Providence Care



# Kingston Standardized Behavioural Assessment

# ADMINISTRATION AND INTERPRETATION MANUAL

(FOR BOTH COMMUNITY AND LONG TERM CARE FORMS)

Seniors Mental Health, Providence Care Mental Health Services, Kingston, Canada K7L 4X3

The Kingston Scales and Manuals can be freely downloaded from: www.kingstonscales.ca

email: kscales@queensu.ca © Copyright 2005, 2018 R.W. Hopkins, L.A. Kilik

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#### **PURPOSE**

Since progressive dementias such as Alzheimer's disease are characterized by behavioural as well as cognitive disturbances, the **Kingston Standardized Behavioural Assessment** (**KSBA**) was designed to complement cognitive assessment tools such as the **Kingston Standardized Cognitive Assessment - Revised** (**KSCAr**) or the **Brief Kingston Standardized Cognitive Assessment - Revised** (**BKSCAr**) by providing a measure of the behavioural impairment which currently affects an individual with dementia. See last pages of this manual for references. There are two versions of the KSBA, the KSBA(comm) for use in the community, and the KSBA(LTC) (long term care form) for use in nursing homes, chronic hospitals, or other long term care facilities. The differences between the two forms are explained on page 13. The examples and most of the data in this manual refer to the KSBA(comm) form. The KSBA(comm) and KSBA(LTC) are also available in French, thanks to translations by Dr. Veronique Parent. The authors also greatly appreciate the work of Dr. Jeremia Heinik of Tel Aviv, Israel, who has translated the KSBA(comm), and other Kingston Scales, into Hebrew.

#### Caregivers

The KSBA(comm) also provides validation for caregivers struggling with the issue of moving their relative into a long term care setting. This, in our experience, is often a difficult and stressful decision for many family members that they usually leave too late; compromising their own health as well as that of their relative. By being able to provide an objective score that reflects behavioural issues, a decision about long term care can often be made more easily. This can help to alleviate the distress and sense of guilt caregivers often experience. The information can also be used to facilitate the introduction of home support services. Likewise, for patients already in long term care settings, the KSBA(LTC) allows staff to monitor and assess the behavioural status of an individual and request further professional assessments or consultations. Since both the introduction of home support services, and the decision to place someone in long term care, not to mention caregiver stress, are almost always triggered by behavioural, rather than cognitive issues, a behavioural analysis of the individual is of great importance and not something that can be gained easily from other sources.

#### **ADMINISTRATION**

#### Scale Form

The informant is an individual, who knows the person on a day-to-day basis, i.e. spouse or other relative, or in the case of an individual living in a long term care setting, the staff member who knows that individual best. The scale may be completed by the informant, or one can read the items to the informant and ask for a yes/no answer. In many cases, especially in long term care settings, scoring may have to be a collaborative effort among several staff, or family members.

The KSBA, both comm and LTC forms, consist of two parts, the informant page (first 2 pages), which is a list of 68 (for comm form and 74 for the LTC form) commonly observed behaviours in dementia (with checkoff boxes), broken into groups of related behaviours, referred to as "domains", and a third page, the Analysis Form for summarizing the reported behaviours. The behaviours are described in plain English with an attempt to avoid jargon that would be unfamiliar to or confuse a lay informant. It should also be noted that unlike many other scales, no information on severity or frequency is required. These latter two pieces of information are often handled poorly by family members, and consequently are often no more than a source of error. See Hopkins et al. 2006, for further data and discussion on this aspect of the scale.

On the reverse side of the Analysis Form page is the **Behaviour Analysis Procedures** page, which is a brief set of instructions on how to use the Analysis Form. This Analysis Form (see Examples) is used by the health care professional, and is not given to the informant. The KSBA provides a powerful behavioural analysis that is normally only available to behaviourally trained clinicians (e.g. psychologists, psychometrists, etc.).

#### Instructions

The instructions are: "Please check all of the following behaviours that have occurred in the last month or are presently occurring, and that are <u>a change</u> from your spouse/relative/client's earlier behaviour (prior to illness). Indicate those items that apply by marking the box beside the appropriate statement. The Total Score equals number of boxes checked." Only items that apply should be checked.

It should be noted that while many behaviours are discrete acts (like biting or hitting people), that can be easily identified in both time and place, other behaviours like "unable to handle personal finances" or "unsafe in daily activities, if left unsupervised" are ongoing. Usually, once an individual is deemed incompetent to perform a task or is shown to be a risk for some behaviour, he or she is not given another chance to demonstrate his or her incompetence, but rather is kept away from such activities or closely supervised while performing them. These ongoing behaviours **are checked** as if they had recently occurred, as it is assumed that once one is unable to perform a task, the individual will continue to be unable. This situation only pertains to progressive dementias and similar disorders where no significant improvement is expected.

#### Diagnosis

Since the **first** administration of the KSBA is usually at the time of first diagnostic investigations, it should be stressed to the informant that the critical time period is **since the onset of the problems** being investigated, rather than some arbitrary period such as the last month. The first administration is, therefore, an attempt to determine what behavioural changes have occurred since the onset of the disorder. This has proven to be an increasingly important means of diagnosing dementia, especially in the early stages of the disease.

#### Monitoring Behaviour Change

The KSBA can be used a powerful tool to monitor behaviour changes over time; therefore subsequent administrations can assess changes in the "last month" or other time period, e.g. 1 week, 2 days, 6 months, etc.

#### Glossary

To aid in the explanation of the behaviours to the informant, a **glossary** providing a more detailed description of the behaviours on the KSBA forms, is found near the end of this manual (page 24).

#### INTERPRETATION

The Analysis Form is divided into two parts; the Total Score Analysis and the Behaviour Profile.

Total Score Analysis

On the right side of the **Analysis Form** page is a group of columns marked "**TOTAL SCORE ANALYSIS**" (see page 6). The pair of columns on the far right (**INST**) are for patients living in a long term care facility or other institution, and the two on the left KSBA(comm) are for community dwelling individuals. One simply counts the number of ticked items on the informant form (previous 2 pages) and circles that total in the appropriate "Total Score" column (under **COMM** if community dwelling or under **INST** if institutional dwelling).

The "Total Score Descriptions" column provides a "thermometer" style description for scores in that range. (See Examples on pages 17 to 22). The "Consult / Concern" range for either community dwelling or institutional living patients represents the lower part of the response range. Scores in the range of "Consider Placement" (or in the case of institutional living patients "Crisis"), are at a level that may indicate some serious difficulties. Normally, we have found that when community dwelling patients have a Total score at or above the mid 30's, it becomes increasingly difficult for family caregivers to continue to be able to provide care at home, or at least without considerable help. Even a Total score in the 20's or lower, might indicate that additional services or supports are required by some caregivers. High-scoring institutional-living patients might well benefit from a specialist consult or other intervention. However, it is advised that such consults or interventions be considered long before the "Crisis" point is reached.

It must be remembered that these descriptive ranges are merely labels placed on a continuum, and that there are no true demarcation points. Page 6 shows how these points relate to the means and standard deviations of the scale. What caregivers, lay or professional, can handle will vary between individuals and institutions. It must also be remembered, that there are differences between individual patients. Even if a patient scores only a few points, yet one of the behaviours is related to violent physical outbursts, there might be need for extra care and support.

# Kingston Standardized Behavioural Assessment - ANALYSIS FORM

|       | СС   | MM                       | IN   | ST                       |
|-------|--|--------------------------|--|--------------------------|
|       | Total Score  | Total Score Descriptions | Total Score  | Total Score Descriptions |
|       | 8 6 6 6 6 6 6 6 6 6 6 6 6 6 6 6 6 6 6 6  | CONSIDER                 | 67<br>66<br>65<br>64<br>63<br>62<br>61<br>60<br>58<br>56 | CRISIS                   |
| +1 sd | 54<br>54<br>55<br>55<br>56<br>56<br>56<br>56<br>56<br>56<br>56<br>56<br>56<br>56<br>56 | PLACEMENT                | 54<br>52<br>50<br>48<br>46<br>44<br>42<br>40<br>38<br>36 | 00                       |
| Mean  | <br>34<br>32<br>30<br>28<br>26<br>24<br>22<br>20<br>19                                 | CONSULT / CONCE          | 34<br>32<br>30<br>28<br>26<br>24<br>22<br>20<br>18       | CONSULT / CONCER         |
| -1 sd | <br>17<br>16<br>14<br>11<br>9<br>6<br>5<br>4<br>3<br>2                                 | CONCERN                  | 16<br>14<br>12<br>10<br>8<br>6<br>5<br>4<br>3<br>2       | RN                       |

#### Behaviour Profile

The large chart on the left side of the Analysis Form page is the Behaviour Profile which provides a column for each of the 12 behavioural domains. For each column the number of possible behaviours in that domain is displayed, starting with 0 (zero) at the bottom and going up to the maximum number of behaviours in that group, at the top. To fill out the profile, simply go to the informant pages and add up the number of ticked items for each domain and put that value in the domain total box at the end of each group. Then transfer these values to the profile chart. If desired, these points can be joined up with a line to create a visual profile for that patient. See Examples on pages 17 to 22. The profile is also useful in identifying specific behaviours to target for intervention.

On the extreme left side of the Profile chart is a "Comparison Scale" column that is used to give each of the other column scores a relative standardized value, allowing all domains to be compared to each other. For example, if the score on Judgement/Insight equals 5 and on Misperceptions, the score equals 3, then both can be said to have a relative score of 7.5. Or if the score on Judgement/Insight equals 4 and on Paranoid Behaviour, the score equals 2, then the scores represent relative values of 6 and 4 respectively. In this way, relative comparisons (i.e. degree of impairment or sparing) across the 12 domains can be made.

#### Examples

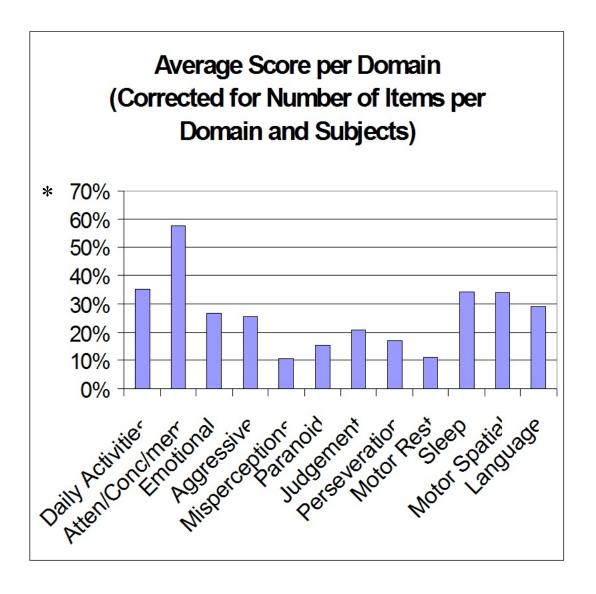
On pages 17 to 22 are some samples taken from actual cases. Example 1 is an example of a complete scale, while examples 2 to 4 show only the Analyses Forms for those cases. Examples 1 and 2 are both community dwelling individuals but the individual in Example 1 has a relatively low to moderate number of responses (i.e. 14), while Example 2 is an individual at a more advanced stage of dementia with a much larger number of responses (i.e. 49). In this latter case, placement was being actively pursued. Due to space limitations on the "Analysis Form", some numbers are skipped in the "Total Score" column. (See Example 2.) In these cases indicate the obtained score by placing a mark between the two numbers nearest to the score. Examples 3 and 4 are patients who both obtained the same total score (i.e. 19) but have distinctly different profiles. The "U shaped" profile found in Examples 1 and 3, are typical of relatively early dementia, that is, one dominated by Neuropsychological rather than Neuropsychiatric behaviours (see below).

#### NEUROPSYCHIATRIC VS. NEUROPSYCHOLOGICAL BEHAVIOURS

Traditional behaviour scales used for dementia have all concentrated on what has become known as the "behavioural and psychological symptoms of dementia" (or BPSD). These symptoms are ones that typically encompass behaviours related to emotions, aggression, and psychotic disorders (such as paranoia), problems in judgement, or delusions and hallucinations (misperceptions).

Factor analysis of the KSBA(comm) has shown that its behavioural domains fall into two groups or factors. The first factor included emotional, aggressive, and paranoid behaviour, misperceptions, judgement, perseveration, and motor restlessness, and represents the traditional BPSD behaviours, also called "neuropsychiatric" behaviours. The second factor included Daily Activities, Attention/ Concentration/Memory, Sleep, Motor/Spatial and Language difficulties. We have termed this constellation of nontraditional and more functionally based behaviours as the "neuropsychological" factor. The following figure (page 9) shows the average rates of endorsed items per domain, for all 12 domains. Therefore, the KSBA(comm) provides a broader and more realistic portrait of dementia than would obtain from other scales.

The domains on the KSBA(comm) are arranged in an order that makes interpretation meaningful. The first 2 (Daily Activities and Attention/Concentration/Memory) and the last 3 (Sleep, Motor Spatial and Language) are located at the beginning and end of the scale respectively, to facilitate informant interviewing, and create distinct profiles to assist clinicians. These neuropsychological domains are behaviours that are not always measured in more traditional BPSD scales, yet these five domains account for nearly 90% of the endorsed behaviours in the earliest stages of dementia in our normative sample. In contrast, rates of neuropsychological and neuropsychiatric behaviours approach parity late in the disorder. For example, in the figure on page 21, most of the scores appear in the outer groups producing a U-shaped profile; i.e. the neuropsychological behaviours. The more traditional neuropsychiatric behaviour groups are arranged in the middle. See also, Examples on pages 17 to 22.



Average Score per Domain = Total endorsements for that domain divided by the number of items in that domain and divided by the number of cases in the normative sample (n = 198)

<sup>\*</sup> Percent of items endorsed in each domain

#### REPEATED ADMINISTRATIONS

The KSBA(comm) can be used to capture a current "snapshot" of an individual's behaviour. Typically, "current" has been taken to mean behaviours that have occurred in the last month. However, the KSBA(comm) can also be used to track behaviour change over time including change attributable to specific interventions. In such cases the KSBA(comm) may be administered repeatedly, and the interval may also be shorter than one month. When doing so, the reporting interval should match the repetition interval. For example, if you give it once a week to a patient, then only ask for behaviours that have been noted in that past week. The chosen interval should be clearly stated in any clinical reports.

#### STATISTICS AND PERCENTILES

The following statistics and percentiles currently apply to the KSBA(comm).

| SCORE SUMMARY                 | C     | COMMUNITY |     |     | INSTITUTIONS |       |     |     |
|-------------------------------|-------|-----------|-----|-----|--------------|-------|-----|-----|
|                               | n =   | 238       |     |     | n =          | 41    |     |     |
|                               | Mean  | sd        | Min | Max | Mean         | sd    | Min | Max |
| Total Score /68               | 20.02 | 11.56     | 1   | 56  | 31.02        | 12.76 | 10  | 61  |
| Neuropsychiatric Behaviours   | 5.54  | 4.81      | 0   | 25  | 10.39        | 6.91  | 2   | 28  |
| Neuropsychological Behaviours | 14.47 | 7.76      | 1   | 32  | 20.63        | 6.92  | 8   | 34  |

## PERCENTILES <u>COMMUNITY DWELLING SUBJECTS</u> (n = 194)

| TOTAL SCORE | % ile        | Neuropsychological<br>Score | % ile | Neuropsychiatric<br>Score | % ile |
|-------------|--------------|-----------------------------|-------|---------------------------|-------|
| 50          | 99.5         | 32                          | 99    | 19                        | 99    |
| 49          | 98.9         | 31                          | 97.4  | 18                        | 96.8  |
| 48          | 98.4         | 30                          | 95.3  | 17                        | 95.8  |
| 46          | 97.9         | 29                          | 94.2  | 16                        | 94.2  |
| 45          | 95.2         | 28                          | 92.1  | 14                        | 93.2  |
| 43          | 94.2         | 27                          | 89.5  | 13                        | 91.6  |
| 42          | 93.7         | 26                          | 87.4  | 12                        | 89.5  |
| 41          | 93.1         | 25                          | 86.3  | 11                        | 86.8  |
| 40          | 92.1         | 24                          | 84.2  | 10                        | 83.2  |
| 39          | 91.5         | 23                          | 82.6  | 9                         | 72.6  |
| 38          | 90           | 22                          | 79.5  | 8                         | 69.5  |
| 37          | 89.4         | 21                          | 76.3  | 7                         | 65.3  |
| 36          | 88.4         | 20                          | 71.1  | 6                         | 59    |
| 35          | 87.8         | 19                          | 67.9  | 5                         | 52.6  |
| 34          | 87.3         | 18                          | 65.8  | 4                         | 41.1  |
| 33          | 84.1         | 17                          | 60    | 3                         | 33.2  |
| 32          | 82           | 16                          | 58.4  | 2                         | 25.8  |
| 31          | 79.9         | 15                          | 53.7  | 1                         | 13.7  |
| 30          | 76.2         | 14                          | 49    |                           |       |
| 29          | 75.7         | 13                          | 44.7  |                           |       |
| 28          | 74.1         | 12                          | 37.4  |                           |       |
| 27          | 73.5         | 11                          | 32.1  |                           |       |
| 26          | 70.9         | 10                          | 27.4  |                           |       |
| 25          | 68.3         | 9                           | 22.6  |                           |       |
| 24          | 64.6         | 8                           | 20.5  |                           |       |
| 23          | 63.5         | 7                           | 17.4  |                           |       |
| 22          | 59.3         | 6                           | 13.2  |                           |       |
| 21          | 55           | 5                           | 10.5  |                           |       |
| 20          | 50.3         | 4                           | 9     |                           |       |
| 19          | 47.6         | 3                           | 5.3   |                           |       |
| 18          | 43.9         | 2                           | 1.2   |                           |       |
| 17          | 40.7         |                             |       |                           |       |
| 16          | 38.6         |                             |       |                           |       |
| 15          | 35.5         |                             |       |                           |       |
| 14          | 31.2         |                             |       |                           |       |
| 13          | 29.1         |                             |       |                           |       |
| 12          | 25.4         |                             |       |                           |       |
| 11          | 22.8         |                             |       |                           |       |
| 10<br>9     | 18.5<br>16.4 |                             |       |                           |       |
|             |              |                             |       |                           |       |
| 8<br>7      | 15.9         |                             |       |                           |       |
| 6           | 14.3<br>11.6 |                             |       |                           |       |
| 5           | 7.9          |                             |       |                           |       |
| 4           | 5.8          |                             |       |                           |       |
|             |              |                             |       |                           |       |
| 3           | 3.2          |                             | ]     |                           |       |

# PERCENTILES <u>INSTITUTIONAL DWELLING SUBJECTS</u> (n = 41)

| TOTAL SCORE | % ile | Neuropsychological<br>Score | % ile | Neuropsychiatric<br>Score | % ile |
|-------------|-------|-----------------------------|-------|---------------------------|-------|
| 58          | 97.5  | 33                          | 97.5  | 24                        | 95    |
| 55          | 95    | 32                          | 95    | 23                        | 90    |
| 50          | 92.5  | 30                          | 92.5  | 19                        | 87.5  |
| 49          | 90    | 28                          | 87.5  | 18                        | 85    |
| 45          | 85    | 27                          | 75    | 15                        | 80    |
| 43          | 82.5  | 25                          | 72.5  | 14                        | 70    |
| 41          | 80    | 24                          | 65    | 13                        | 65    |
| 40          | 77.5  | 23                          | 57.5  | 12                        | 62.5  |
| 39          | 75    | 22                          | 52.5  | 11                        | 57.5  |
| 38          | 70    | 21                          | 42.5  | 10                        | 55    |
| 37          | 67.5  | 20                          | 37.5  | 9                         | 52.5  |
| 35          | 65    | 17                          | 32.5  | 8                         | 45    |
| 34          | 60    | 16                          | 30    | 6                         | 35    |
| 33          | 57.5  | 14                          | 22.5  | 5                         | 17.5  |
| 30          | 55    | 13                          | 15    | 4                         | 15    |
| 29          | 50    | 12                          | 10    | 3                         | 7.5   |
| 28          | 42.5  | 11                          | 7.5   |                           |       |
| 27          | 37.5  | 10                          | 5     |                           |       |
| 26          | 35    |                             |       |                           |       |
| 23          | 32.5  |                             |       |                           |       |
| 22          | 30    |                             |       |                           |       |
| 21          | 27.5  |                             |       |                           |       |
| 20          | 25    |                             |       |                           |       |
| 19          | 17.5  |                             |       |                           |       |
| 18          | 15    |                             |       |                           |       |
| 16          | 7.5   |                             |       |                           |       |
| 15          | 5     |                             |       |                           |       |
| 11          | 2.5   |                             |       |                           |       |

#### THE LONG TERM CARE FORM

As behavioural problems often significantly increase the amount of nursing care that an individual requires, a measure of behavioural disturbance is a very useful type of information for long term care, or other nursing care facilities. In addition to the 68 item community form (the KSBA(comm)), the KSBA also comes in a Long Term Care form for use in long term care facilities (the KSBA(LTC)). The LTC form differs from the community form in that 25 new items have been added, while 19 items were removed from the original scale, yielding 74 items for the KSBA(LTC). The removed items were ones that were unlikely to be applicable to a person in a long term care facility (e.g. "Shows poor judgement about driving"; "Is unable to perform usual household tasks"). The new items are ones that are much more likely to be seen in long term care residents (e.g. "Resistant to bathing"; "Repeatedly rearranges furniture"). The KSBA(LTC) is therefore better able to capture the essence of the behavioural disturbances seen in long term care patients.

Administration and interpretation of the KSBA(LTC) is basically the same as the community form; the rater being the staff member (or members) who knows the patient best. It should be noted that using the "INST" scale on the Community form is not the equivalent of using the KSBA(LTC). The KSBA(comm) and the KSBA(LTC) are two separate (although very closely related) scales; each designed for slightly different purposes. Before the KSBA(LTC) was developed, the KSBA(comm) was sometimes used in long term care facilities, and the "INST" column on the Analysