content as appropriate but added comments that suggested limitations)<br>- NOT appropriate | 20<br><br><br><br>3 |
| FORMAT:<br>- Easy to use<br>(those asterisked rated the format as easy to use but added comments that suggest limitations)<br>- NOT easy to use<br>- Variable (see comments below) | <br>16<br><br><br>1 (this SLT only had the opportunity to administer the CDP once)<br>5 |

| **Area of interest** | **Comments**<br>**(verbatim transcription taken from the feedback forms)** |
|---|---|
| Reasons for NOT administering the CDP or stopping once started | Significantly reduced comprehension<br>Very early stages of recovery<br>Client anxious - overwhelmed by any form of assessment<br>Client could not understand the purpose of the assessment-unable to relate situations to self (very recently acquired aphasia)<br>Concern that person would be unable to differentiate between problems due to aphasia and problems due to |

| | |
|---|---|
| | shingles<br>Chose not to do with people who had aggressive high grade tumours currently undergoing treatment<br>In-patients – too soon after CVA e.g. poor attention, distress<br>It was not age appropriate, he was a young stroke patient who could express himself well. He also had a lot of unresolved issues relating to his relationship with his wife and wanting to go back to work. He also did not relate well to other people with strokes as he saw them as all old and had nothing more to do in life compared with him who still had his whole life ahead of him. The pictures mainly depicted an older person who had a stroke therefore it was difficult for him to related or he may feel depressed by this. |
| CONTENT:<br>- general | Some situations he avoids or has never done<br>Generally very good<br>Participation section was really important section for him<br>Content good and relevant as shown by strong reaction to some of the pictures and questions<br>Content was appropriate<br>Content relevant with the opportunity for him to elaborate<br>*Opens up several other issues for client that SLT not necessarily able to deal with<br>Pictures were very appropriate – identified well with them and also the 'what helps'.<br>Felt pictures were useful – easy to identify with<br>Felt all content relevant<br>Felt participation section was over too quickly and was rather generalised<br>'worried' and 'content' queried by both participants<br>One client commented that single word and headline reading varied - sometime she could and sometimes she couldn't<br>Mostly apart from emotional factors; patient insight heightened by the negative changes<br>Items were relevant but perhaps need to choose/omit some if patient becomes anxious<br>The items were relevant to all situations that an aphasic person may experience post stroke |
| - aphasia separate from other areas: | Looking to the future brought up general issues i.e. the uncertainty she was feeling about future strokes.<br>Still participating actively in daily life however emotional issues have greatest impact<br>*Found it difficult to explain looking only at aphasia and not mobility problems in case of impact on participation. |

| | |
|---|---|
| | * Had some difficulty explaining only looking at aphasia NOT mobility fatigue<br>* Fatigue experienced in CVA also has big impact so not always easy to distinguish.<br>*Difficult to isolate dysphasia from other difficulties e.g. hemiplegia and hearing loss<br>*Required cues ++ to rate linguistics of writing (tended to focus on mechanics-dyspraxic)<br>Some areas not relevant because housebound and physical impairment having more impact on daily life. |
| FORMAT:<br>- general | Easy to use<br>Scoresheet simple<br>Relatively easy to use<br>We couldn't have covered the ground without this format<br>Scoring was good ,<br>Easy to use<br>Fairly easy – domains 1-20 for example – but not the barriers section or emotional consequences section. |
| - Structure: | *Initially difficult using lots of pictures but got easier, difficult reading from the script<br>*Initially difficult switching between pictures and scale – settled down with time<br>*Too many pictures initially however, this did get easier<br>*Difficulty underst. emotions positive rating, rating each participn domain,<br>*Not sure if rating one or 3 emotions pictures<br>* did get a bit lost (no page numbers, asking for totals for the participation sections)<br>*At times my explanations were a bit wordy<br>Lots of information presented e.g. the groupings of things you want to do and then the rating scale<br>Fewer laminated sheets to choose from or combining one/two |
| - Length: | I think the CDP is an appropriate length<br>Tended to elaborate on each section so the TIME taken increased<br>*Can be quite time consuming<br>* took a long time to administer and long time to respond (cognitive problems)<br>Felt needed to spent more time discussing the last section (when and why do you feel that)<br>Took longer than anticipated and would have liked to have spent more time going into 'when are things better and why?'<br>Need to discuss with PWA that administration may be lengthy |

| | |
|---|---|
| | Very lengthy to do in one session – might be tempted to skip the discussion which we felt was very very useful (inoperable tumour)<br>Took 1 and ½ hours – one session (inoperable tumour)<br>Exhausting but liked the fact that it enabled him to give HIS perspective – he surprised his wife (positive) (brain tumour)<br>Do sections only of the CDP rather than in entirety<br>Both clients had mild expressive aphasia and it took 2-3 sessions to complete<br>Took time to elicit the scores – undertaken over 2-3 sessions – shorter format would be helpful |
| - Script/scoresheet: | Further instructions would have been good for scoring<br>Once mastered the script relatively straightforward<br>Easy to use though verbatim text could be improved with boxes, upper case etc.<br>* could instructions be bigger or somehow more obvious<br>*Found it difficult reading from a script felt this affected the interaction<br>* + and – on scoresheet - not immediately apparent what it means<br>Not sure that quantification was terribly relevant – would look at which emotional issues there were rather than lumping them all together – though I can see some merit in quantifying in this way<br>Scoring was OK once patient was focused |
| - Accessible: | Felt would be able to use with all abilities<br>Emotional scales took time and practice – definitely needed repetition and gesture<br>*Don't know that he understood the 'understanding' section.<br>*When administered at home appropriate table space required and tricky keep using all cue cards<br>* table space tricky esp. at home<br>* additional questions in emotional section were very difficult with client with severe aphasia<br>* some confusion over which end of the scale to use, needed lots of repetition (cognitive changes so slower at grasping task)<br>Unable to convey difference between talking and expressing your self (memory problems)<br>Couldn't understand the 'able' picture<br>Accessible but a bit fiddly with using different pages. |
| - Acceptable: | Less 'flow' in barriers section – not all situations applied |

| | |
|---|---|
| | *Occasionally the person wanted to score in between ratings<br>*Floundered a bit talking about things you have to do – client wanted to talk about each one specifically<br>* emotional scale - very complex and difficult to be black and white in such a grey area (found I was able to discuss the issues re; the scales BUT adds to already lengthy consultation)<br>Wanted to be placed between scale points |
| - General comments: | *hadn't used it for weeks started expression section inappropriately<br>*became easier with use/familiarity<br>* On occasion responded in a 'concrete' way as opposed to the concept as a whole (cognitive impairments)<br>People with memory problems = recapping on previous sessions very difficult if done over no. of sessions |
| RELEVANT TO CLINICAL PRACTICE? | I think you have devised a very useful and well thought out instrument. The comments are mere suggestions<br>CDP used on client who had previously identified conversation with wife as a problem (so did the SPPARC programme – unsuccessful – wife reported they never have had big conversations (pre-morbidly). Was hoping that CDP would clarify this) and it did – it showed that conversations were OK<br>It enabled us to discuss some issues more and highlight others e.g. confidence was a bigger issue than I had realised.<br>Nice comparison between their in-patient stage…there can be quite a shift and that's implied but you can reflect that<br>Really useful (to do serially) showed them the numbers and we negotiated what we were going to do…seeing it in front of them in a concrete way was really useful<br>It has lead on to further discussion and moving away from impairment towards living with aphasia<br>It was a gentleman I know quite well but there were still a few surprises<br>Both felt it was directly relevant to their daily lives/living with aphasia<br>Highlighted issues within their support/family network and their individual coping skills<br>Gave 'objective/formal' structure as a forum for discussing emotional issues – increased confidence to address these BUT perhaps needs to be done in separate session – difficult to return to sensitive areas that may not need dealing with as is uncovered/revealed<br>Information useful, provided additional information that helped in subsequent sessions<br>Definitely guided management as I knew what the main concerns were and could use that in treatment |

| | |
|---|---|
| | Both information gained and process were useful<br>Helped to bring out the positives and for the person to reflect on them<br>Useful to get an immediate and emphatic reaction – show you what's really important<br>PWA expressed an interest in working on writing which he had not articulated before despite me knowing him well over a long period of time<br>Gave me specific ideas re; advice to family based on HIS experiences rather than my viewpoint as a therapist<br>The CDP enabled him to be more assertive in expressing his views.<br>I've enjoyed doing it and haven't come across anything which covers such a lot of ground (from the aphasic person's perspective) so neatly. It's different, and highly useable.<br>NO did not provide me with additional information possibly due to knowing the client very well and so had already investigated these areas<br>For this patient the CDP confirmed information already obtained or deduced. Did not guide my management but gave me further insight.<br>Definitely useful in the community setting to highlight areas which client themselves was concerned about/wanted to work on<br>Directed team goals i.e. – transport and shopping<br>Identified several issues that were not previously recognised by the SLT to be important for client (therefore very beneficial) |
| INFORMING PRACTITIONER? | Helps you reflect on why some people with severe aphasia adjust well while others with mild aphasia are very negative about their skills<br>I was surprised and interested by the occasional strength of feeling expressed e.g. barriers section.<br>Helped me to understand the impact of people interrupting/looking away<br>I can be really confident that apparently simple things really do make a big, positive difference (e.g. people talking slowly)<br>Someone's perceptions of their skills can be very different to their actual skills<br>NO – made me feel quite positive about previous practice as it appears the areas have been covered though not in such a structured way (this SLT only had the opportunity to administer the CDP once)<br>More holistic approach – addressing what they want to do as opposed to focussing on impairment biased<br>Recognising that what you see as a clinician to be the area of difficulty may not be what is important for |

| | |
|---|---|
| | this person<br>Assessment will be useful as adjunct to other areas of assessment<br>Interesting that most able client (able because had most access to language) scored least on domains (don't think this was because of increased awareness)<br>Did highlight with someone with mild aphasia the huge impact on their ability to participate in activities and how affected everything they did/wanted to do<br>Made me very keen to do more education/teaching in hospitals, nursing homes, day centre on aphasia and facilitating communication highlighting increased difficulties understanding different accents and need to use strategies<br>Makes you think about the need to inform the general public more – difficulties with bus drivers etc. despite being shown ADA card |

# Appendix 6.13
# Consent form used in this project (page 2)

It **won't affect** my **speech therapy**.

There is **NO DANGER**

Everything is **confidential**.

No one will know what I said.

Do you **agree** to **take part** in the project?

YES

NO

Signed: Date:

Name in CAPITALS:

Signature of Kate Swinburn:

Table 5.11

Suggestions to be taken to advisory group following pilot testing

| **Manner of change** | **Suggested changes** |
|---|---|
| Content | 1. Female version of 'what is fun for you' picture |
| | 2. Condense who helps and who hinders into ONE picture but have MULTIPLE pictures (ethically diverse as for scales)?<br>And maybe have a 'who makes it better' and 'who makes it worse' picture thumbs up and thumbs down?<br>Add to the who is important picture<br>Delete Q42 – important people |
| | 3. Delete 'someone helping you' from help page<br>because maybe already covered in who is important? |
| | 4. An acute stage page (for participation ? – calling nurse, ward rounds? ordering from menu – see aphasia handbook?, and/or external influences) - ? is this appropriate |
| | 5. Remove lightening strike on 'during the last week' page |
| | 6. Change order so that self image comes AFTER emotional state |
| | 7. 'Content' and worried' are opposites of same construct – choose another positive one |
| Format | 1.Rate EACH of the participation domains separately (but they felt the CDP was an appropriate length so would have to reduce somewhere?). If so how ? introduce using all on one page and then have one per page? |
| | 2. Page numbers on pictures |
| | 3. Section dividers |
| | 4. Relocate 'work' so that it is less prominent in participation section |
| | 5. Add ? to anywhere where ..and anything else – 7. external influences particularly |
| | 6. Smaller stimulus sheets for scales and during the day cards ? flip chart?<br>Maybe double backed so that during the last week appears above each time and the scale appears below each time |
| | 7. LOOK carefully at emotions rating esp last 2 future and ? |
| Wording | 1. 'lonely' for 'isolated' (isolation can be desirable) |
| | 2. Check wording of participation section (see Megan Q21/22/24) |

| | |
|---|---|
| | 3. Emphasis change of scale |
| | 4. Change 'a lot' to 'very' |
| | 5. Pages 34 and 32 delete 'how are' so that focus on here are things you might want to do |
| Other comments | Exhausting, too many pictures, neither positive nor negative but not a useful experience |

Table 5.12

Changes to the CDP draft 2 after advisory group ratification of pilot testing suggestions

| **Type of change** | **Changes made.** | **CDP draft 2** | **CDP draft 3** | **Rationale for changes** |
|---|---|---|---|---|
| Acceptability | Extra item added<br>(not rated) | No mention of present mood state | 'Overall, how are you today?' | Acknowledgement that current mood can significantly influence all rating, and that some recording of this should be attempted |
| Accessibility | Wording change in introduction and throughout | 'Since your stroke, during the last week' | 'During the last week' | 'Since your stroke ', sometimes led to conversation being side-tracked. 'During last week' was shorter and more focused |
| Accessibility and acceptability. | Rating of participation section | 'So overall, how is talking for all those things you have to do?'<br>(Sweep hand across **all the pictures)** | 'How is work - can you show me on the scale?'<br>(Rate **each** domain **separately**) | PWA* and SLTs reported that a summary rating was difficult to explain and administer and unpopular |
| Accessibility and acceptability. | Reorder pictures | 'Work' is the first item to be addressed in how are things you HAVE to do section | 'Work' becomes the last item in this section | The majority of PWA no longer work. Though important to be able to rate and then discuss and why this might, thought to be challenging to have it given such prominence |
| Accessibility and acceptability. | Condense 'who helps' and 'who hinders' into ONE 'who is important' picture but have MULTIPLE | Two pictures each rated - 'who helps' and 'who hinders' | One 'who is important' picture | Duplication of information avoided<br>Reduces length of tool |

| | | | | |
|---|---|---|---|---|
| | ethically diverse pictures | | | |
| Accessibility and acceptability. | Reordering of self confidence and emotional states | Emotions associated with self image (such as feelings of competence, control and confidence) came before emotional states (such as frustration, anxiety and determination) | Emotional states begin the exploration of emotions | Those emotional states most immediately associated with having aphasia should be explored first. Emotions that may RESULT from these feelings (self image emotions) should follow<br>Less threatening to begin section with emotional states |
| Acceptability | Wording change | 'isolated' | 'lonely' | PWA commented that you may CHOOSE to be isolated (on your own) but that you would not choose to be lonely |
| Accessibility and. | Addition of a large ? whenever the PWA's individual situation is tapped | Is there anything else? (no graphic representation) | Is there anything else about X that is important? (graphic representation using ?) | Emphasizing that CDP will not have covered everything that might be pertinent to the PWA<br>PWA's contributions are as significant as the pre-determined categories |
| Accessible and acceptability | Change the rating of the emotional section to a one stage rating process | Two stage rating only (Appendix 4.3a page 72-3) | One-stage rating (Appendix 4.3a page 74) | Some PWA* and SLTs reported that emotional rating was difficult to administer<br>Advisory group choose one stage rating (Appendix 4.3a page 74) |
| Accessible | Format change to presentation of 'during the last week' picture | Presented as a separate laminated sheet | Presented within the body of the tool, on page above the one being rated (when book is open there will be | Some commented that physical manipulation of so many pieces of information was difficult |

| | | | | |
|---|---|---|---|---|
| | | | two pages visible – one on top and one below) | |
| Additional pictures for 'what do you **enjoy**?' | New pictures added. Presented all on double-spread page to enable 12 pictures with male/female interspersed | Male dominated activities | Added some activities than were female-orientated. | Several pilot testers commented that this page was male-dominated |

Table 5.13
Origins of the modifications between DQ5 and CDP2

| **Domains explored** | **Examples in DQ5** | **Examples in CDP2** | **Type of modification** | **Modification attributable to whom?** |
|---|---|---|---|---|
| Communication activities | 4 modalities<br>(Understanding, Talking, Reading, Writing)<br>4 items per modality<br>(all rated) | 5 modalities<br>(added modality of Expressing Yourself)<br>4 items per modality<br>(all rated) | Reordering of domains (each modality the following domains: activities, participation, external influences) | Suggested by SLT focus group<br>Confirmed by advisory panel |
| Participation | 4 items (all rated)<br>(one Q per modality;<br>what's that like on a day to day basis?) | 3 items<br>(three Qs; things you have to do, things you want to do,<br>at home?) | 1.Introduction of concept to expand participation section.<br>2. Modifying, perfecting and selecting domains and items for expansion of participation section<br>3. Modifying, perfecting and selecting rating for participation section | 1.Reviewing literature on participation/discussion with researcher<br>2. In-depth interviews<br>3. Advisory panel |
| External influences | None | 4 items (none rated) | 1.Introduction of concept of external influences section<br>2. Modifying, perfecting and selecting items for external influences section | 1.Expert SLT<br>2. In-depth interviews<br>3. Advisory panel |
| Emotional consequences | 9 emotional constructs<br>(Self image Qs separated from feelings section)<br>All expressed negatively | 14 emotional constructs<br>(Self image subsumed into emotional section)<br>8 expressed negative, 4 expressed positive, 2 expressed neutral | 1. Modifying and selecting the items for emotional consequences section<br>2. Reconsidering the concepts behind the emotion Qs<br>3. Selecting items and perfecting presentation of items | 1. Advisory panel (supported by data from in-depth interviews)<br>2. Advisory panel<br>3. Advisory panel |
| All | All items negatively expressed, questionable accessibility and acceptability | Accessibility, acceptability and wording all seen as appropriate by the advisory panel | Modification to wording<br>- accessibility & acceptability<br>- negativity | Advisory panel |
| All | None | Pictures used to support every concept and question within the CDP2 | 1. Introduction of concept to use pictures<br>2. Modifying, perfecting and selecting of pictures | 1. Both user focus groups<br>2. Advisory panel |

Table 5.14

Table to show the factor analysis for the DQ

| **Domain** | Factor 1 |
|---|---|
| Variance accounted for (n=60) | 63% |
| *Disability associated with comprehension* | **.696** |
| Disability associated with expression | **.817** |
| Disability associated with reading | **.808** |
| Disability associated with writing | **.800** |
| Intrusion | **.911** |
| Self Image | **.769** |
| Emotional Impact | **.735** |

Table 5.15

Table to show test-retest on the DQ

| **Domain/section** | **r** | **n** |
|---|---|---|
| Disability associated with comprehension | 0.881 | 18 |
| Disability associated with expression | 0.608 | 17 |
| Disability associated with reading | 0.863 | 17 |
| Disability associated with writing | 0.901 | 17 |
| Intrusion | 0.789 | 17 |
| Self Image | 0.871 | 18 |
| Emotional Impact | 0.929 | 18 |
| Disability Total | 0.973 | 16 |
| Handicap | 0.936 | 17 |
| Disability total | 0.978 | 15 |

Table 5.16

Cronbach's Alpha data on DQ for people who have lived with aphasia for a year

| **Domain/section** | **alpha** | **n** | **items** |
|---|---|---|---|
| DQ (total) | 0.95 | 42 | 33 |
| Sections: | | | |
| Activities | 0.9 | 41 | 16 |
| Participation | 0.79 | 51 | 4 |
| Emotional consequences | 0.94 | 42 | 13 |

Table 6.1
Manner of involvement of users in research project

| Stage and phase | Process | No. of PWA involved | Purpose | Level & type of involvement of PWA |
|---|---|---|---|---|
| **Stage 1**<br>- Phase 1 | Write original instrument based on clinical experience | 0 | Construct instrument | None (professionally conceived concepts and construction) |
| | Administer DQ | 15 | Pre-test items | Respondents |
| | Modify tool | 0 | | None |
| - Phase 2 | Administer DQ | 15 | Pre-test items | Respondents |
| | Seek expert colleague advice | 1 | Obtain expert opinion | Advisor |
| | Modify tool | 0 | Ensure face validity | None |
| - Phase 3 | Administer DQ | 10 | | Respondents |
| | Modify tool | 0 | | None |
| **Stage 2** | Conduct focus groups with DQ users (SLTs & people with aphasia) | 7 | Obtain expert opinion<br>Ensure face/content validity | Consultants |
| | Modify tool | 0 | | None |
| | Administer CDP 1 | 40 | Field testing | Respondents |
| **Stage 3** | Group interviews | 13<br>(7+6) | Ensure content validity | Respondents |
| | Individual in depth interviews | 13 | Ensure content validity | Consultants |
| | Convene advisory group | 3 | Ensure validity of research process | Advisors |
| | Modify tool | 3 | | Advisors |
| **Stage 4** | Pilot testing (CDP draft 2) | 23 | Establish clinical usability | Participants in administration plus **solicited** comment |
| | Modify tool | 3 | Ensure validity of research process | Advisors |

*LIST OF APPENDICES*

*(All appear sequentially)*

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**CHAPTER 4**

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Appendix 5.5 WHO helps? (specific) original draft

Appendix 5.6 Things you WANT to do original and final draft

Appendix 5.7 Things you HAVE to do - original and final draft

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Appendix 5.9 WHO helps your talking? (specific) second draft

Appendix 5.10 What THINGS help? (specific)

Appendix 5.11 What makes things HARDER (concept) second draft

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Appendix 5.13 What THINGS makes it HARDER (specific) original draft

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Appendix 5.16 Talking under pressure - original draft

Appendix 5.17 Looking to the future – original draft

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Appendix 6.9 Information and consent form used in other SLT research project

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Appendix 2.1

The Comprehensive Aphasia Test

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A) THE COGNITIVE SCREEN
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2. Semantic memory
3. Word fluency
4. Recognition memory
5. Gesture object use
6. Arithmetic

B) THE LANGUAGE BATTERY
Language comprehension
7. Comprehension of spoken words
8. Comprehension of written words
9. Comprehension of spoken sentences
10. Comprehension of written sentences
11. Comprehension of spoken paragraphs
Repetition
12. Repetition of words
13. Repetition of complex words
14. Repetition of non-words
15. Repetition of digit strings
16. Repetition of sentences
Spoken naming
17.Naming objects
18.Naming actions
19.Spoken picture description
Reading aloud
20.Reading words
21.Reading complex words
22.Reading function words
23.Reading non-words
Writing
24.Writing: copy
25.Writing picture names
26.Writing to dictation
27.Written picture description

Appendix 2.2

# DISABILITY QUESTIONNAIRE

Name: Date:

Please read the following questions. Think about them carefully then circle the number that you think best describes how you feel. We are particularly interested in the **effects of the stroke on communication and how easy or difficult it is for you to do things SINCE your stroke.** Thank you for completing the questionnaire.

## Disability

| UNDERSTANDING SPEECH | Unable/Very Difficult | | | | Easy No problem |
|---|---|---|---|---|---|
| **Compared with before your stroke,** how difficult is it for you to | (5) | < ---------- | | | > (1) |
| 1. understand **your wife/husband** | 5 | 4 | 3 | 2 | 1 |
| 2. understand **one other person** | 5 | 4 | 3 | 2 | 1 |
| 3. understand **in a small group of people who are not family** | 5 | 4 | 3 | 2 | 1 |
| 4. understand **TV or radio** | 5 | 4 | 3 | 2 | 1 |

| TALKING | Unable/Very Difficult | | | | Easy No problem |
|---|---|---|---|---|---|
| **Compared with before your stroke,** how difficult is it for you to | (5) | < ---------- | | | > (1) |
| 5. find the right words/put sentences together when talking with **your family** | 5 | 4 | 3 | 2 | 1 |
| 6. find the right words/put sentences together when talking to **close friends** | 5 | 4 | 3 | 2 | 1 |
| 7. find the right words when speaking with **someone you don't know** | 5 | 4 | 3 | 2 | 1 |
| 8. find the right words when talking **on the phone or behind a glass screen e.g. post office/ticket office** | 5 | 4 | 3 | 2 | 1 |

(if you avoid any of these situations put down 5)

| READING | Unable/Very Difficult | | | | Easy No problem |
|---|---|---|---|---|---|
| **Compared with before your stroke,** how difficult is it to | (5) < - | ---------- | ---------- | ---------- | > (1) |
| 9. read and understand **single words** | 5 | 4 | 3 | 2 | 1 |
| 10. read and understand **a short phrase** (e.g. newspaper headline) | 5 | 4 | 3 | 2 | 1 |
| 11. read and understand **an official form** e.g. a bill | 5 | 4 | 3 | 2 | 1 |
| 12. read and understand **an article in the paper or page in a book** | 5 | 4 | 3 | 2 | 1 |

| WRITING | Unable/Very Difficult | | | | Easy No problem |
|---|---|---|---|---|---|
| **Compared with before your stroke,** how difficult is it to | (5) < - | ---------- | ---------- | ---------- | > (1) |
| 13. spell/write **your name and address** | 5 | 4 | 3 | 2 | 1 |
| 14. spell/write **other single words** | 5 | 4 | 3 | 2 | 1 |
| 15. spell/write **a letter or a card** | 5 | 4 | 3 | 2 | 1 |
| 16. Complete an **official form** e.g. a household bill | 5 | 4 | 3 | 2 | 1 |

| **HANDICAP** | Yes A lot | | | | No None |
|---|---|---|---|---|---|
| | (5) < - | ---------- | ---------- | ---------- | > (1) |
| 17. Do you feel you have any difficulties with communication since the stroke? | 5 | 4 | 3 | 2 | 1 |
| 18. If you have difficulties – do they worry you? | 5 | 4 | 3 | 2 | 1 |

19. Does your communication affect your daily life?

| | | | | | |
|---|---|---|---|---|---|
| | 5 | 4 | 3 | 2 | 1 |

20. Which aspects of the difficulty affect your daily life?

| | | | | | | |
|---|---|---|---|---|---|---|
| - | reading | 5 | 4 | 3 | 2 | 1 |
| - | writing | 5 | 4 | 3 | 2 | 1 |
| - | understanding | 5 | 4 | 3 | 2 | 1 |
| - | talking | 5 | 4 | 3 | 2 | 1 |

**EMOTIONS**

21. Could you indicate which words describe how you feel about communication since your stroke?

| | Very | a little | not at all |
|---|---|---|---|
| **frustrated** | | | |
| **depressed** | | | |
| **angry** | | | |
| **unfair** | | | |
| **helpless** | | | |
| **stupid** | | | |
| **accepting** | | | |
| **pleased** | | | |
| **optimistic** | | | |
| **negative** | | | |

**Thank you** for completing the questionnaire.

Please return to ....

**Oct 1993**

Appendix 2.3

The DQ rating scale

| Unable | Very difficult | Difficult | OK | Same as before |
|---|---|---|---|---|
| 4 <----------> | 3 <----------> | 2 <----------> | 1 <----------> | 0 |
| X | | | | √ |

Appendix 2.4

Example of a DQ help-sheet introduced (page 1)

# Understand

- Person closest to you
- A Stranger
- 3 or 4 friends or family
- Speaking quickly or someone in authority - doctor or benefits officer

Appendix 2.5

Example of a DQ help-sheet introduced (page 2)

How these problems affect you on a

# Day to Day basis

Get in the way of everyday life

Appendix 2.6

Cronbach's alpha scores for the DQ draft 5

| **Domain** | **Number of participants** | **Number of items in each section** | **Alpha score** |
|---|---|---|---|
| DQ as a whole | 42 | 33 | 0.95 |
| Sub-scaled:- | | | |
| Activities | 41 | 16 | 0.9 |
| Impact | 51 | 4 | 0.79 |
| Emotional conseq | 42 | 13 | 0.94 |

Appendix 2.7a
Information sheet for user field trial focus group

## INFORMATION SHEET

**Kate Swinburn**
(Speech and Language Therapist)
Richmond Rehabilitation Unit,
Evelyn Rd. Richmond TW2 9TF SURREY
Phone: 0171-228-8400

This is a **project** about **how** your **talking problems affect your life.**

It is **NOT speech therapy.**

The project is looking at **how speech therapists look** at your **talking difficulties.**

An **assessment** has been **written**

It asks **lots of questions.**

It looks at **how** your talking **gets in the way** of day to day life.

It has **questions** about **how you feel** about your talking difficulties.

You can **answer** the questions **just by pointing** if you want.

The tool is called a **Rating Scale.**

**You** will be **asked what you think** of the rating scales.

**Your views** are **really important**.

**Your thoughts** about it will help to **make the rating scale better.**

This will be the **first time** views of **people with talking problems** have **been included** in developing a tool.

If you would like to help - **here's what will happen:**

- Kate Swinburn **(a speech therapist)** will **come to see you**

- She will **do the rating scales** with you

# Appendix 2.7b Information sheets for people with aphasia user field trial focus group - page 2

later on ...

- 6 weeks later you will come to join other people with talking problems.
- You will be picked up and taken home by taxi.
- The group will run at City Dysphasic Group, Goswell Place, near the Angel.
- Susie Parr (a different speech therapist) will run the group.
- You will chat with everyone about the rating scales.
- The group will take about 2 hours.

If you don't like it, you can STOP.

If you change your mind, you don't have to COME.

No one will ask any questions.

Your speech therapy will not change if you stop.

If you want to take part:

- talk to (name of the relevant speech therapist)

(she will make all the arrangements)

OR

- ring Kate Swinburn on 0171-228-8400

(say "I'm phoning about the rating scales project")

This project has been looked at by.....Ethics Committee (they check the project is fair and good).

They say it can go ahead.

# Appendix 2.8a
# Consent form for people with aphasia user field trial focus group - page 1

## CONSENT FORM

Kate Swinburn,
Speech and Language Therapist,
Richmond Rehabilitation Unit,
Evelyn Rd, Richmond.

Telephone 0171-228-8400

The **project** has been **explained**.

YES NO

**I understand** what I have to do.

YES NO

**I spoke** to ..... about the pr

**I can STOP at any time.**

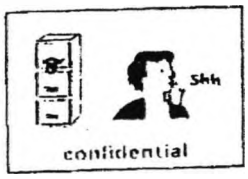
Appendix 2.8b
Consent form for people
with aphasia user field trial focus group
- page 2

It **won't affect** my **speech therapy**.

There is **NO DANGER**

Everything is **confidential**.

No one will know what I said.




Do you **agree** to **take part** in the project?

YES

NO

Signed:

Date:

Appendix 4.1

**Communication Disability Profile (draft 1)**

*"I'm going to ask you some questions. They look at how you **feel** about communication.*

*There is no right or wrong. It is **your** view of how things feel since the stroke. I'll ask a question and then I'll also show you a scale like this. Let's try an example. Since your stroke, how easy is it to chat to a friend.*

*"**so** if ;*

*chatting is very easy, the same as before your stroke point here;*

*if you cannot chat at all you would point here;*

*but maybe its somewhere in between* " (sweep hand across scale).

Disability self-rating.

Talking

*"Let's look at you **talking** - finding your words and saying a sentence.*

*Since your stroke how easy is it for you to:*

1. *talk to **the person closest to you (use person's name)*** **Rating:**
**Comments** **0 1 2 3 4**

2. *talk to **someone you don't know*** **Rating:**
**Comments** **0 1 2 3 4**

3. *talk to **3 or 4 family or friends*** **Rating:**
**Comments** **0 1 2 3 4**

4. *talk **if you are stressed**"* **Rating:**
**Comments** **0 1 2 3 4**

5. *any **other people or situations** that are difficult reinstated?* (transcribe)

*"so you've told me that its most difficult for you when...but that ... is easier, is that right?*

6(*M) *what's that like on **a day to day** basis?* **Rating:**
**Comments** **0 1 2 3 4**

7.(*S) *does that **worry you*** ? **Rating:**
**Comments** **0 1 2 3 4**

Understanding

"*So you've told me about talking ... this next section is about you **listening** and understanding **when other people talk to you**. So this is **not** you talking, its you **following** what's said to you.*

*Since your stroke how easy is it for you to:*

8. *understand **the person closest to you (use person's name)*** **Rating:**
**Comments** **0 1 2 3 4**

9. *understand **someone you don't know*** **Rating:**
**Comments** **0 1 2 3 4**

10. *understand **3 or 4 family or friends*** **Rating:**
**Comments** **0 1 2 3 4**

11. *understand **when you're under pressure*** **Rating:**
**Comments** **0 1 2 3 4**

12. *any **other people or situations** that are – difficult reinstated(transcribe)*

*"so you've told me that its most difficult for you when...but that ... is easier, is that right?*

13(*M) *what's that like on **a day to day** basis?* **Rating:**
**Comments** **0 1 2 3 4**

14.(*S) *does that **worry you?*** **Rating:**
**Comments** **0 1 2 3 4**

Reading

*"So we've discussed talking and understanding, now lets look at reading. This is reading in your head not reading aloud*

*Since your stroke how easy is it for you to:*

15. *read and understand a **single word** like a word on a list* **Rating:**
**Comments** **0 1 2 3 4**

16. *read and follow **a newspaper headline*** **Rating:**
**Comments** **0 1 2 3 4**

17. *read and follow **piece in a paper*** **Rating:**
**Comments** **0 1 2 3 4**

18. *read and follow **an official letter*** **Rating:**
**Comments** **0 1 2 3 4**

19. *any **other situations** or things that make reading difficult (transcribe)*

*"so you've told me that its most difficult for you when...but that ... is easier, is that right?*

20(*M) *so how is reading on a **day to day** basis?* **Rating:**
**Comments** **0 1 2 3 4**

21(*S) *does that **worry you** ?* **Rating:**
**Comments** **0 1 2 3 4**

Writing
(pre-morbid literacy practices will significantly influence this section and must be borne in mind when choosing whether to administer this section and with interpretation of this section)

*"Lets have a look at writing – NOT holding the pen – the spelling. What about spelling words ?*

*Since your stroke how easy is it for you to:*

22. *spell/write your **name and address*** **Rating:**
**Comments** **0 1 2 3 4**

23. *spell **other single words** like a shopping list* **Rating:**
**Comments** **0 1 2 3 4**

24. *write a **letter to a friend*** **Rating:**
**Comments** **0 1 2 3 4**

25. *write an **official letter*** **Rating:**
**Comments** **0 1 2 3 4**

26. *any **other situations** or things that make writing difficult?* (transcribe)

*"so you've told me that its most difficult for you when...but that ... is easier, is that right?*

27(*M) *so how is writing on a **day to day** basis?* **Rating:**
**Comments** **0 1 2 3 4**

28(*S) *does that **worry you** ?* **Rating:**

**Comments** **0 1 2 3 4**

Emotional consequences

*We're going to talk about your mood now. Since your stroke:*

29. *are you **confident** about communicating?(+)* **Rating:**
**Comments** **0 1 2 3 4**

30. *does your communication make you **angry?(-)*** **Rating:**
**Comments** **0 1 2 3 4**

31. *does your communication make you **frustrated? (-)*** **Rating:**
**Comments** **0 1 2 3 4**

32. *does your communication make you **sad? (-)*** **Rating:**
**Comments** **0 1 2 3 4**

33. *do you feel **in control** of your communication? (+)* **Rating:**
**Comments** **0 1 2 3 4**

34. *some people **feel stupid** because their communication has changed, do you ever **feel a bit daft? (-)*** **Rating:**
**Comments** **0 1 2 3 4**

35. *when you **look to the future,** how do things look? (neutral)* **Rating:**
**Comments** **0 1 2 3 4**

36. *how do things **look today? (neutral)*** **Rating:**
**Comments** **0 1 2 3 4**

37. *do you have **people who are important to you**?(+)* (do not rate)

Appendix 4.2

Topic Guide for in-depth interviews/living with aphasia

**Introduction**

(include consent for recording)

- "Tell me about yourself and those you live with"

**Impairments**

- "Tell me a bit about **what happened** when you had your stroke?"
- "how did it affect you?"
- "when did you first notice your talking had changed"
- "who explained it to you"
- "what was the most important thing that has changed since the stroke?"
  - physically
  - communication
  - reading & writing
  - speech
  - understanding,
  - other ways (probe mood)
- "do you have a name for all of that?"
- "is...their term.. important to you"
- "Have you heard the term 'dysphasia-what does it mean do you think?"

Probe:

- other people's reactions
  - in hospital,
  - when discharged
- your reaction
  - in hospital,

  when discharged
- "do you think you've got a problem with your talking?

...to what extent.

...what makes you say that?"

**Participation-based changes**

"did these changes affect **every day life** for you after the stroke?

- in what way?"
- "what's the most important thing that (their term) has stopped you doing?"
- "What do you still do now...What did (their term) stop you doing?"

Probe:

- friends
- family
- social life
- hobbies
- work
- how you felt about yourself
- other people's reactions
- emotions
- ?result of dysphasia or other things
- "when you meet someone for the first time do you tell them?"
- "what is it that makes you ?unhappy/sad/lonely (whatever they've said)?"
- "Can you tell me how things have changed over this year?"
- "has anything good come out of it?"

**Barriers and facilitators**

- "What/who has **helped** you to **live with** these changes?"
- "What/who makes it **easy** or **more difficult**?"

Probe

- family
- friends
- environment
- attitudes
- mood
- therapy
- anything about you as a person that helped
- anything in the past
- specific things that you do when you can't find a word/follow what
- someone's said to you

- "Some people have talked about feeling disabled? Do you feel that you are disabled?
- "why are you/or are you not disabled?"
- "Is there anything important about the effects of dysphasia that we haven't discussed?"

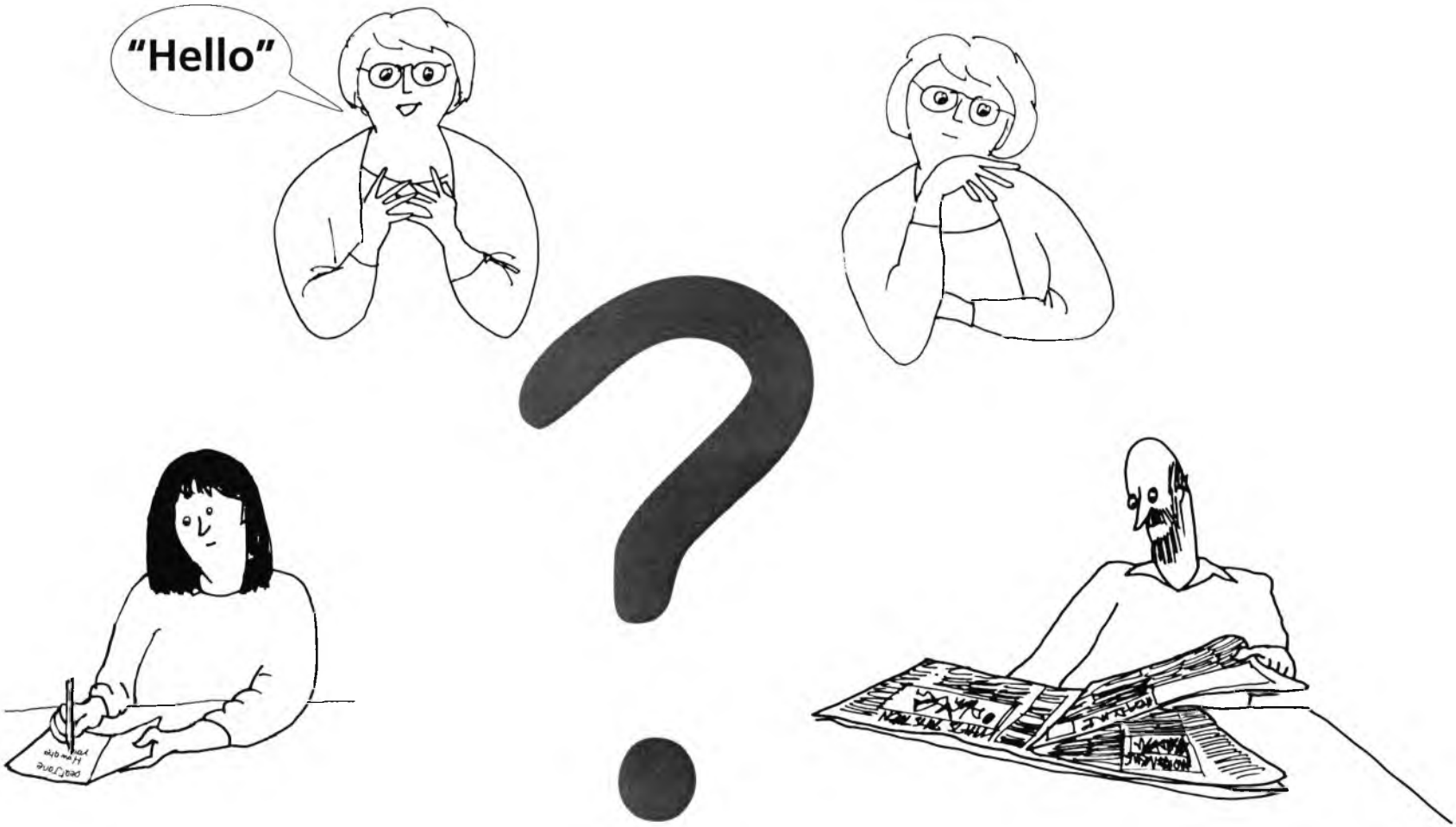
**Thank yous**

Appendix 4.3a
The CDP (draft 2 - pilot test version)

# Communication Disability Profile

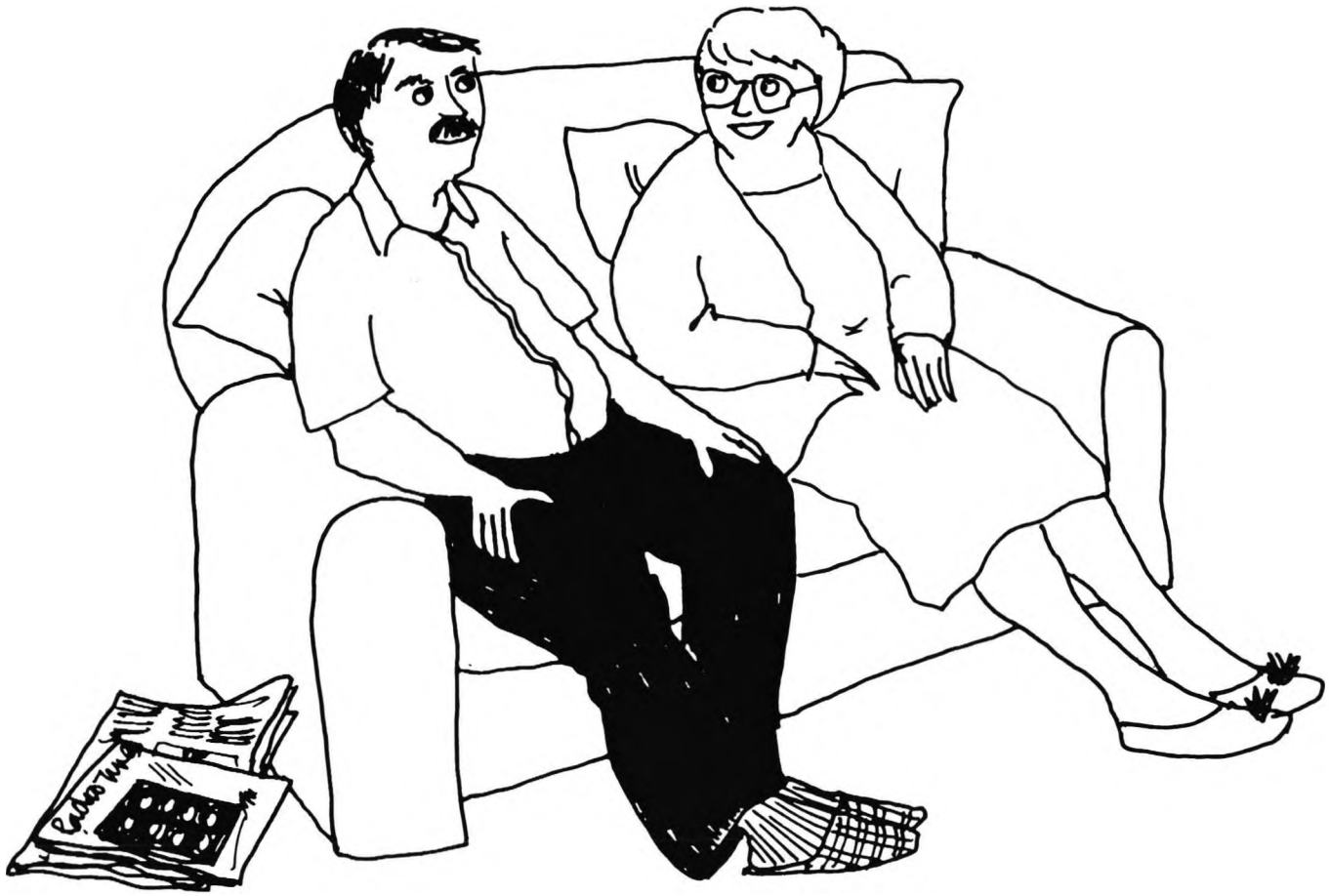
Conceived and written by **Kate Swinburn** with **Sally Byng**
Designed and drawn by **Caroline Firenza**

# Aphasia

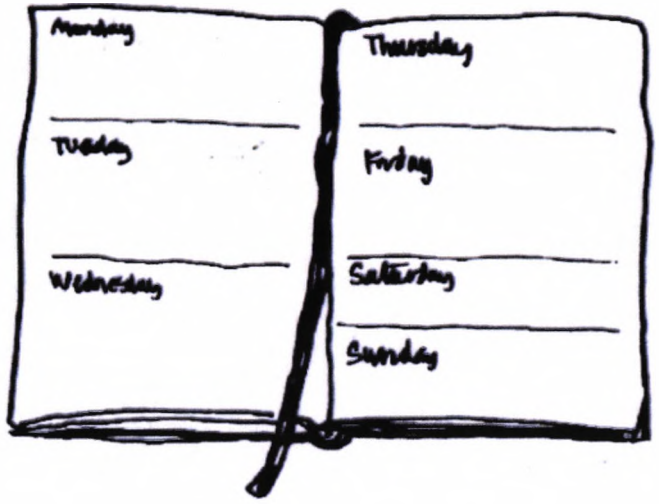


What you **do**

How you **feel**

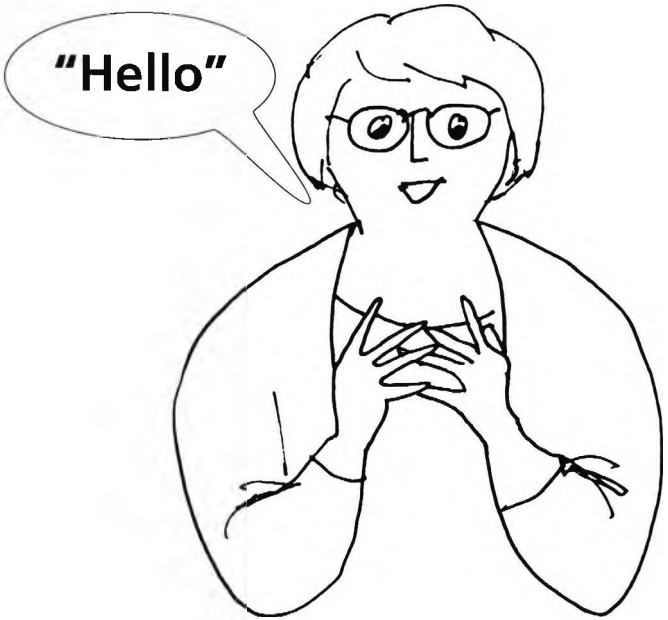


# During the last week...

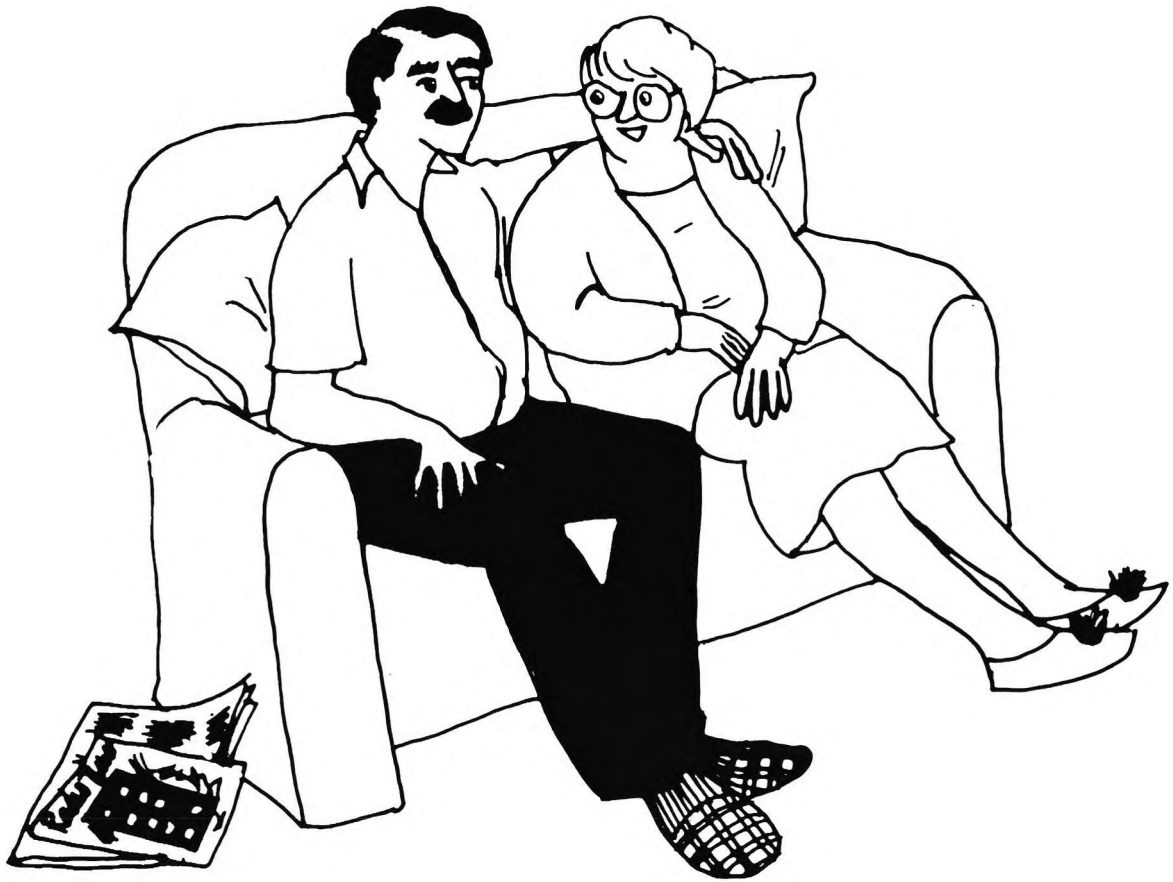


# How easy is it for you to **chat** to a friend?

# Talking



# How easy is it for you to **talk** to...?



How easy is it for you to **talk** with a **group of friends**?

How easy is it for you to **talk** to a **stranger**?

How easy is it for you to **talk under pressure**?

# Expressing yourself

How easy is it for you to **express** yourself with...?

How easy is it for you to **express** yourself in a **group**?

How easy is it for you to **express** yourself with a **stranger**?

# How easy is it to **express** yourself **under pressure**?

# Understanding

# How easy is it for you to **understand**...?

How easy is it for you to **understand** a **stranger**?

How easy is it for you to **understand** in a **group**?

How easy is it for you to **understand under pressure**?

# Reading

How easy is it for you to **read one word** only?

# How easy is it for you to **read** a **headline**?

How easy is it for you to **read** a **whole story** in a newspaper?

How easy is it for you to **read** an **official letter**?

# Writing

How easy is it for you to **write your name**?

# How easy is it for you to **write** a **list**?

How easy is it for you to **write** a letter to a **friend**?

How easy is it for you to **write** an **official letter**?

# Aphasia

# How are things you **have** to do?

Work

Money

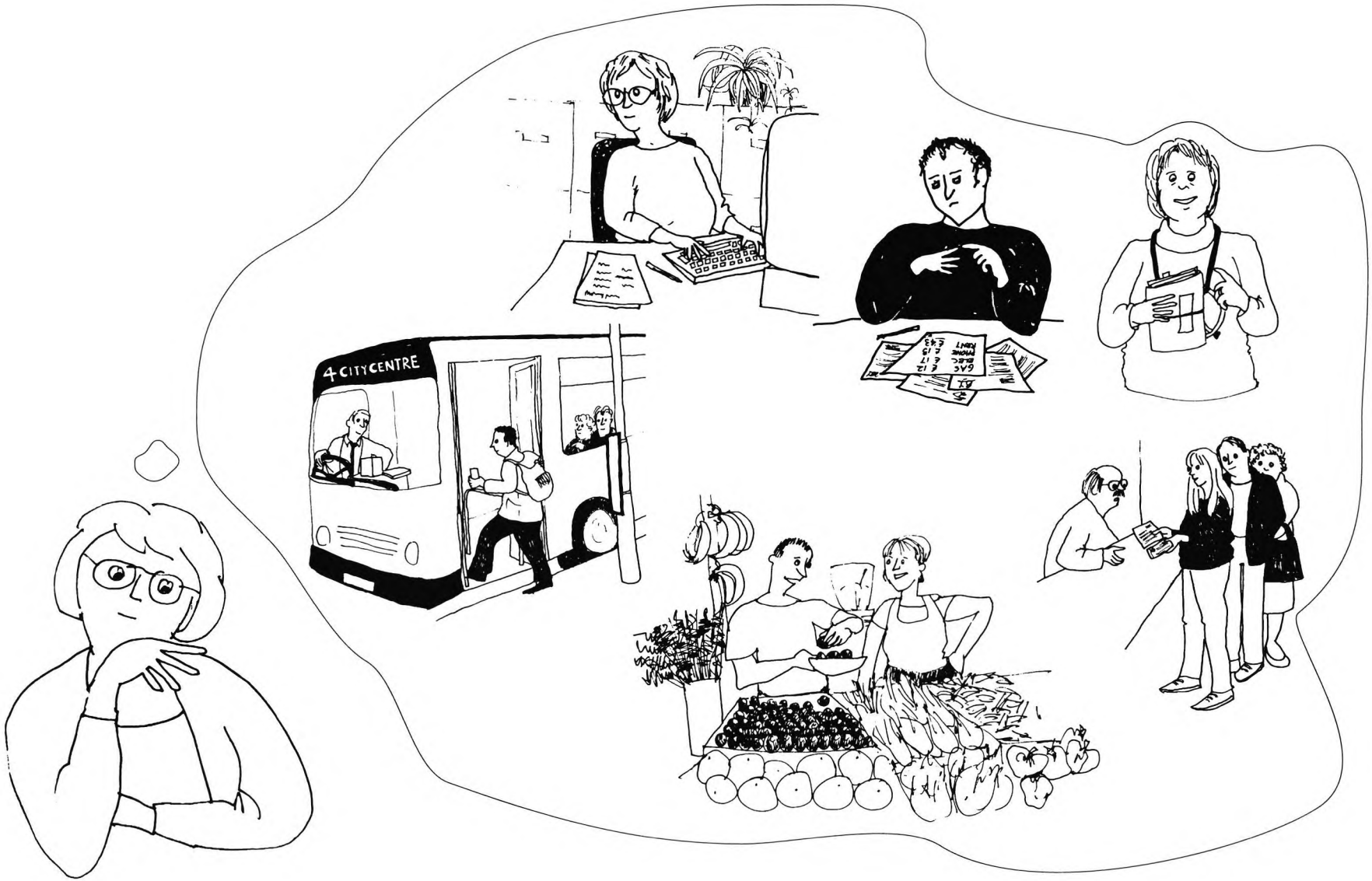
Health

Transport

Shopping

Business

# How are things you **have** to do?



# How are things you **want** to do?

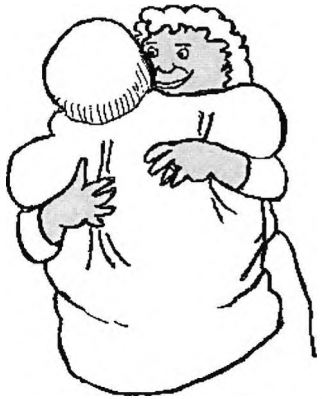
Hobbies

Clubs

Holidays

Going out

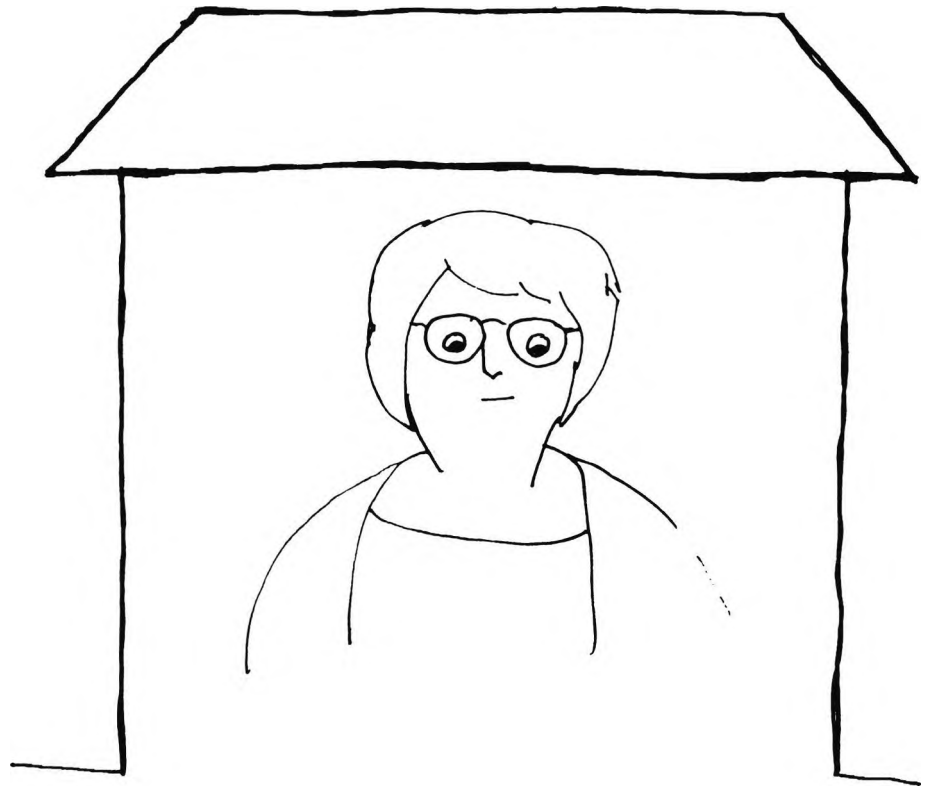
Meeting friends



Relationships

# How are things you **want** to do?

# How are things at **home**?



# **What** helps?

# Who **helps** you?

# Who **helps** you?

# Who **helps** you?

# What **things help** you?

Listen to me

Telling people

Extra time

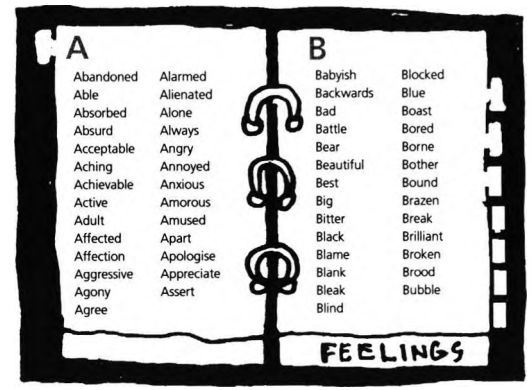
Pictures

Write things down

# What **things help** you?

Someone helping

Dictionary




Speaking books

Computer

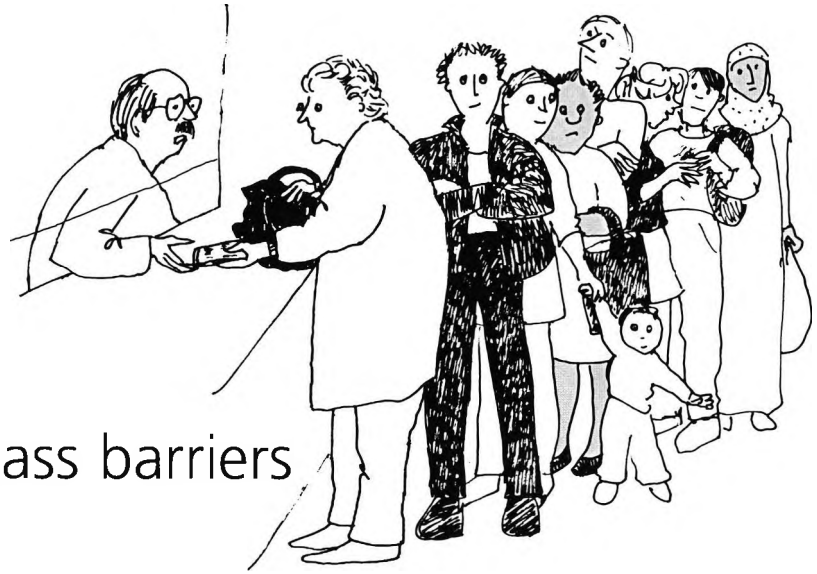
# What makes it **harder**?

# Who makes it **harder**?

# Who makes it **harder**?

# Who makes it **harder**?

# What makes it **harder**?



Queues

Glass barriers

Being under pressure

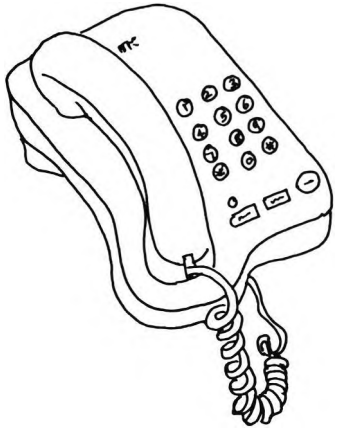
Being upset

The wrong hand

# What makes it **harder**?

Being tired

Too much



Telephones

# What makes it **harder**?

Two people talking at once

Speaking quickly

Look away

Noisy/busy

Interrupting

Far away

# Aphasia

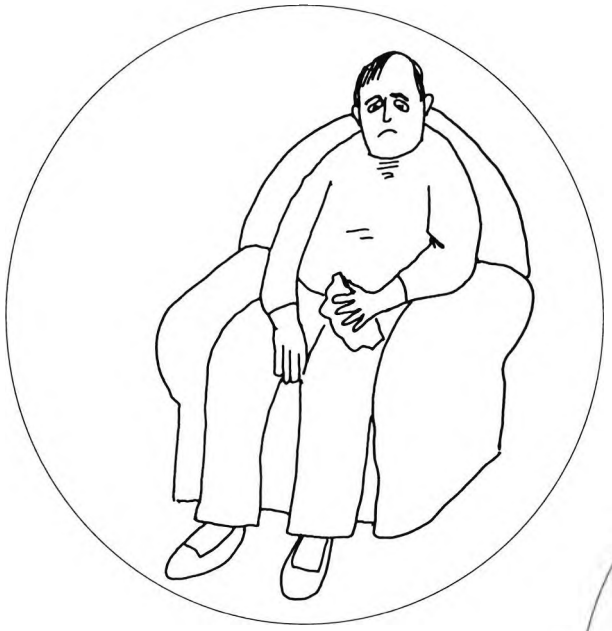
# How does that make you **feel**?

Frustrated

Angry

Determined

Unhappy



Content

Worried

Less confident

Less control

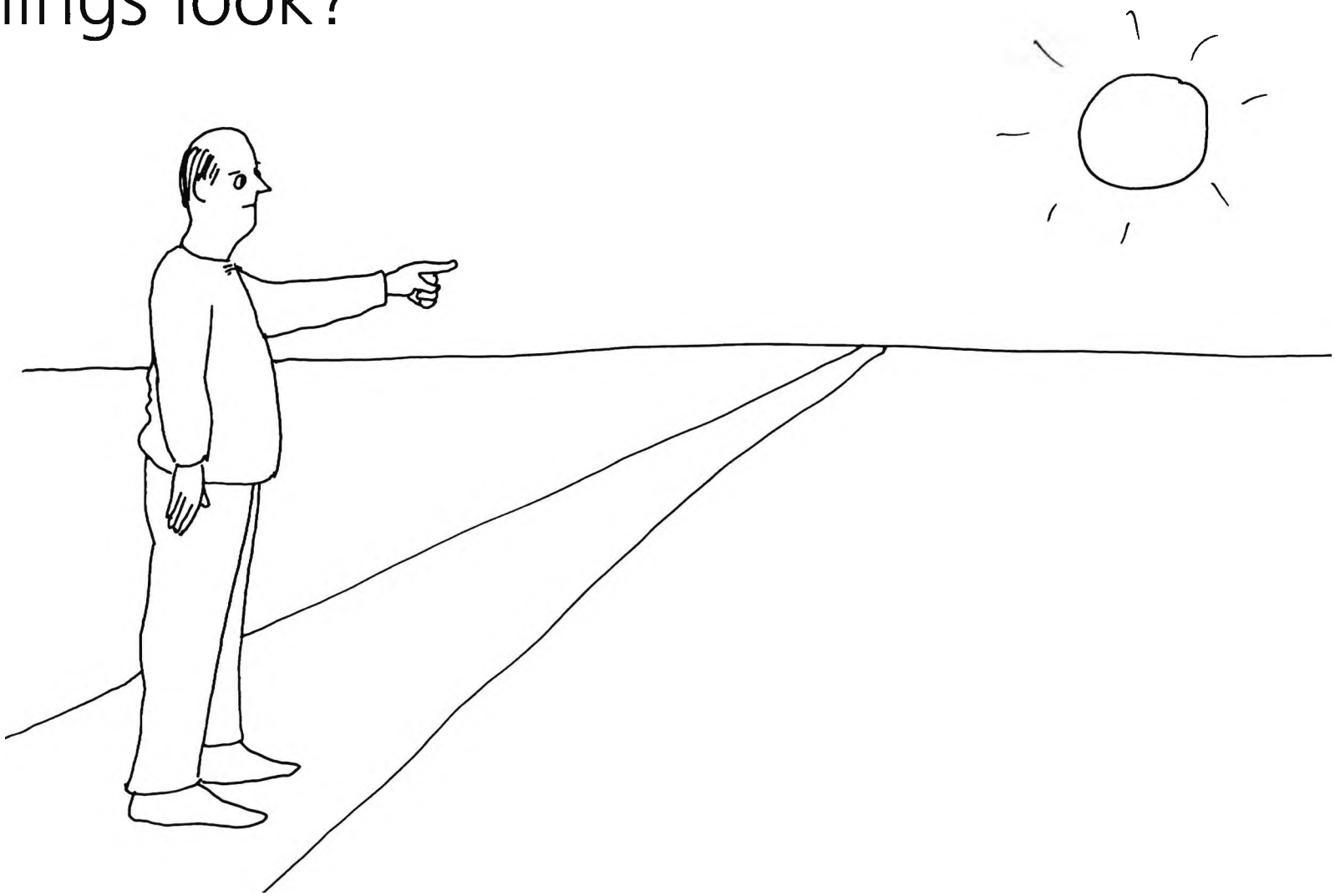
Able

Isolated

Valued

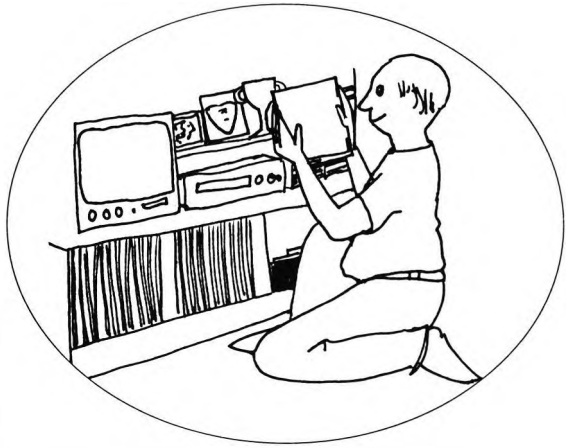
Embarrassed

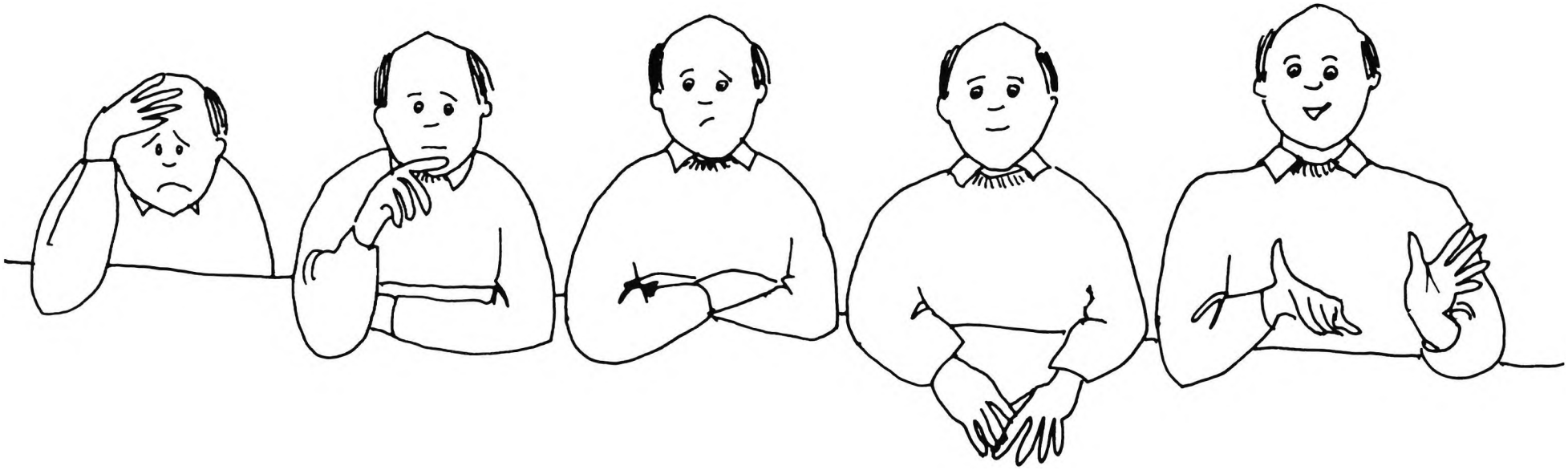
When you look to the **future**, how do things look?

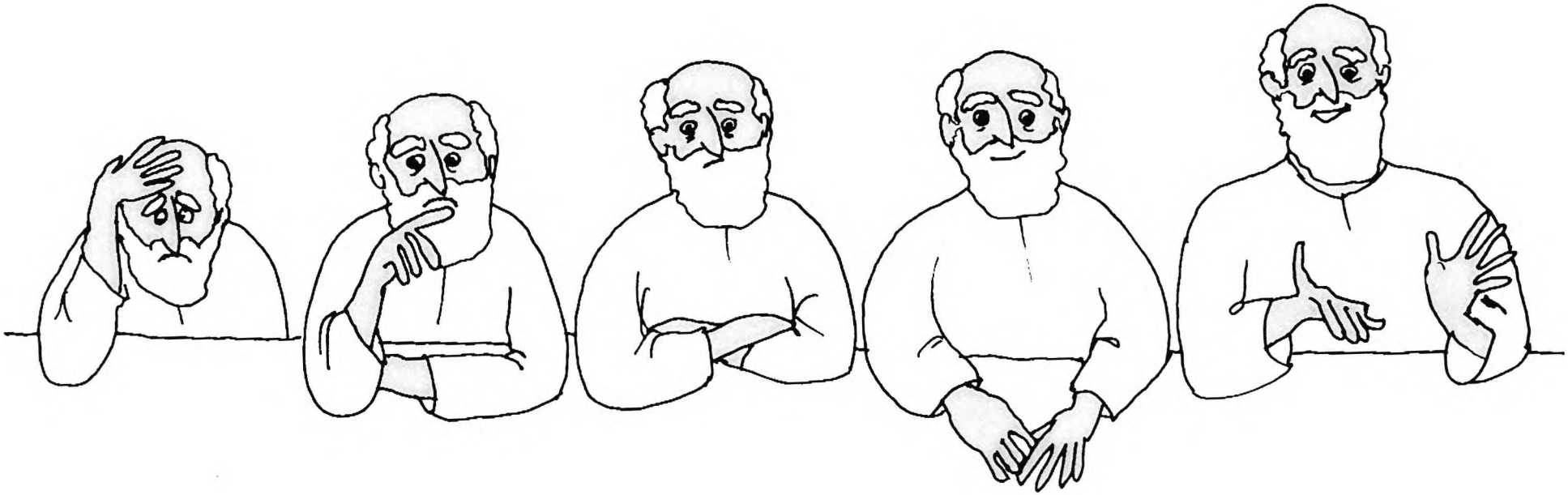


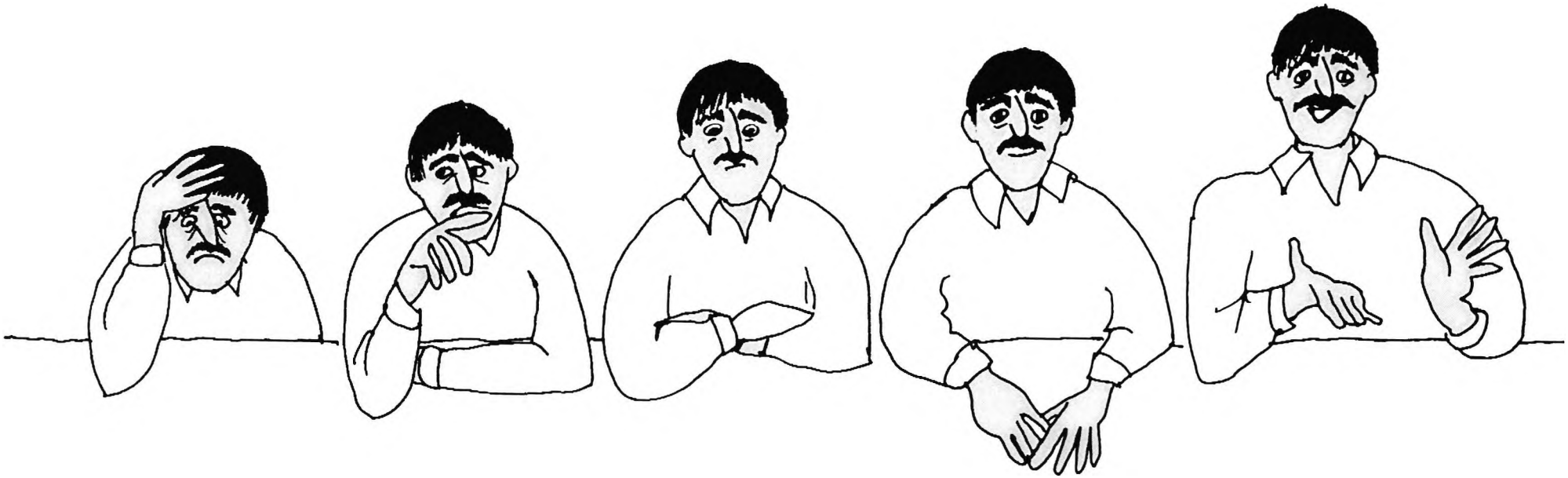
How do things look **today**?

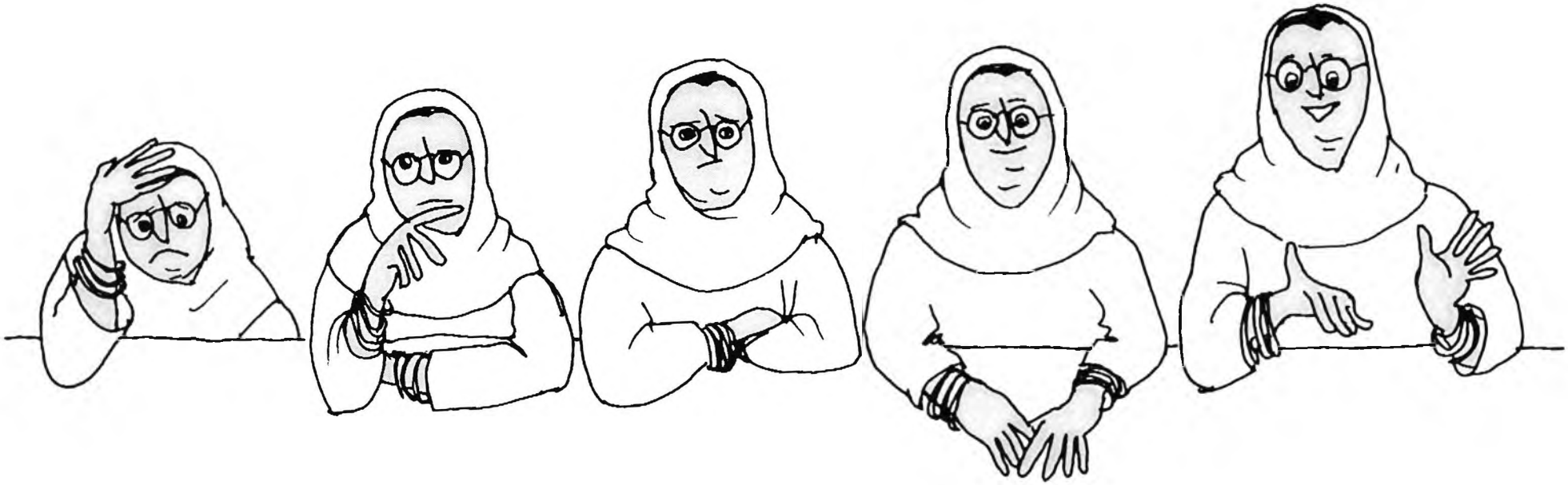
# What is **fun** for you?

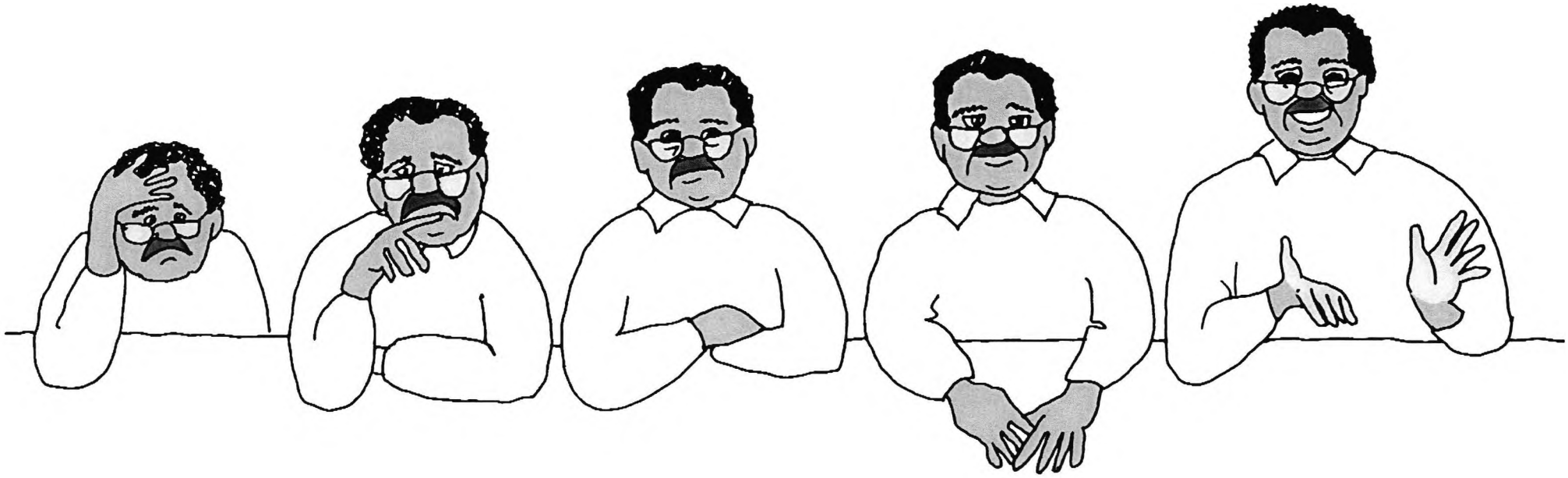


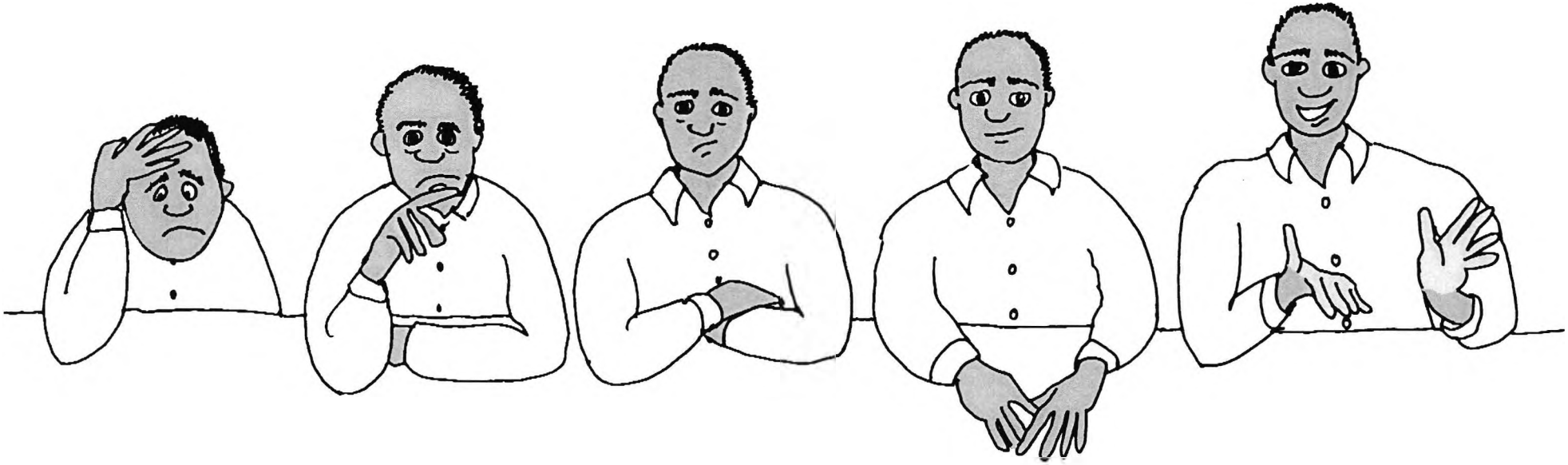


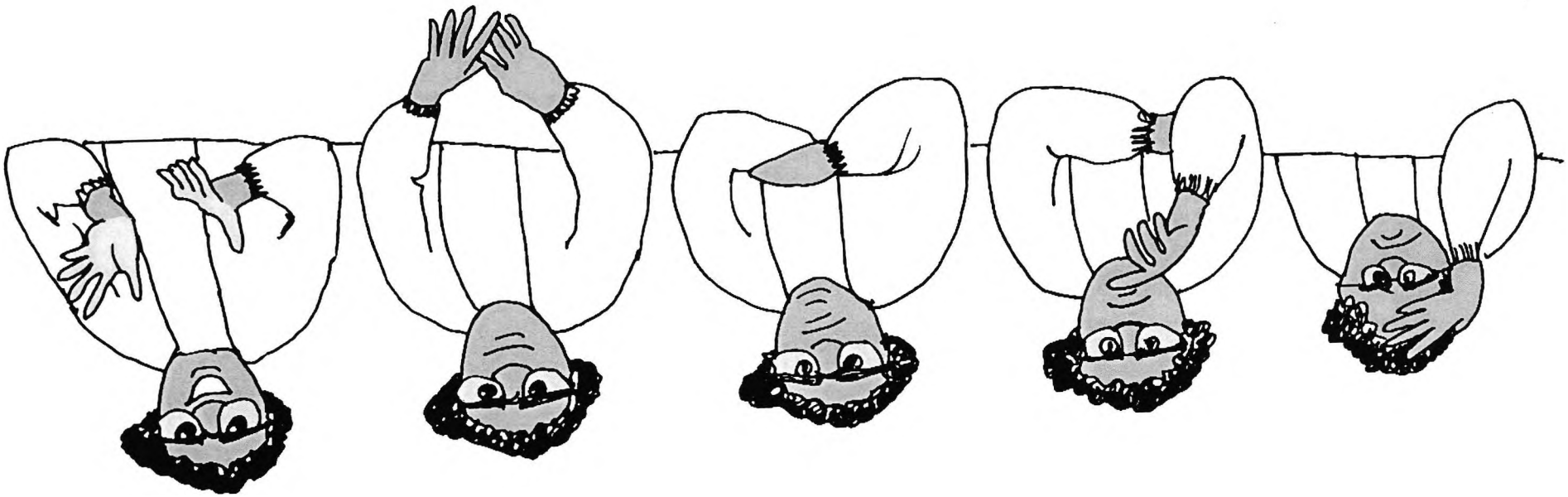


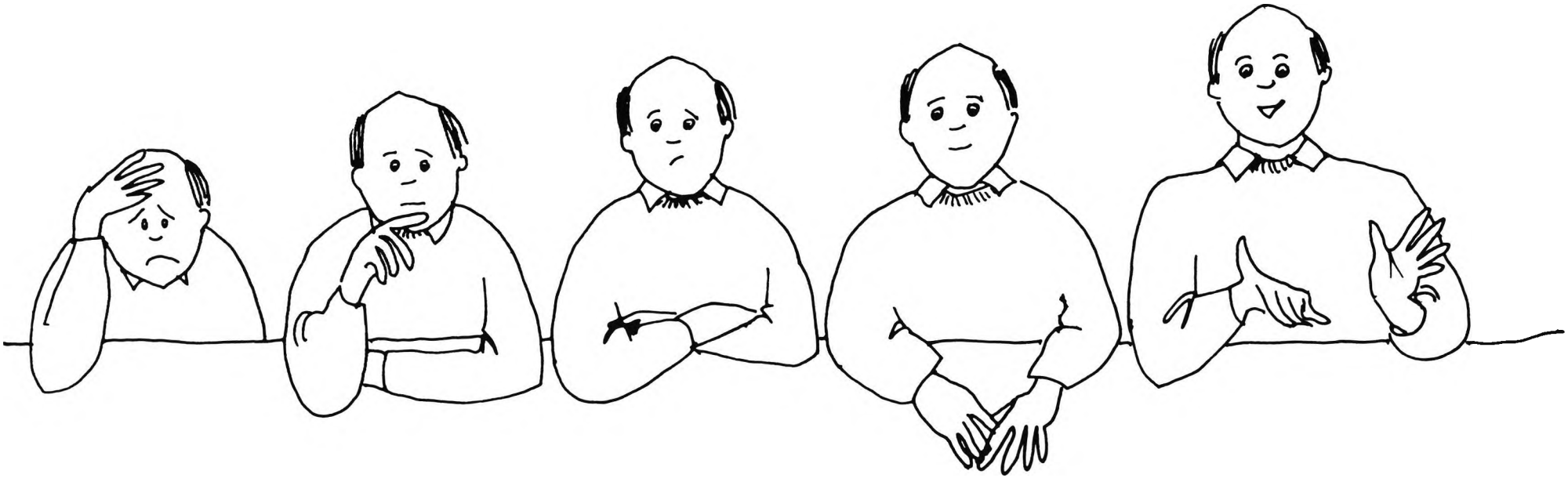


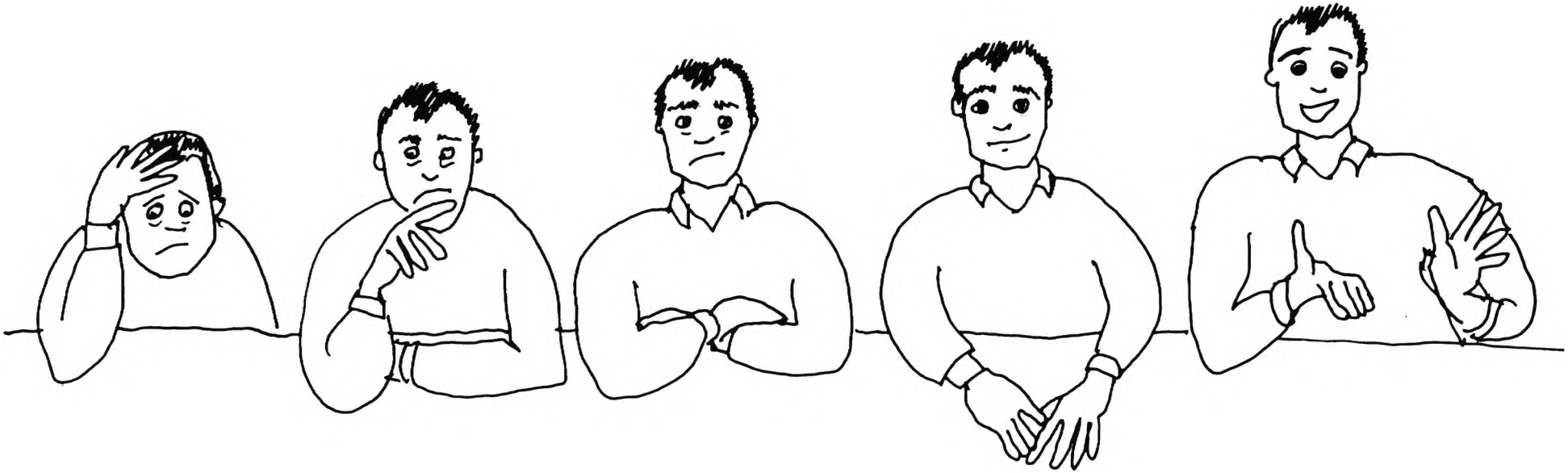


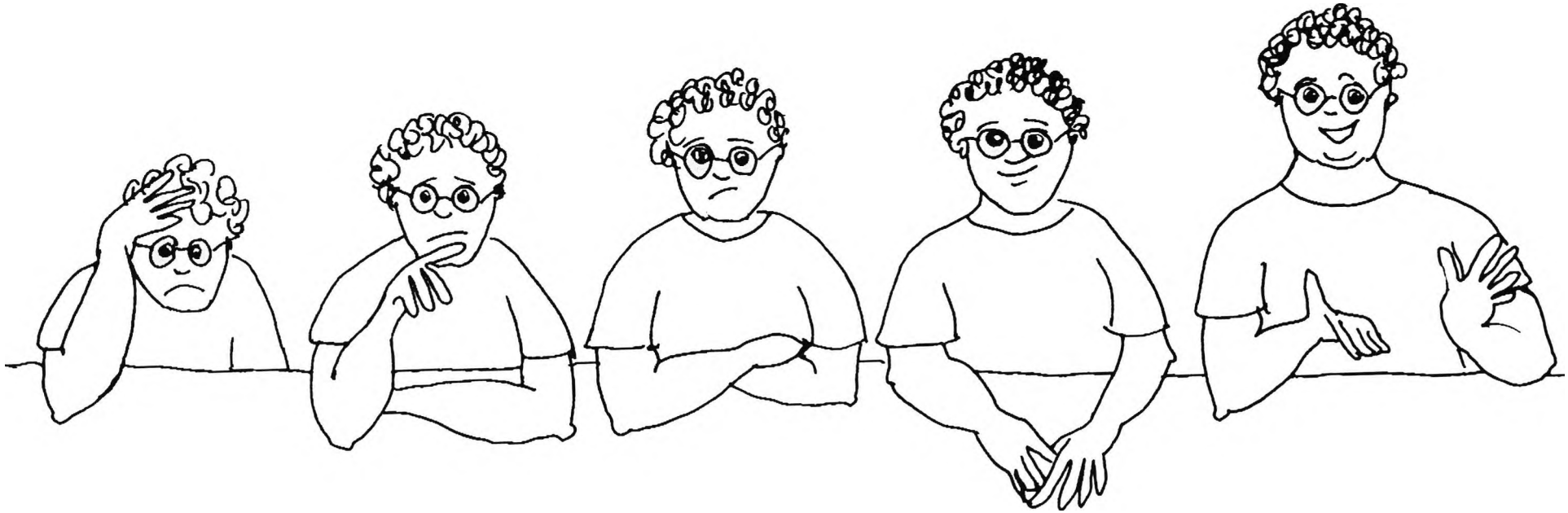




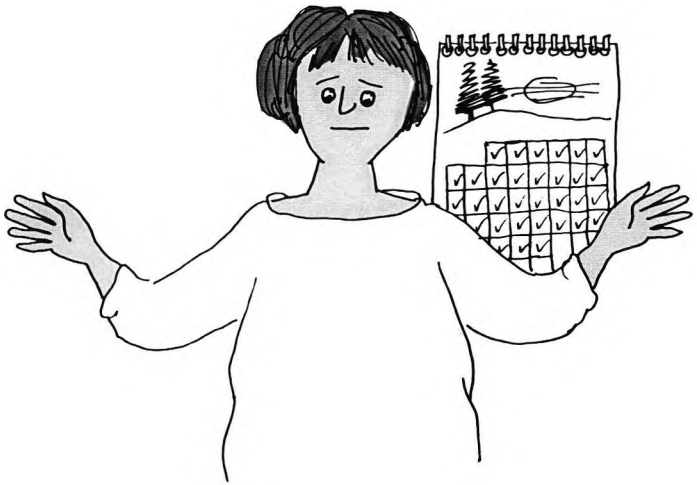








# Always



# Sometimes

# Never

A **little** or a **lot**

Appendix 4.3b
The CDP – draft 2

## THE COMMUNICATION DISABILITY PROFILE

Name: Date:

**NOTE: Discussion around the question is encouraged. Space is available to record verbatim responses and elaborations. Use of gesture and supported conversation is encouraged to elucidate any potential comprehension difficulties.**

All the words in *italics* are to be read. Instructions to be followed are in **bold.**

*"Aphasia is difficulty with talking, understanding, reading and writing.*
**(show picture 1)**.

*We're going to talk about what its like for you living with aphasia.*

*does it affect what you do and how you feel.* **(picture 2)**

*We're going to go through some questions.*

*The questions are all about how things have been since your stroke, during the last week.*
**(picture 3)**

*It is your view of how things are. There is no right or wrong.*

*I'll ask a question.*

*It will look at how easy it is for you to do something.*

*I'll also show you a scale like this.* **(show scale 1)**

*You show me how easy that thing is for you.*

*Let's try an example.*

*During the last week* **(picture 4)***, how easy is it to chat to a friend* **(show picture 5)**

***so;***

**(present scale 1)**

*if chatting is very easy, the same as before your stroke point here*
**(point to far right of the scale)**;

*if you cannot chat at all, impossible you would point here*
**(point to far left of the scale);**

*but maybe its somewhere in between* **(sweep hand across the scale).**

*So it can be any one of these points* **(point to all five pictures).**

*What do you think – how easy is chatting to a friend ... show me on the scale?*
**NOTE: Sweep hand across each page to ensure the aphasic person has noted the whole of the page**

**TALKING**

*Let's look at your talking* **(show picture 7)** *- finding your words and saying a sentence.*

Talking: Activities

*During the last week* **(show laminated picture** *), how easy is it for you to (***laminated scale 1***):*

1. **(picture 8)** *talk to the person closest to you?* **(use person's name)** **0 1 2 3 4**

**Comments:**

2. **(picture 9)** *talk with a group of friends?* **0 1 2 3 4**
**Comments:**

3. **(picture 10)** *talk to a stranger, someone you don't know?* **0 1 2 3 4**
**Comments:**

4. **(picture 11)** *talk under pressure?* **0 1 2 3 4**
**Comments:**

**Note: Only complete the next section if you believe non-verbal communication is an acceptable option, which is likely to be in use now or in the near future**

**EXPRESSING YOURSELF**

*"If talking is tricky, let's look at how you express yourself – get your message across in other ways, like pictures or actions* **(picture 12)** .

Expressing yourself: Activities
*During the last week,* **(laminated picture)** *how easy is it for you to (***laminated scale 1***):*

5. **(picture 13)** *express yourself with the person closest to you* **(use person's name)**
**Comments:** **0 1 2 3 4**

6. **(picture 14)** *express yourself with a group of friends* **0 1 2 3 4**
**Comments:**

7. **(picture 15)** *express yourself with someone you don't know* **0 1 2 3 4**
**Comments:**

8. **(picture 16)** *express yourself if you are under pressure"* **0 1 2 3 4**
**Comments:**

**UNDERSTANDING**

*This next section is about you understanding* **(picture 17).**

*So other people are talking. This is you following what's said.*

Understanding: Activities

*During the last week,* **(laminated picture)** *how easy is it for you to (***laminated scale 1***):*

9. **(picture 18)** *understand the person closest to you* **(use person's name)**
**Comments:** **0 1 2 3 4**

10. **(picture 19)** *understand a stranger, someone you don't know* **0 1 2 3 4**
**Comments:**

11. **(picture 20)** *understand in a group* **0 1 2 3 4**

**Comments:**

12. (**picture 21**) *understand when you're under pressure* **0 1 2 3 4**
**Comments:**

**READING**

**Note: Pre-morbid literacy practices will significantly influence this section and must be borne in mind when choosing whether to administer this section and with interpretation of this section.**

*"Can we talk about reading.*(**picture 22**)

*This is reading in your head not reading aloud*

Reading: Activities

*During the last week,* (**laminated picture** ), *how easy is it for you to (***laminated scale 1***):*

13. (**picture 23**) *read and follow one word* **0 1 2 3 4**
**Comments:**

14. (**picture 24**) *read and follow a headline* **0 1 2 3 4**
**Comments:**

15. (**picture 25**) *read and follow a whole story in a paper* **0 1 2 3 4**
**Comments:**

16. (**picture 26**) *read and follow an official letter* **0 1 2 3 4**
**Comments:**

**WRITING**

**Note: Pre-morbid literacy practices will significantly influence this section and must be borne in mind when choosing whether to administer this section and with interpretation of this section.**

*"Lets have a look at writing – NOT holding the pen – the spelling.* **(picture 27)**

*What about finding words and spelling them?*

Writing: Activities
*During the last week* **(laminated picture )** *how easy is it for you to (***show laminated scale 1***):*

17. **(picture 28)** *write your name* **0 1 2 3 4**
**Comments:**

18. ( **picture 29)** *write other single words like a list* **0 1 2 3 4**
**Comments:**

19. **(picture 30)** *write a letter to a friend* **0 1 2 3 4**
**Comments:**

20. **(picture 31)** *write an official letter* **0 1 2 3 4**
**Comments:**

Participation

*So if you remember, aphasia can make ALL these things tricky (***picture 32***).*

*So told me when things are easy and difficult (***gesture good and bad***).*

21. *You've told me ……..(* **summarise what was easy and difficult for that person***)*

*So, lets look at whether aphasia affects things you have to do?*

*Here are some things you might have to do.*
**(picture 33 - point to the each picture one by one).**

*Let's talk about them first.*
*Does aphasia affect:* **Do not rate YET**
**Discuss**

- *Work*

- *Money*
- *Health*
- *Transport*
- *Shopping*
- *Business*
- *Other things you have to do, where aphasia gets in the way?*

*So overall, how are all those things you have to do?*
**(Sweep hand across all the mini-pictures in bubble picture 34)**

*Can you show me on the scale*
**(show laminated scale 1, establish a rating)** **RATE** **0 1 2 3 4**

22. **(picture 35)** *Here are some things you might want to do.*

*We're going to look at things you want to do?*

**(Point to the each picture one by one)**
*Lets talk about them first.*

*Does aphasia affect your:* **Do not rate YET**
**Discuss**

- *Hobbies*
- *Clubs*
- *Holidays*
- *Going out*
- *Meeting friends*
- *Relationships*
- *Other things you want to do, where aphasia gets in the way?*

*So overall, how are all the things you want to do?*
**(Sweep hand across all the mini-pictures in bubble 36),**

*Can you show me on the scale?*
**(show laminated scale 1, establish a rating)** **RATE** **0 1 2 3 4**

23. **(picture 37)** *How's communication at home?* **Discuss then rate**

**0 1 2 3 4**

External influences

*Some people have found there are things that help.*

*We're going to look at what helps* **(picture 38).**

24. **(pictures 39-41- choose picture with closest appropriate ethnicity)**
*First of all are there people who help?*

*WHO helps?*

**Do not rate**

**Comments:**
*Partner*

*Brother(s)/sister(s)*

*Son(s)/daughter(s)*

*Grandson(s)/granddaughter(s)/other children*

*Friend(s)/neighbour*

*Other people/health or social care workers/volunteer/warden*

25. **(picture 42)** *Are things or situations that help?*

*What things help?* **Do not rate**
**Comments:**

*When people listen to you*

*If you tell people (help-cards)*

*Extra time*

*Pictures*

*Write things down*

*Someone helping*

*Speaking books*

*Dictionary computer*

*Other things that help that we haven't talked about?* (use gesture to signal this)

*Sometimes communication might be made even harder*

*We're going to look at what it harder* **(picture 43).**

26. **(pictures 44-46 - choose picture with closest appropriate ethnicity)**
*Are people who make things harder?'*

**Do not rate**

**Comments:**
*Partner*

*Brother(s)/sister(s)*

*Son(s)/daughter(s)*

*Grandson(s)/granddaughter(s)/other children*

*Friend(s)/neighbour(s)*

*Other people/health or social care workers/volunteer/warden*

27. **(pictures 47, 48 and 49)***What about things or situations?*

*'What makes it harder?'* **Do not rate**
**Comments:**

**Picture 47**
*If there is a glass barrier*

*What about queues*

*If you are under pressure*

*If you are upset/struggling*

*Having to use the wrong hand*

**Picture 48**
*Tired*

*If there's too much*

*Telephones*

**Picture 49**
**Point to the person in the picture depicting each barrier, as you read the list.**

*2 people talking at once*

*Speaking quickly*

*Looking away/not listening*

*Noisy or busy*

*Interrupting*

*If someone's far away*

*Other things that make it difficult?*

**Note: Only complete the next section if you believe non-verbal communication is an acceptable option, which is likely to be in use now or in the near future**

## EMOTIONAL CONSEQUENCES

*You've told me about things that are easy and difficult for you and how that affects your life.*

*Those difficulties are caused by aphasia* **(see picture 50).**

*If you remember aphasia is difficulty with talking, understanding, reading, writing.*

*We're going to look at how living with aphasia makes you feel?* **(picture 51)**

*We're going to use a scale like this*

**Show laminated scale 2.**

*To see if you have a feeling all the time or just sometimes?*

**Show laminated scale 3.**

*And if that feel that a lot or a little?*

Self image

**Show picture 52.**

*Do any of these show how your aphasia makes you feel?*

**Encourage the aphasic person to choose one emotion from the page**

*And do you feel that all the time or just sometimes* **(show laminated scale 2)**

*And when you have that feeling do you feel that a lot or a little* **(show laminated scale 3).**

28. *Does your aphasia make you feel less confident?*
*when/why do you feel that?*

*When is it better - why?*

| always a lot | sometimes a lot | always | sometimes a little | never a little |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |

29. *Do you feel you have less control?*

*when/why do you feel that?*

| always a lot | sometimes a lot | always | sometimes a little | never a little |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |

*hen is it better - why?*

30*[1]. *Do you feel <u>able</u>?*
*when/why do you feel that?*

*When is it worse - why?*

| always a lot | sometimes a lot | always | sometimes a little | never a little |
|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 |

**<u>picture 53</u>**
*Do any of these show how aphasia makes you feel?*
**Encourage the aphasic person to choose one emotion from the page.**
**Having done so – then go through each emotion one by one, obtaining a rating by using laminated scale 2 and scale 3.**

31. *Do you feel <u>isolated</u>?*
*when/why do you feel that?*

*When is it better - why?*

| always a lot | sometimes a lot | always | sometimes a little | never a little |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |

32. *Do you feel <u>embarrassed</u>?*
*when/why do you feel that?*

*When is it better - why?*

| always a lot | sometimes a lot | always | sometimes a little | never a little |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |

33*. *Do you feel <u>valued</u>?*
*when/why do you feel that?*

*When is it worse - why?*

| always a lot | sometimes a lot | always | sometimes a little | never a little |
|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 |

**<u>picture 54</u>**
*Do any of these show how aphasia makes you feel?*

34. *Do you feel <u>angry</u>?*
*when/why do you feel that?*

*When is it better - why?*

| always a lot | sometimes a lot | always | sometimes a little | never a little |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |

35. *Do you feel <u>frustrated</u>?*
*when/why do you feel that?*

| always a lot | sometimes a lot | always | sometimes a little | never a little |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |

[1] * indicates reverse scoring

*When is it better - why?*

36*. *Do you feel determined?*
*when/why do you feel that?*

*When are you not determined - why?*

| always a lot | sometimes a lot | always | sometimes a little | never a little |
|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 |

**picture 55**
*Do any of these show how aphasia makes you feel?*

37. *Do you feel unhappy?*
*when/why do you feel that?*

*When is it better - why?*

| always a lot | sometimes a lot | always | sometimes a little | never a little |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |

38. *Do you feel worried?*
*when/why do you feel that?*

*When is it better - why?*

| always a lot | sometimes a lot | always | sometimes a little | never a little |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |

39*. *Do you feel content?*
*when/why do you feel that?*

*When are you not content - why?*

| always a lot | sometimes a lot | always | sometimes a little | never a little |
|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 |

40. **(picture 56 + laminated scale1)** *when you look to the future, how do things look?*
*Let's go back to this first scale – do you remember this one?* **Use laminated scale 1**
**Comments:** **0 1 2 3 4**

41. **(picture 57 + laminated scale1)** *how do things look today?*
**Comments:** **Use laminated scale 1**
**0 1 2 3 4**

42. (choose from **pictures 58, 59 and 60)** *do you have people who are important to you?*
**Do not rate**
**Discuss**

43. **(picture 61)** *what is fun for you?* **Do not rate**
**Discuss**

44. *Is there anything else that is important to you about aphasia? Anything you feel we haven't covered?*

45. *Is there anything you would like to say about your life now?*

**Once you have completed the profile, you can obtain a score if desired. Add the raw scores to the score-sheet.**

Appendix 4.4

Feedback form 1(to be completed after each administration)

**The Communication Disability Profile**

## Thoughts, comments and suggestions form

Please complete after each CDP administration

Details of person with aphasia:

Age: under 40 41-50 51-60 61-70 over 70

Sex: Male Female

Ethnic background : (Please specify).....

Other relevant information about the person with aphasia?

Any comments made by the person with aphasia about the procedure?

Overall, do you think the procedure felt positive or negative for the perspective of the person with aphasia? (circle appropriate one)

**Positive** **Negative** **Unable** to comment

P.T.O.

Therapist comments and suggestions on CDP

Comments/suggestions on the **content** of the CDP

- Did the **content** seem **appropriate** for the person you were interviewing?

- If not, **why not**?

- **suggestions** for changes

Comments/suggestions on the **format** of the CDP

- was the CDP **easy to use**?

- If not **why not** (be as specific as possible please)

- Suggestions for changes

Any other comments from this administration of the CDP?

Appendix 4.5

Feedback form 2

**The Communication Disability Profile**

## Feedback questionnaire

Please complete at end of field-test period

How many administrations of the CDP did you complete?

Were there people with aphasia, who you chose not to administer the CDP with, or you stopped having started?

If so, what stopped you?

Is there anything that could have overcome that?

What are your overall perceptions of the CDP, in terms of:

1. **Content**
   (e.g. are the items relevant, have any areas been omitted?)

2. **Format and style**
   (e.g. how **easy**/difficult was it **to use**, were there **sections**/items that caused **problems**, how easy was it to **score**, was it **accessible** to you and people with aphasia?)

P.T.O.

3. Relevance to **clinical practice**
   (e.g. was the **information** provided useful, was the **process** useful?)
   did the information **guide** your management, if so **how**, if not **why not**?)

4. Informing **practitioner**
   (e.g. did anything about the process make you **reflection** on your **previous practice,** if so **in what are your conclusions/thoughts?)**

Any other thoughts or suggestions?

THANK YOU so much for helping to field test the CDP.

Please return to me, by .....:

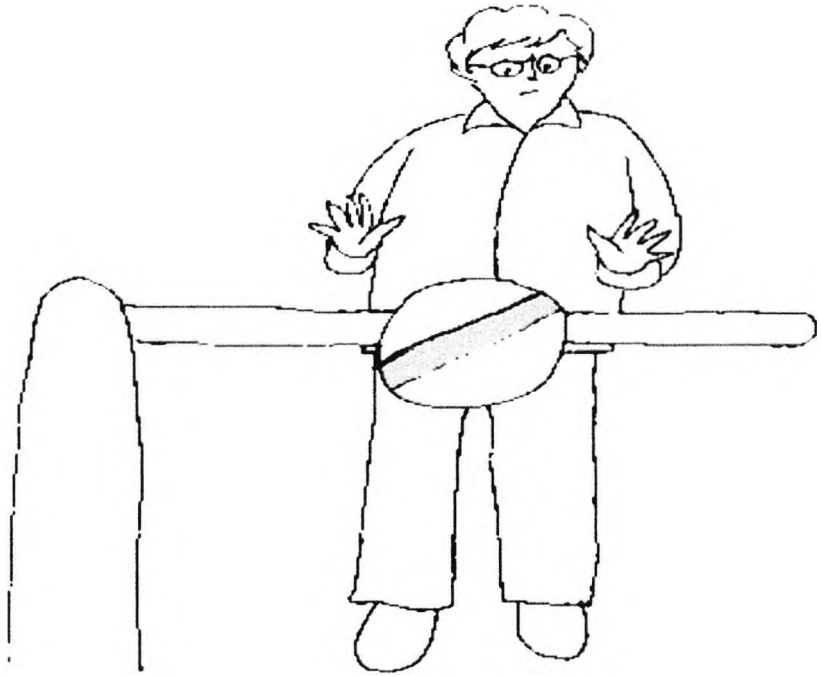
Kate Swinburn
6, Brodrick Road
London SW17 7DZ

**Appendix 5.1**
**How much does it get in the way - original draft**

How much do these things **get in the way** of everyday life for you?

Appendix 5.2
How much does it get in the way - second draft

# How is talking in everyday life?



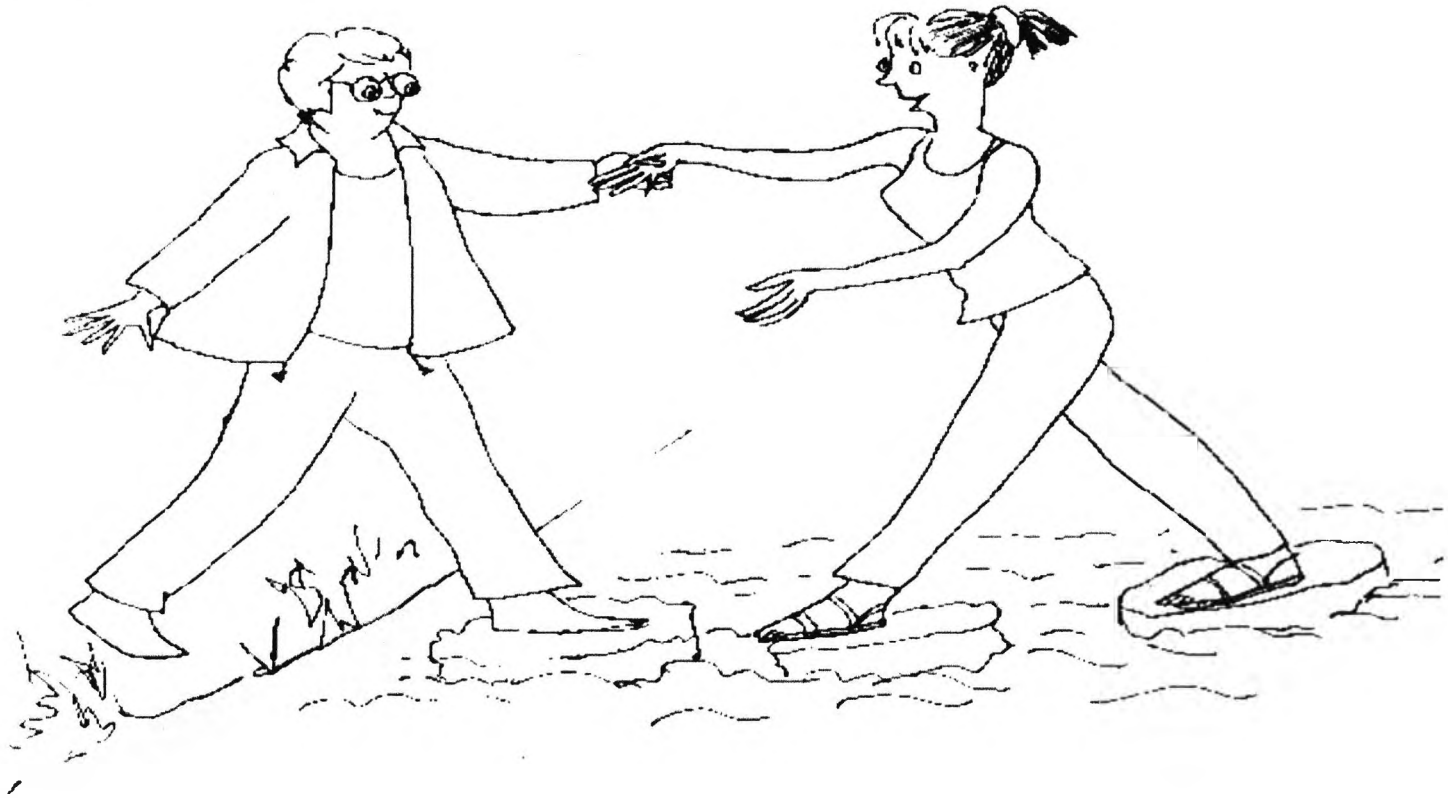
Appendix 5.3

What makes it worse (concept)- original draft

# Worse

Appendix 5.4
What makes it easier (concept) - original and final draft

**Easier**



Appendix 5.5
Are there people who make things easier - original draft

# Are there **people** who make **things easier**?

Appendix 5.6
How are things you WANT to do
(original and final)

# How are things you **want** to do?

Hobbies

Clubs

Holidays

Going out

Meeting friends

Relationships

Appendix 5.7
Things you HAVE to do - original and final draft

# Things you **have** to do – talking

Work

Money

Health

Transport

Shopping

Business

Appendix 5.8
At HOME original and final draft

# At home

Appendix 5.9
WHO helps your talking (specific) second draft

# **Who helps** your talking?

Appendix 5.10

What THINGS help your talking (specific)- original and final draft

# What **things help** your talking?

Listen to me

Help card

Extra time

Pictures

Write things down

Appendix 5.11
WHAT makes talking HARDER (concept)

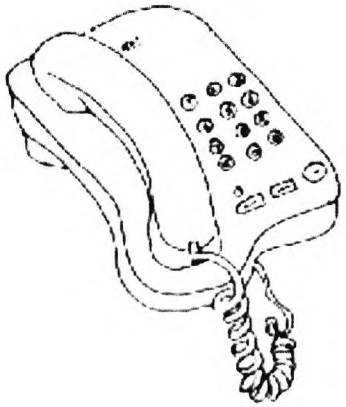
# What makes talking **harder**?

Appendix 5.12
WHO makes talking HARDER (specific)

# **Who helps** your talking?

Appendix 5.13
What makes talking HARDER picture (specific)- original draft

# Are there **things** that make things **worse**



Appendix 5.14
What THINGS makes talking HARDER (specific) final draft (one of three pages)

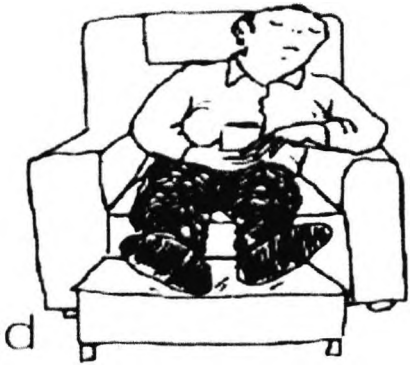
# **What** makes talking harder?

Glass barriers

Queues

Telephones

Being upset



Being tired

Appendix 5.15

What THINGS makes talking HARDER (specific) conversational barriers

# What makes talking **harder**?

Interrupted

Look away

Bored

Noisy

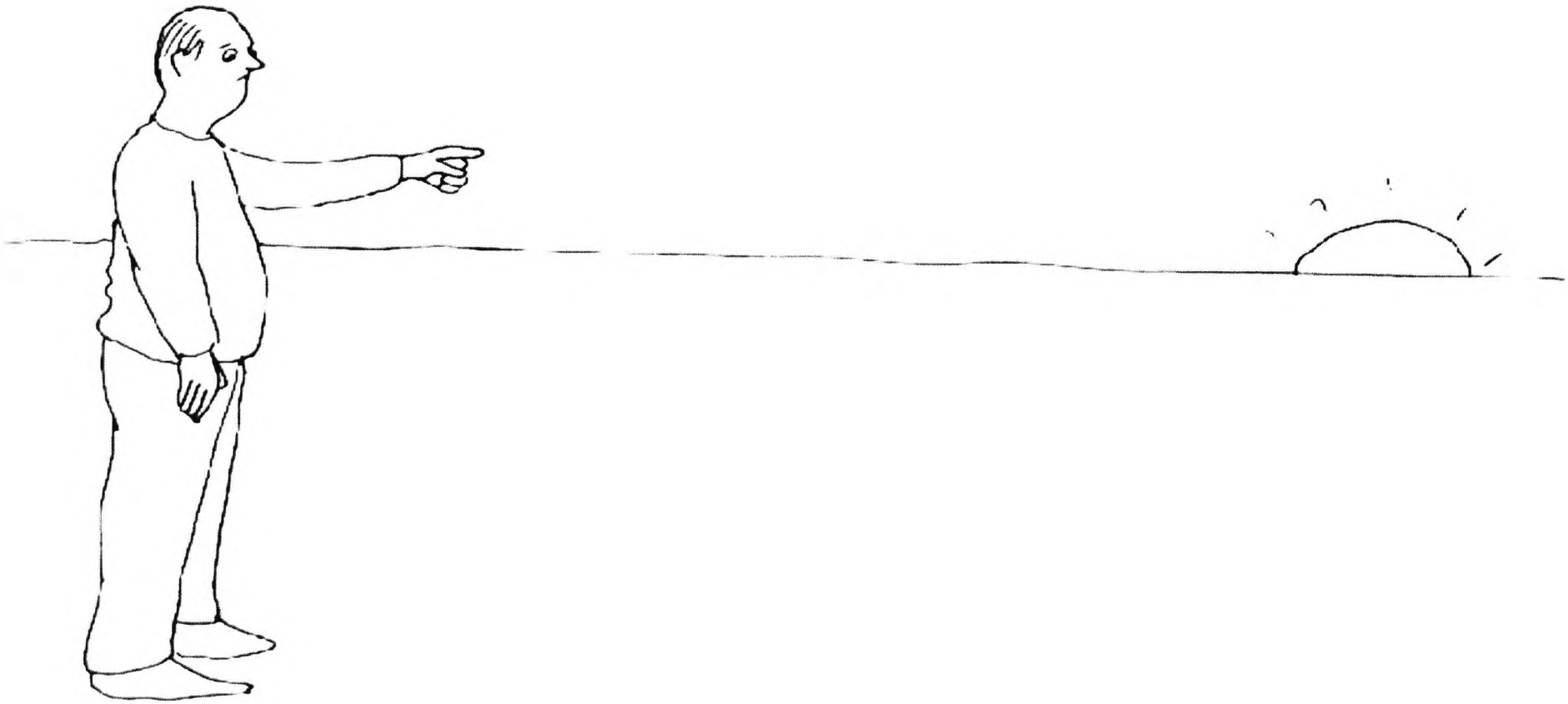
Far away

Appendix 5.16
Talking under pressure original draft

# How easy is talking under pressure?

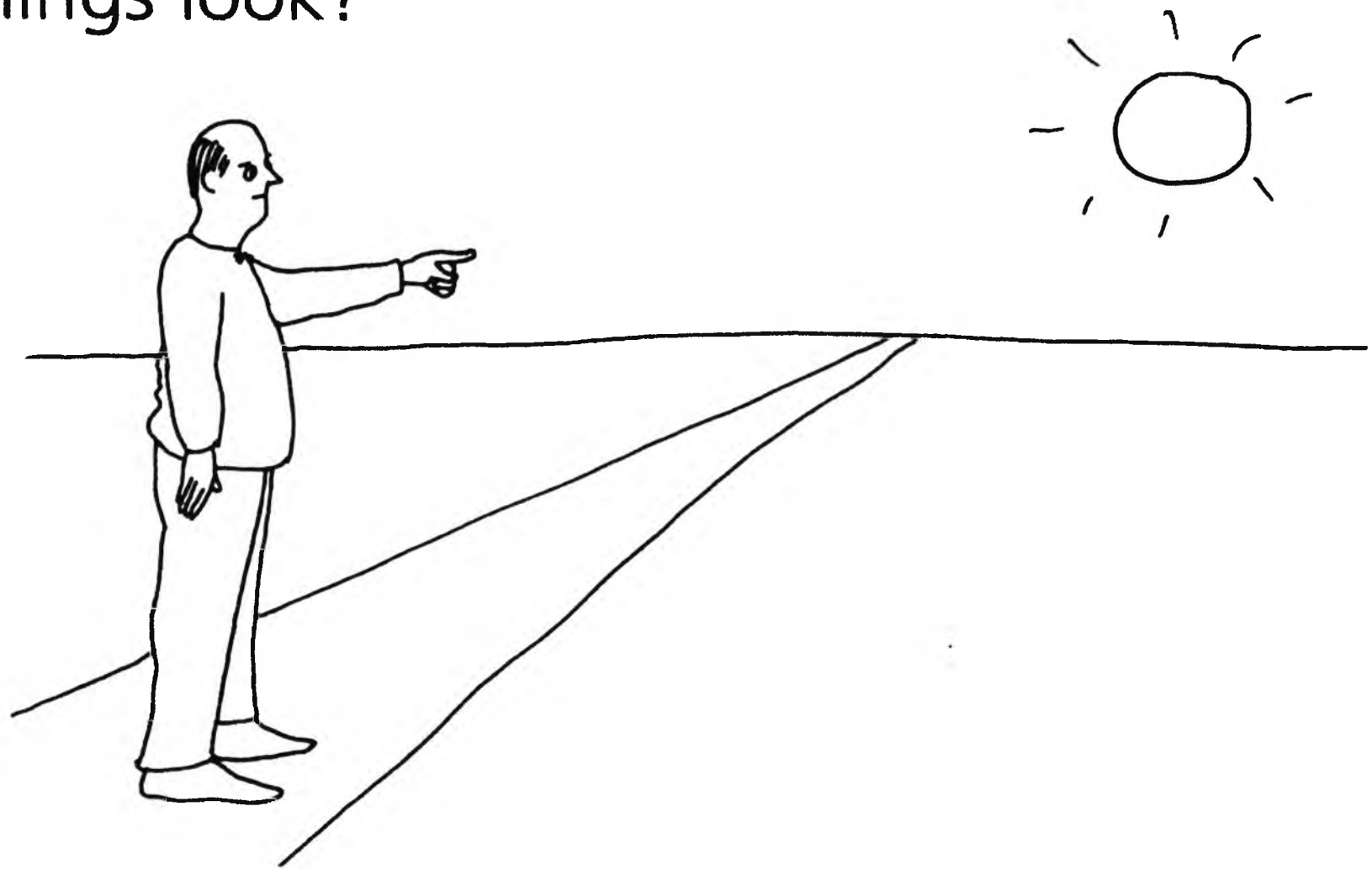
Appendix 5.17
Looking to the future - original draft

When you look to the **future**, how do things look?



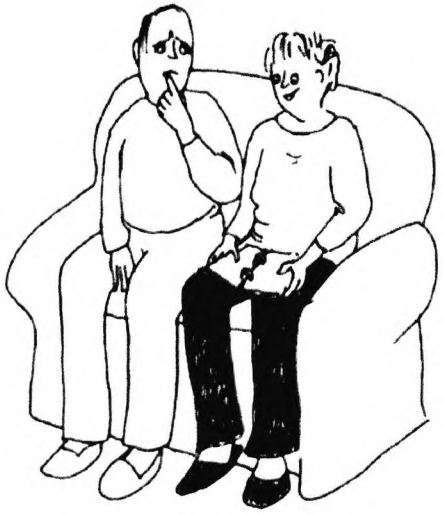
Appendix 5.18
Looking to the future - final

When you look to the **future**, how do things look?



Appenidx 5.19
Original 3 per page emotions picture

Unhappy



Worried

Whole

Appendix 5.20

Concepts that appear in the qualitative interviews.

| *Domain within the CDP* | *Exemplar from the qualitative interviews* | *Existing items within CDP (draft 1) that cover this example* |
|---|---|---|
| Communication activities | Can't say children's names, husband can't understand her | Talk-person closest |
| Communication activities | Difficulty conversing in a group, feel limited in group, restricts talk in a group | Talk-group |
| Communication activities | Avoid talking to stranger | Talk-stranger |
| Communication activities | Speech worse under pressure (doctor/teacher), unable to ask Dr questions | Talk-pressure |
| Communication activities | I can understand my wife | Understand-closest |
| Communication activities | Can't understand what strangers say to me, avoid strangers, concentrates on children to avoid conversation at school pick-up | Understand-stranger |
| Communication activities | Can't focus in a group, can't understanding in a group | Understand-group |
| Communication activities | Can't phone | Understand-pressure |
| Communication activities | Can't read little words | Read-word |
| Communication activities | Read at the front and the back and get a rough idea | Read-headline |
| Communication activities | Can't read the paper, effort to read the paper | Read-article |
| Communication activities | Can't read official letters | Read-official |
| Communication activities | Can't write cheques, can write signature, unable to write name | Write-name |
| Communication activities | Spelling problematic, can't write a shopping list , address difficult, | Write-word |
| Communication activities | Writing a letter, difficulty writing sentences, can't write to friends, writing letters, able to write a | Write-friend |

| | | |
|---|---|---|
| | card, can't write letter to friends properly | |
| Communication activities | Letter to bank | Write-official |
| Participation | Degree course, can't do dictation, can't chair meetings, loss of job, reduced hours, work mates check his writing, can't read reports | Things HAVE to do (work) |
| Participation | Writes list to overcome problems in bank, misperceived as being drunk when dealing with bank on phone, unable to access money due to signature changes, role change – wife now writes cheques finances, bank statement, shares, can't do cheques, can't write cheques, can't do money, writes list to overcome problems in bank | Things HAVE to do (money) |
| Participation | Unable to ask Dr questions | Things HAVE to do (health) |
| Participation | Unable to handle difficult situations like the bus, can't go where I want to, get a bus pass (avoids having to speak), reading timetable (added/agreed by advisory panel) | Things HAVE to do (transport) |
| Participation | Checkout at supermarket problematic, husband explains about aphasia if possibility of incorrect assumptions when shopping, perceived as being drunk in shops, have to go into shops several times to ask, role change for shopping, can't write a shopping list | Things HAVE to do (shopping) |
| Participation | Make notes before making business calls, wills, organise reunion, can't help with homework, can't do Christmas cards, can't do forms | Things HAVE to do (business) |
| Participation | Unable to handle telephone numbers | Other |
| Participation | Evangelising, can't keep up at classes, don't go to bowls because no-one talks to me, read history books, betting slips, crosswords, leisure activities-reading, read people's testimonies, read the bible, can't read subtitles, unable to return to PT degree course, can no longer navigate/read maps | Things WANT to do (hobbies) |

| | | |
|---|---|---|
| Participation | Reduced involvement with church, can't go to local discussion groups, discussion group, stopped attending French club | Things WANT to do (clubs) |
| Participation | Holidays | Things WANT to do(holidays) |
| Participation | Going to pub, social life, can't go places he wants to, restricts conversation to fillers to appear 'normal', change in status in conversation (no longer speech leader, become a listener, can't be initiator, use of humour), reduced social contacts, avoids conversational opportunities, restricts conversation, approaches strangers and chats – didn't used to | Things WANT to do (going out) |
| Participation | Friends don't visit, keeps quiet at dinner parties, talks one to one in groups, see friends individually since stroke, loss of friends seen as a 'loser', loss of friends, use of humour now restricted, can't be spontaneous, rejection by friends, meeting friends made him aware of difficulties because had to extend conversation/less relaxed, feels contribution is not interesting because of speed of delivery<br>Increased number of friends since stroke | Things WANT to do (meeting friends) |
| Participation | Can't phone friends, less contact with friends, loss of role in conversation, stay silent with others, son no longer phones, more empathic towards others, more sensitive to friends needs, read to grandchildren, less contact because can't write to friends, write to son is Australia, Christmas cards | Things WANT to do (relationships) |
| Participation | Diary | Things WANT to do (making plans) |
| Participation | Can't use the telephone | Things WANT to do (other) |
| Participation | Can't control grown up son, loss of power with husband when arguing, lost partner, end | At HOME |

| | | |
|---|---|---|
| | relationship, rebuking son, wife grabs the phone from him, restricts conversation, with children to avoid frightening them by making mistakes, simplifies language with own children to keep their attention, change in mood in family since having aphasia, family's feelings of hopelessness because of aphasia, turned into a negative person, son become more abusive since aphasia, son now has power over mother, strained relationship with wife, husband now does , shopping and therefore chooses what to eat etc – wife resents change in control of domestic domain | |
| External influences (barrier or facilitator) | Wife, partner, partner encouraging person with aphasia to think for himself, partner offers clues, husband supplies word, help with children's homework, can't read to children, role change with wife (she now writes cheques, does paperwork – PWA happy with that), wife more involved in paperwork, dislikes switch of locus of control, unhappy about dependence due to paperwork, wife feels she is better than him because she does the paperwork, husband now does household finances, letter writing, can't write notes to remind wife to do things in morning (disabled wife), sons respect important/contrasts with other sons behaviour, one son congratulates his mother for reading aloud well, other not | People (partner) |
| External influences (barrier or facilitator) | Brother | People (brother/sister) |
| External influences (barrier or facilitator) | Daughter helps, one son good, one son not | People (son and daughter) |
| External influences (barrier or facilitator) | Grandchildren easy, children better | People (children) |
| External influences | Friends at work, old friend, neighbour, friends – rejection, friends less relaxed than family, 2 | People (friend/neighbour) |

| | | |
|---|---|---|
| (barrier or facilitator) | good friends treat me the same, friends very helpful | |
| External influences (barrier or facilitator) | Nurse wrote letter to the bank, speech therapy, volunteer, surveyor | People (other people/health/ social care) |
| External influences (barrier) | Talk over me, interrupted | Conversation (interrupting) |
| External influences (barrier) | Try to get away<br>People don't listen | Conversation (look away) |
| External influences (barrier) | Negative attitudes<br>They talked and not to me | Conversation (look bored/not listening) |
| External influences (barrier) | Too much going on gets in the way | Conversation (noisy or busy) |
| External influences (barrier) | Added/agreed by advisory panel | Conversation (far away) |
| External influences (barrier) | Added/agreed by advisory panel | Conversation (other things that make talking difficult) |
| External influences (barrier) | Added/agreed by advisory panel | Conversation (cover face) |
| External influences (barrier) | Talks quickly | Conversation (speak quickly) |
| External influences (barrier) | Picks out one person in a group to talk to when groups problematic<br>Someone speaks for me | Other barriers/facilitators |

| | | |
|---|---|---|
| External influences (facilitators) | Interested in conversation, keeping interested, interested in conversation, friendly and interested, respect, positive attitudes, positive reactions help | Listen to me |
| External influences (facilitators) | Tell people had a stroke, pretence at being non-aphasic, fine telling close friends about aphasia – not others, helped to tell people | Telling people (help cards) |
| External influences (facilitators) | Talking - extra time, patience, he was impatient, extra time for reading | Extra time |
| External influences (facilitators) | Added/agreed by advisory panel | Pictures |
| External influences (facilitators) | Someone scribing, writes things down in bank, write instead of speak | Writing things down |
| External influences (facilitators) | Someone helping, someone scribing at history class, volunteer helps spelling by doing crosswords, neighbour fills in betting slips | Someone helping |
| External influences (facilitators) | Listen to radio<br>Listens to taped books | Speaking books |
| External influences (facilitators) | Dictionary | Dictionary |
| External influences (facilitators) | Print better than writing | Large print |
| External influences (facilitators) | PC (computer) – can self-correct | Computer |
| External influences | Talks one to one, picks out one person in a group, simplifies language, takes deep breaths, | Other facilitators |

| | | |
|---|---|---|
| (facilitators) | rephrasing, thinks before speaking, use of first letter, repetition, talking slow and posh, rabbit on when stuck for word, others filling in words/ Someone speaks for me, writing instead of speaking, having a laugh about it, reading to self at night, re-reading, reading out loud, using a piece of paper as a guide (reading), leaving writing and coming back to it | |
| External influences (barriers) | Added/agreed by advisory panel | Glass barriers |
| External influences (barriers) | Added/agreed by advisory panel | Queues |
| External influences (barriers) | 'phone | 'phone |
| External influences (barriers) | Agitated, vicious circle, worse if upset, struggling makes it worse | Upset |
| External influences (barriers) | Tiredness<br>Worse when tired | Tired |
| External influences (barriers) | Added/agreed by advisory panel | Wrong hand |
| External influences (barriers) | Multi-tasking | Too much |
| External influences (barriers) | Others filling in words<br>Changing topic of conversation | other barriers |
| Emotions | Lost confidence, avoid conversations, positive attitude, not worried, more assertive since having | Less confidence |

| | | |
|---|---|---|
| (including both positive & negative aspects of the concept) | aphasia | |
| Emotions | Added/agreed by advisory panel | Less control |
| Emotions | Added/agreed by advisory panel | Able |
| Emotions | Added/agreed by advisory panel | Isolated |
| Emotions | Added/agreed by advisory panel | Embarrassed |
| Emotions | Added/agreed by advisory panel | Valued |
| Emotions | Added/agreed by advisory panel | Angry |
| Emotions | Added/agreed by advisory panel | Frustrated |
| Emotions | Added/agreed by advisory panel | Determined |
| Emotions | Added/agreed by advisory panel | Unhappy |
| Emotions | Added/agreed by advisory panel | Worried |
| Emotions | Added/agreed by advisory panel | Content |
| Emotions | Added/agreed by advisory panel | The future? |
| Emotions | Added/agreed by advisory panel | Today? |

Appendix 5.21

Domains raised by in-depth interviews that ARE covered by CDP.

| *Exemplar from the qualitative interviews* | *Existing item within CDP draft 2 that cover this example* | *Domain within the CDP* |
|---|---|---|
| Can't say children's names, husband can't understand her | Talk-person closest | Communication activities |
| Difficulty conversing in a group, feel limited in group, restricts talk in a group | Talk-group | Communication activities |
| Avoid talking to stranger | Talk-stranger | Communication activities |
| Speech worse under pressure (doctor/teacher), unable to ask Dr questions | Talk-pressure | Communication activities |
| I can understand my wife | Understand-closest | Communication activities |
| Can't understand what strangers say to me, avoid strangers, concentrates on children to avoid conversation at school pick-up | Understand-stranger | Communication activities |
| Can't focus in a group, can't understanding in a group | Understand-group | Communication activities |
| Can't phone | Understand-pressure | Communication activities |
| Can't read little words | Read-word | Communication activities |
| Read at the front and the back and get a rough idea | Read-headline | Communication activities |
| Can't read the paper, effort to read the paper | Read-article | Communication activities |
| Can't read official letters | Read-official | Communication activities |
| Can't write cheques, can write signature, unable to write name | Write-name | Communication activities |
| Spelling problematic, can't write a shopping list , address difficult, | Write-word | Communication activities |
| Writing a letter, difficulty writing sentences, can't write to friends, writing letters, able to write a card, can't write letter to friends properly | Write-friend | Communication activities |
| Letter to bank | Write-official | Communication activities |
| Degree course, can't do dictation, can't chair meetings, loss of job, reduced hours, work mates check his writing, can't read reports | Things HAVE to do (work) | Participation |
| Writes list to overcome problems in bank, misperceived as being drunk when dealing with bank on phone, unable to access money due to signature changes, role change – wife now writes cheques finances, bank statement, shares, can't do cheques, can't write cheques, can't do money, writes list to overcome problems in bank | Things HAVE to do (money) | Participation |
| Unable to ask Dr questions | Things HAVE to do (health) | Participation |
| Unable to handle difficult situations like the bus, can't go where I want to, get a bus pass | Things HAVE to do (transport) | Participation |

| | | |
|---|---|---|
| (avoids having to speak), reading timetable (added/agreed by advisory panel) | | |
| Checkout at supermarket problematic, husband explains about aphasia if possibility of incorrect assumptions when shopping, perceived as being drunk in shops, have to go into shops several times to ask, role change for shopping, can't write a shopping list | Things HAVE to do (shopping) | Participation |
| Make notes before making business calls, wills, organise reunion, can't help with homework, can't do Christmas cards, can't do forms | Things HAVE to do (business) | Participation |
| Unable to handle telephone numbers | Other | Participation |
| Evangelising, can't keep up at classes, don't go to bowls because no-one talks to me, read history books, betting slips, crosswords, leisure activities-reading, read people's testimonies, read the bible, can't read subtitles, unable to return to PT degree course, can no longer navigate/read maps | Things WANT to do (hobbies) | Participation |
| Reduced involvement with church, can't go to local discussion groups, discussion group, stopped attending French club | Things WANT to do (clubs) | Participation |
| Holidays | Things WANT to do(holidays) | Participation |
| Going to pub, social life, can't go places he wants to, restricts conversation to fillers to appear 'normal', change in status in conversation (no longer speech leader, become a listener, can't be initiator, use of humour), reduced social contacts, avoids conversational opportunities, restricts conversation, approaches strangers and chats – didn't used to | Things WANT to do (going out) | Participation |
| Friends don't visit, keeps quiet at dinner parties, talks one to one in groups, see friends individually since stroke, loss of friends seen as a 'loser', loss of friends, use of humour now restricted, can't be spontaneous, rejection by friends, meeting friends made him aware of difficulties because had to extend conversation/less relaxed, feels contribution is not interesting because of speed of delivery<br>Increased number of friends since stroke | Things WANT to do (meeting friends) | Participation |
| Can't phone friends, less contact with friends, loss of role in conversation, stay silent with others, son no longer phones, more empathic towards others, more sensitive to friends needs, read to grandchildren, less contact because can't write to friends, write to son is Australia, Christmas cards | Things WANT to do (relationships) | Participation |
| Diary | Things WANT to do (making plans) | Participation |
| Can't use the telephone | Things WANT to do (other) | Participation |
| Can't control grown up son, loss of power with husband when arguing, lost partner, end | At HOME | Participation |

| | | |
|---|---|---|
| relationship, rebuking son, wife grabs the phone from him, restricts conversation, with children to avoid frightening them by making mistakes, simplifies language with own children to keep their attention, change in mood in family since having aphasia, family's feelings of hopelessness because of aphasia, turned into a negative person, son become more abusive since aphasia, son now has power over mother, strained relationship with wife, husband now does , shopping and therefore chooses what to eat etc – wife resents change in control of domestic domain | | |
| Wife, partner, partner encouraging person with aphasia to think for himself, partner offers clues, husband supplies word, help with children's homework, can't read to children, role change with wife (she now writes cheques, does paperwork – PWA happy with that), wife more involved in paperwork, dislikes switch of locus of control, unhappy about dependence due to paperwork, wife feels she is better than him because she does the paperwork, husband now does household finances, letter writing, can't write notes to remind wife to do things in morning (disabled wife), sons respect important/contrasts with other sons behaviour, one son congratulates his mother for reading aloud well, other not | People (partner) | External influences (barrier or facilitator) |
| Brother | People (brother/sister) | External influences (barrier or facilitator) |
| Daughter helps, one son good, one son not | People (son and daughter) | External influences (barrier or facilitator) |
| Grandchildren easy, children better | People (children) | External influences (barrier or facilitator) |
| Friends at work, old friend, neighbour, friends – rejection, friends less relaxed than family, 2 good friends treat me the same, friends very helpful | People (friend/neighbour) | External influences (barrier or facilitator) |
| Nurse wrote letter to the bank, speech therapy, volunteer, surveyor | People (other people/health/ social care) | External influences (barrier or facilitator) |
| Talk over me, interrupted | Conversation (interrupting) | External influences (barrier) |
| Try to get away<br>People don't listen | Conversation (look away) | External influences (barrier) |
| Negative attitudes<br>They talked and not to me | Conversation (look bored/not listening) | External influences (barrier) |
| Too much going on gets in the way | Conversation | External influences |

| | | |
|---|---|---|
| | (noisy or busy) | (barrier) |
| Talks quickly | Conversation (speak quickly) | External influences (barrier) |
| Picks out one person in a group to talk to when groups problematic<br>Someone speaks for me | Other barriers/facilitators | External influences (barrier) |
| Interested in conversation, keeping interested, interested in conversation, friendly and interested, respect, positive attitudes, positive reactions help | Listen to me | External influences (facilitators) |
| Tell people had a stroke, pretence at being non-aphasic, fine telling close friends about aphasia –not others, helped to tell people | Telling people (help cards) | External influences (facilitators) |
| Talking - extra time, patience, he was impatient, extra time for reading | Extra time | External influences (facilitators) |
| Someone scribing, writes things down in bank, write instead of speak | Writing things down | External influences (facilitators) |
| Someone helping, someone scribing at history class, volunteer helps spelling by doing crosswords, neighbour fills in betting slips | Someone helping | External influences (facilitators) |
| Listen to radio<br>Listens to taped books | Speaking books | External influences (facilitators) |
| Dictionary | Dictionary | External influences (facilitators) |
| Print better than writing | Large print | External influences (facilitators) |
| PC (computer) – can self-correct | Computer | External influences (facilitators) |
| Talks one to one, picks out one person in a group, simplifies language, takes deep breaths, rephrasing, thinks before speaking, use of first letter, repetition, talking slow and posh, rabbit on when stuck for word, others filling in words/ Someone speaks for me, writing instead of speaking, having a laugh about it, reading to self at night, re-reading, reading out loud, using a piece of paper as a guide (reading), leaving writing and coming back to it | Other facilitators | External influences (facilitators) |
| 'phone | 'phone | External influences (barriers) |
| Agitated, vicious circle, worse if upset, struggling makes it worse | Upset | External influences (barriers) |

| | | |
|---|---|---|
| Tiredness<br>Worse when tired | Tired | External influences (barriers) |
| Added/agreed by advisory panel | Wrong hand | External influences (barriers) |
| Multi-tasking | Too much | External influences (barriers) |
| Others filling in words<br>Changing topic of conversation | Other barriers | External influences (barriers) |
| Lost confidence, avoid conversations, positive attitude, not worried, more assertive since having aphasia | Less confidence | Emotions (including both positive & negative aspects of the concept) |
| Helpless, incapable, dependent, being trapped, need to be independent | Less control | Emotions |
| Can't do things, incompetent, a nutter, not being normal (?self esteem), stupid | Able | Emotions |
| Isolated, excluded, being ignored, unloved, rejected, neglected | Isolated | Emotions |
| Embarrassed, (?self esteem) | Embarrassed | Emotions |
| Lack of respect, being small, lower down (?self esteem) | Valued | Emotions |
| Angry, mad, aggressive towards family | Angry | Emotions |
| Frustrated | Frustrated | Emotions |
| Determined | Determined | Emotions |
| Sad, depressed, unhappy, down a bit | Unhappy | Emotions |
| Anxious, frightened, worried | Worried | Emotions |
| Pessimistic, optimistic | The future? | Emotions |
| Positive attitude, dissatisfied with life | Today? | Emotions |

Appendix 5.22

Domains raised by in-depth interviews that are NOT covered within the CDP

| *Exemplar from the qualitative interviews* |
|---|
| Specific communication strategy - giving alternatives |
| Specific communication strategy - restricting own speech |
| Specific communication strategy - keep quiet |
| Need for extra care and effort |
| Value of activities that have been recently taken up eg. Stroke clubs |
| Shocked, shock at discovering impairments |
| Emptiness |
| Confusion |

Appendix 5.23

Pilot comments (from people with aphasia) to show to advisory group

# What did 16 **people with aphasia** think of the CDP?

- ✓ *15/16 thought doing the **CDP** was a **positive experience** (one neither +ve or -ve)*
- ✓ *liked the **pictures***
- ✓ *liked the **no 'right/wrong'***
- ✓ ***Scales useful***
- ✓ ***liked** the fact that it **looked areas** of her life that **weren't usually addressed***
- ✓ *Felt it really **focussed** on **her** as a person and **respected** her point of view*
- ✓ *Helped to bring out the **positives** and for the person to reflect on them*
- ✓ *Very **thought-provoking** –think in **structured** way about impact of aphasia in different settings (tumour)*

but

- ***Emotional*** *scale – more* ***confusing***
- *found it* ***exhausting***

- *Wanted to go into* ***more depth*** *in participation section (things you have to do, things you want to do, at home)*
- *Did not like the* ***lightening strike***
- *'worried' and 'content' the opposite ends of the* ***same emotion****?*
- ***how*** *you* ***rate*** *would* ***depend*** *on where you were*
- ***how*** *you* ***rate*** *would* ***depend*** *on your* ***mood***
- *some situations were* ***variable*** *e.g talking with a group of friends could be easier but sometimes not*

- *Not prepared to be pigeon-holed, especially in the emotions section*

- *wanted to rate* ***between*** *the* ***pictures***

Appendix 5.24

Pilot comments (SLT) to show to advisory group

# What did 7 Speech & Language Therapists think of the CDP?

- ✓ ***Content*** *good and* ***relevant***
- ✓ ***Strong positive reaction*** *to some of the* ***pictures*** *and* ***questions***
- ✓ ***Easy*** *to use*
- ✓ *Score-sheet* ***simple***
- ✓ *Gave* ***structure*** *as a forum for discussing* ***emotional issues***
- ✓ *Gave me* ***specific ideas*** *re; advice to family* ***based*** *on* ***HIS experiences*** *not SLTs*
- ✓ *The CDP enabled him to be more* ***assertive*** *in expressing his views*
- ✓ *I've* ***enjoyed*** *doing it*

- ✓ *haven't come across **anything** which covers such **a lot of ground** (from the aphasic person's perspective) so **neatly**.*

- ✓ *It's **different**, and **highly useable**.*

- ✓ ***Identified** several **issues** that were **not** previously **recognised** by the SLT*

- ✓ ***confident** that **simple** things really do make a **big difference***

- ✓ *what you see as a **SLT** to be the problem, may **not** be what is **important** for this **person***

- ✓ ***highlight** with someone with **mild** aphasia the **huge** impact on **activities***

- ✓ *Made me very **keen** to do more education/**teaching** in **hospitals**, nursing homes, day centre*

- ✓ *Makes you think about the **need** to **inform** the **general public** more about aphasia*

but

- ***opens up*** *several other* ***areas*** *that* ***SLT not*** *able to* ***deal with****?*
- *Can be quite* ***time consuming***
- ***difficult*** *to* ***divide*** *effect of* ***aphasia*** *from* ***other*** *problems:* ***weakness,*** *fatigue*
- ***Too many pictures****, this* ***got easier***
- ***Emotional scales*** *took* ***time*** *and* ***practice***
- ***Participation*** *section* ***not appropriate*** *in* ***hospital*** *setting*
- *table* ***space*** *tricky –* ***too many pictures***
- *Couldn't* ***understand*** *the '****able****' picture*
- ***things you have to do*** *– client wanted to talk about* ***each one specifically***

Appendix 5.25

Example of how pilot suggestions for change were taken to advisory group

## 10th July – decisions

- *Participation section – things you HAVE to do, WANT to do, at HOME*
  - **rate **each** area*
  - **? **appropriate** for hospital setting*
- *Emotional section*
  - ****one** emotion **per page**?*
  - ****two**-stage rating or **one**?*
  - ****mood***
    *"is it a good or a bad day today?"*
  - **change '**able**' picture?*
  - **'worried' and 'content' the **same idea?***
  - **at present can only rate the **absence** of negative emotions – any ideas?*

- ***smaller*** *version – what do you think?*

Appendix 5.26



**The Communication Disability Summary Score sheet**

**Name :** **Date:**

| Q | Domains | Raw scores (circle) | Section totals | Percentage totals |
|---|---|---|---|---|
| 1 | Talk-person closest | 0 1 2 3 4 | | |
| 2 | Talk-group | 0 1 2 3 4 | | |
| 3 | Talk-stranger | 0 1 2 3 4 | | |
| 4 | Talk-pressure | 0 1 2 3 4 | | |
| | *Talk total* | | /16 | |
| 5 | Express-person closest | 0 1 2 3 4 | | |
| 6 | Express-group | 0 1 2 3 4 | | |
| 7 | Express-stranger | 0 1 2 3 4 | | |
| 8 | Express-pressure | 0 1 2 3 4 | | |
| | *Express total* | | /16 | |
| 9 | Understand-person closest | 0 1 2 3 4 | | |
| 10 | Understand- stranger | 0 1 2 3 4 | | |
| 11 | Understand- group | 0 1 2 3 4 | | |
| 12 | Understand-pressure | 0 1 2 3 4 | | |
| | *Understand total* | | /16 | |
| 13 | Reading-word | 0 1 2 3 4 | | |
| 14 | Reading-headline | 0 1 2 3 4 | | |
| 15 | Reading-story | 0 1 2 3 4 | | |
| 16 | Reading-official | 0 1 2 3 4 | | |
| | *Reading total* | | /16 | |
| 17 | Writing-name | 0 1 2 3 4 | | |
| 18 | Writing-list | 0 1 2 3 4 | | |
| 19 | Writing-friend | 0 1 2 3 4 | | |
| 20 | Writing-official | 0 1 2 3 4 | | |
| | *Writing total* | | /16 | |
| | ***Activities total:*** *(with express yourself)* *(without express yourself)* | | ***(-express)*** ***/64*** ***(+express)*** ***/80*** | ***Activities*** **%** |
| | **Life style/ Participation:** | | | |
| | have to: | 0 1 2 3 4 | | |
| 21 | Money | 0 1 2 3 4 | | |
| 22 | Health | 0 1 2 3 4 | | |
| 23 | Transport | 0 1 2 3 4 | | |
| 24 | Shopping | 0 1 2 3 4 | | |
| 25 | Business | 0 1 2 3 4 | | |
| 26 | Work | 0 1 2 3 4 | | |
| | want to: | 0 1 2 3 4 | | |
| 27 | Hobbies | 0 1 2 3 4 | | |

| | | | | |
|---|---|---|---|---|
| 28 | Clubs | 0 1 2 3 4 | | |
| 29 | Holidays | 0 1 2 3 4 | | |
| 30 | Going out | 0 1 2 3 4 | | |
| 31 | Meeting friends | 0 1 2 3 4 | | |
| 32 | Relationships | 0 1 2 3 4 | | |
| 33 | At home | 0 1 2 3 4 | | |
| | ***Participation*** | | /48 | ***Participation*** **%** |
| | Facilitators:<br><br>Barriers: | | | |
| 28 | Angry | 0 1 2 3 4 | | |
| 29 | Frustrated | 0 1 2 3 4 | | |
| 30 | *Determined* | **0 1 2 3 4* | | |
| 31 | Unhappy | 0 1 2 3 4 | | |
| 32 | Worried | 0 1 2 3 4 | | |
| 33 | *Content* | **0 1 2 3 4* | | |
| 34 | Less confident | 0 1 2 3 4 | | |
| 35 | Less control | 0 1 2 3 4 | | |
| 36 | *Able* | **0 1 2 3 4* | | |
| 37 | Lonely | 0 1 2 3 4 | | |
| 38 | Embarrassed | 0 1 2 3 4 | | |
| 39 | *Valued* | **0 1 2 3 4* | | |
| 40 | Future | 0 1 2 3 4 | | |
| 41 | Today | 0 1 2 3 4 | | |
| 42 | Enjoy? | | | |
| | ***Emotions total*** | | ***/56*** | ***Emotions*** **%** |

| | | | | |
|---|---|---|---|---|
| | ***Grand totals:*** | | | |
| | **Activities:** | **Participation:** | **Emotions:** | |
| | ***/64 %*** | ***/48*** | ***/56*** | |
| | ***/80 %*** | ***%*** | ***%*** | |

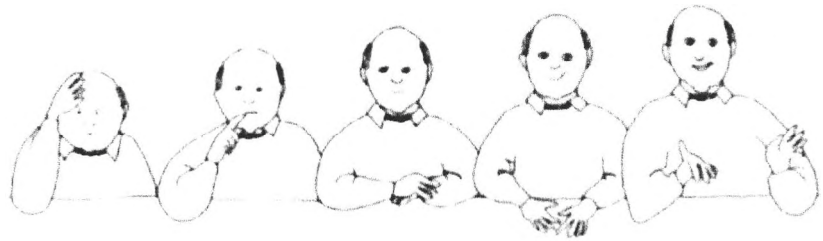
Key people:

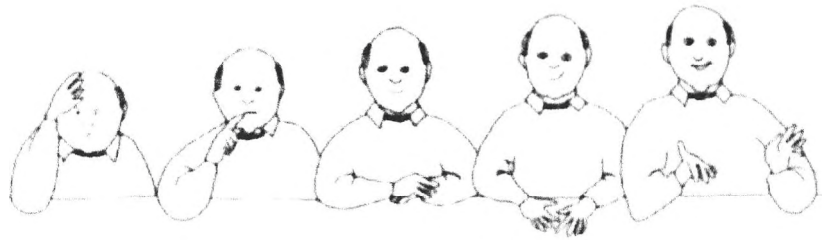
Key issues:

Possible action:

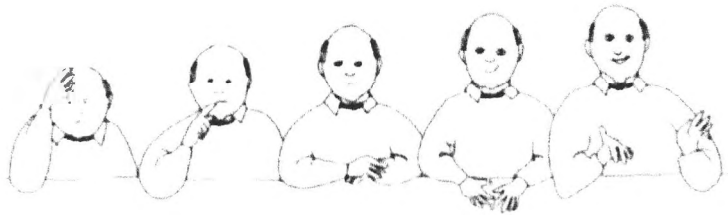
J:\Personal Folders\Kate\CDP\CDP development\final current versions\Summary score sheet CDP prefield test.doc

Appendix 5.27
Options for one-stage rating stage (condensed)





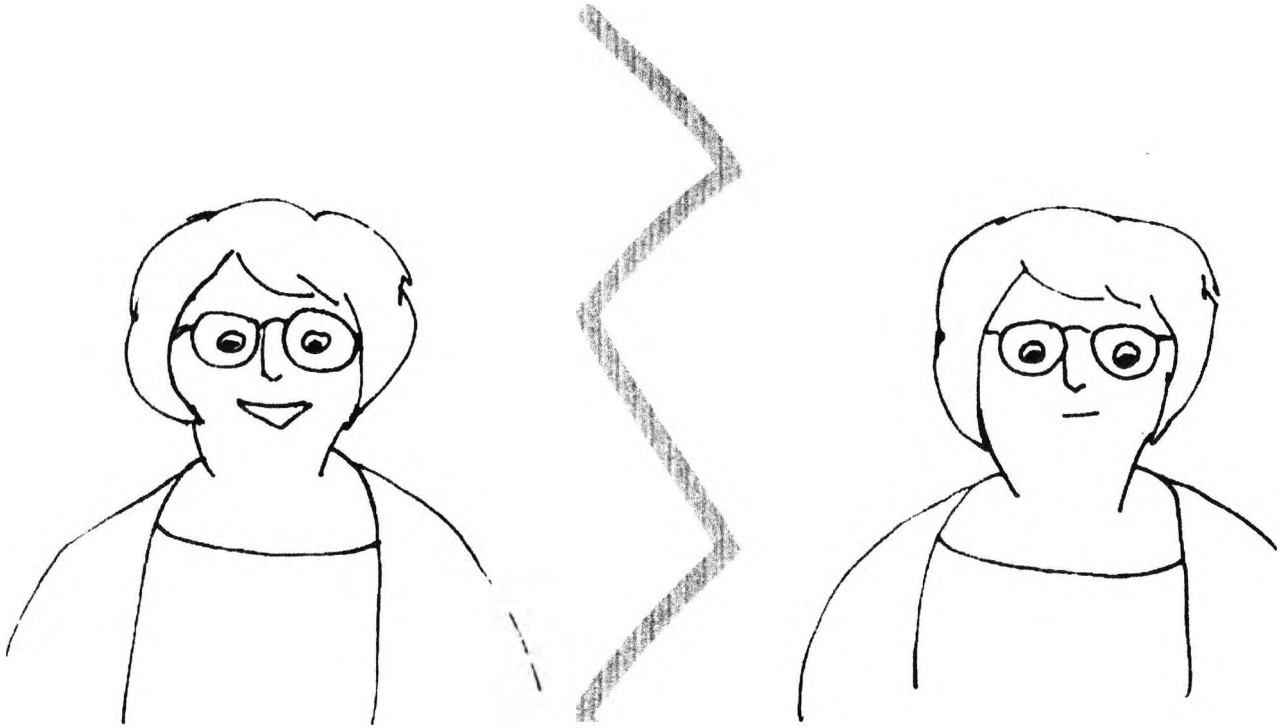
4 3 2 1 0



✖✖ ✖ — ✔ ✔✔

Appendix 5.28
Before and after stroke - original draft

Since your **stroke...**



Appendix 5.29
Condensed 'since your stroke' - final draft

# **Since** your stroke... during the **last week**

Appendix 5.30
During the last week - original draft

...during the **last week**...

Appendix 6.1

Appointment letter to John

*Kate Swinburn*

**Home address given**

02.10.2001

Dear John,

We have **two** meetings in the **next two weeks**.

1. **Tuesday 9th October**
   11-1.30
   **Connect**

2. **Tuesday 16th October**
   **11 - 2.30**
   **Start** at **Connect** for an hour or so.
   We will then **move out** to **TAZ**.

I believe this is a nice local **restaurant**!!

See you then

Appendix 6.2

Email to Sue with conclusions and next appointment times

**Conclusions for Sue**

The following emotions came out as the winners (with the following wording):

Valued
Able
Determined
Whole

Rejected 'spontaneous' and 'strong minded'. Strong minded was rejected because it was felt that though strong minded people may want to rate this after their stroke – their may be others who were NOT strong minded BEFORE their stroke who would be a bit alientated by it – therefore 'determined' was chosen as being more of an emotion rather than a personality trait

The group agreed to rate the social participation section in the way that we discussed i.e. to discuss each area of things you have to do, and then rate overall, then discuss areas of life that you want to do that are affected by aphasia.

I did have a thought after this – at the moment we are proposing to rate:

1. how is talking in every day life?
2. how are things you want to do?
3. how are things you have to do?
4. how is talking at home?

**Do you think we need the first one of these, now?**

We discussed all the new pictures – there are still some problems particularly with the abstract ones but basically we're nearly there I think

We discussed the quote about subjective well being and whether it changes with time – you remember we discussed that on the 'phone.
Harry felt that 6 months was about right but that that was based on the expectation of him revering his speech fully – that's what he had been told by the therapists.
John felt that 6 years on he had still not recovered his sense of well-being SOOOOOOOOOOOOOO!

Anyway next meeting booked for **October 16th** (Tuesday I'm afraid but I thought if you had notice it would be OK – I hope so). Meet at **11** then I want to **take everyone out to lunch afterwards to say thanks**. So put it in your diary – and let me know any suggestions for places to eat around Connect

Appendix 6.3
Issues for consideration letter for John

*Kate Swinburn*
Home address given

22.06.01

Dear John,

Welcome home!

I hope you had a **good holiday**.

We **missed you** at the aphasia **advisory group**.

Our next meeting is on:

**Tuesday 10th July**

**12.00** until 2.30

at **Connect.**

I have some **questions** for you.

Look at the next sheet – which words do you **like best**?

Can you tick the ones you think are EASIEST to understand?

If it's too hard – don't worry – I'll bring it on the 10th to discuss.

Hope to see you on 10th

Each line **means the same** but the **words** are **different**.

Can you tick the words you think are the **best**?

1.

How is talking **day to day?** ☐
How is talking in your **daily life** ☐
How is talking in your **everyday life** ☐

**********

2.

**What people** help your talking? ☐
**Who** helps your talking? ☐

**********

3.

What makes talking **harder?** ☐
What makes talking **worse?** ☐

**********

4.

Understand (what people say)? ☐
Follow (what people say)? ☐

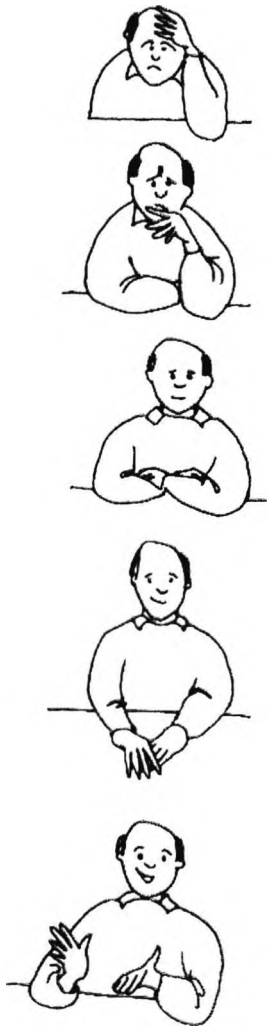
If it's too hard – don't worry – I'll bring it on the 10th to discuss.

If you can do it – please send it to me at home

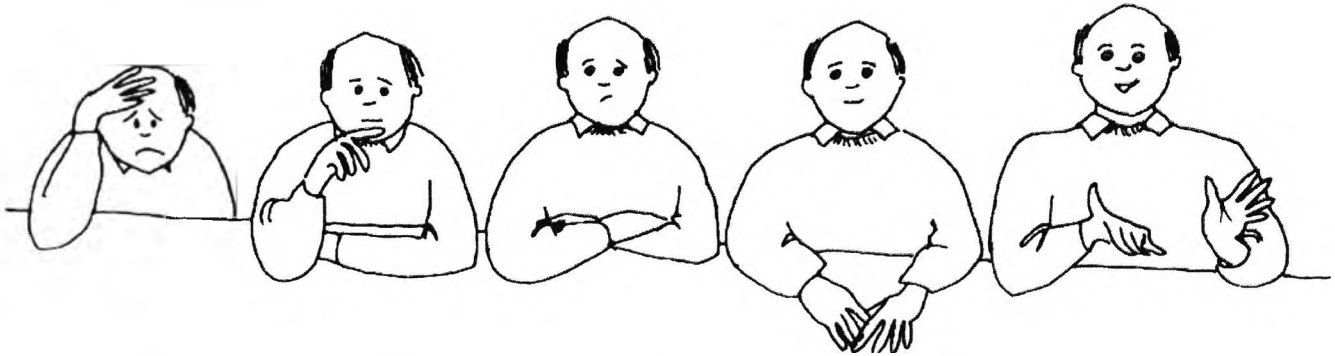
(Home address given)

Thank you!!!!!!!

# Appendix 6.4
## Rating scale 1 - version 1



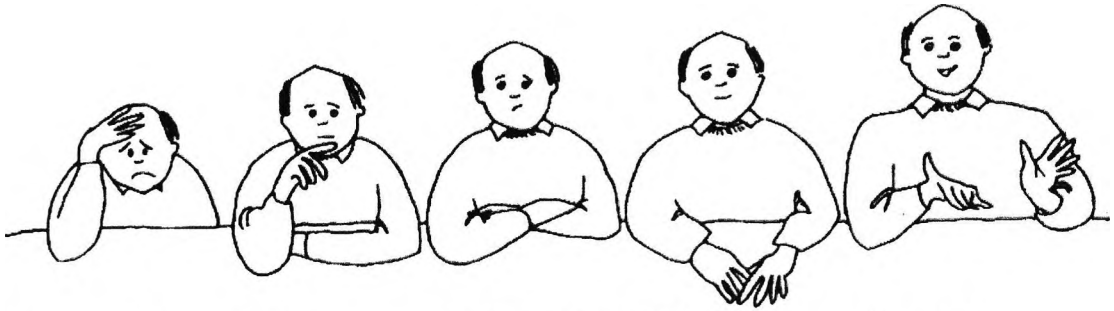
Appendix 6.5
Rationg scale 1 version 2



5 4 3 2 1

# Appendix 6.6
## Rating scale 1 version 3

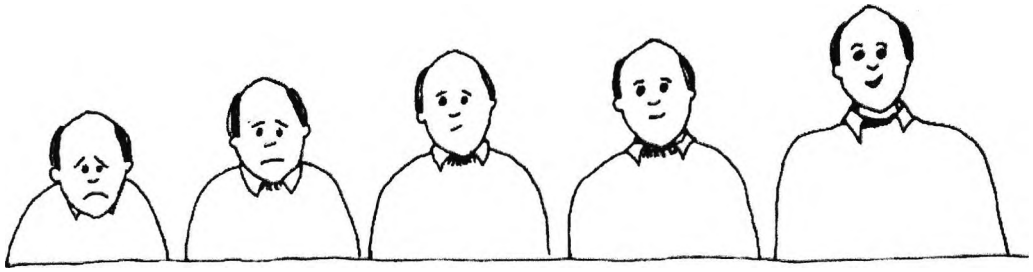
How easy is it for you...?



| Impossible | Really difficult | Difficult but manageable | Bit of a problem | Same as before – no problem at all |
|---|---|---|---|---|

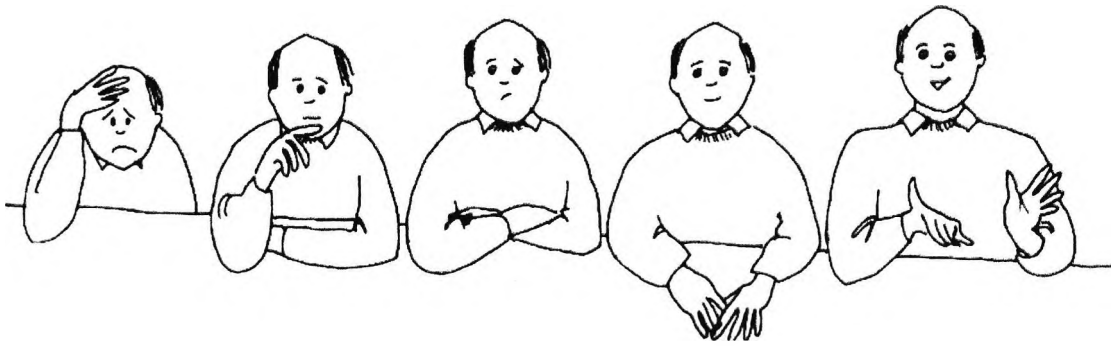
# Appendix 6.7
# Rating scale 1 version 4

How easy is it for you...?



| Impossible | Really difficult | Difficult but manageable | Bit of a problem | Same as before – no problem |
|---|---|---|---|---|

Appendix 6.8
Rating scale 1 version 5



4 3 2 1 0

# Appendix 6.9
# Consent form from another SLT project

Subject Information and Consent Form

You are being invited to participate in a research project conducted by a graduate student in the

conducted under the direction of
Communication Disorders and Speech Science.

This project has been designed to study factors that contribute to quality of life for persons with aphasia. The effect that aphasia has upon the life experience of individuals differs greatly and does not appear to be solely predicted by the severity of language impairment. The purpose of this investigation is identify the degree to which an aphasic individual's social environment impacts outcome.

If you agree to participate in this project, you will be asked to attend two sessions. In session one, the investigator will interview you and your significant other for approximately 1 1/4 hours; in session two, you will be given an aphasia test that will take approximately 1 1/2 hours. These two sessions will be scheduled at times convenient for you over the course of four weeks. Sessions will take place either at the clinic in which you received(d) treatment or in your home.

In the interview session will be asked a series of questions having to do with the types and frequency of supportive assistance you have received in the last month. For example, you might be asked, "How many times in the last month has someone helped you get around town?" or "How many times in the last month has someone offered you advice?" or "How many times in the last month has someone let you know that they enjoyed being with you?" Your significant other will be asked to accompany you during the interview session to help you respond to questions if talking or understanding language is difficult for you. The aphasia test will be like those you received as part of your treatment. You will be asked to complete tasks involving listening, reading, speaking and writing.

There is no risk to you as a participant in this project except that some of the aphasia test questions may be difficult or frustrating for you and some interview questions may touch upon sensitive subjects. If you are upset by any of the activities or you become fatigued, you may take a break, or you can tell us that you want to stop. You also have the right to refuse to answer any questions for any reason.

While there are no anticipated direct personal benefits to your participation in this project, you may experience a sense of satisfaction in knowing that you have contributed to our effort to better understand aphasia. If you would like, your test results from this study can be shared with you and/or your therapist if you are currently in a therapy program.

Your participation in this project is voluntary and you may stop all further participation in the project at any time. Just let us know that you want to quit, and we will stop testing or questioning.

If you participate in this study, you also need to give us separate written permission to look at your medical and speech-language pathology records.

All sessions will be audio and video recorded to allow later scoring verification. However, your individual privacy will be maintained in all published and written data resulting from this study. All data, medical record information, audio video recordings will be referred to by a subject number. The only record of subject identifying information will be kept in a locked file in the office of the principle investigator. All test records, medical records and recordings will be destroyed when they are no longer being used for research purposes.

If you,of your family have any questions regarding your rights as a subject, and concerns regarding this project or any dissatisfaction with any aspect of this study, you may contact
or the

You or your family may also ask the Executive Secretary for a copy of the University's statement to the Federal Government entitled "Assurance of Compliance, in the Health and Human Services (HHS) Regulations."

A copy of the Informed Consent form will be provided to you at the time you sign it.

I understand the above information and voluntarily consent to participate in the research project entities.

Subject Signature date

Print Subject Name

Legal Guardian Signature date

Print Legal Guardian Name

(If a legal guardian is signing this form, the signature of the legal guardian assures that the legal guardian has witnessed the verbal explanation of the contents of the consent form to the subject and the legal guardian agrees that the subject understands the nature of the study and wishes to participate in the study.)

# INFORMATION SHEET

**Kate Swinburn**
(Speech and Language Therapist)
Richmond Rehabilitation Unit,
Evelyn Rd. Richmond TW2 9TF SURREY
Phone: 0171-228-8400

This is a **project** about **how** your **talking problems affect your life.**

It is **NOT speech therapy.**

The project is looking at **how speech therapists look** at your **talking difficulties.**

An **assessment** has been **written**

It asks **lots of questions.**

It looks at **how** your talking **gets in the way** of day to day life.

It has **questions** about **how you feel** about your talking difficulties.

You can **answer** the questions **just by pointing** if you want.

The tool is called a **Rating Scale.**

**You** will be **asked what you think** of the rating scales.

**Your views** are **really important.**

**Your thoughts** about it will help to **make the rating scale better.**

This will be the **first time** views of **people with talking problems** have **been included** in developing a tool.

If you would like to help - **here's what will happen:**

- Kate Swinburn **(a speech therapist)** will **come to see you**
- She will **do the rating scales** with you

Appendix 6.11
Information sheet used in this research project (page 2)

later on ...

- **6 weeks later** you will come to **join other people** with talking problems.
- You will be **picked up** and **taken home** by **taxi.**
- The group will run at **City Dysphasic Group, Goswell Place,** near the **Angel.**
- Susie Parr (**a different speech therapist**) will **run the group**.
- You will **chat with everyone about** the **rating scales**.
- The **group** will take about **2 hours**.

If you **don't like it,** you **can STOP.**

If you **change your mind,** you **don't have to COME.**

**No one** will **ask any questions**.

Your **speech therapy** will **not change** if you stop.

If you **want** to **take part**:

- **talk** to **(name of the relevant speech therapist)**

**she** will **make** all the **arrangements**)

OR

- **ring Kate Swinburn** on **0171-228-8400**

say "I'm phoning about the rating scales project")

This project has been **looked at** by.....Ethics **Committee** (they **check** the project is **fair and good**).

**They say** it can **go ahead.**

# Appendix 6.12
# Consent form used for this project (page 1)

CONSENT FORM

Kate Swinburn,
Speech and Language Therapist,
Richmond Rehabilitation Unit,
Evelyn Rd, Richmond.

Telephone: 0171-228 8400

The **project** has been **explained.**

YES _____

NO _____

**I understand** what I have to do.

YES _____

NO _____

**I spoke** to ..... about the project.

I can **STOP** at any time.

√

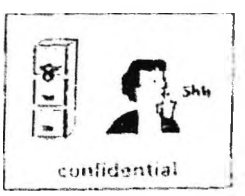
# Appendix 6.13
## Consent form used in this project (page 2)

It **won't affect** my **speech therapy**.

There is **NO DANGER**

Everything is **confidential**. No one will know what I said.

√




Do you agree to **take part** in the project?

YES

NO

Signed: Date:

Name in CAPITALS:

Signature of Kate Swinburn: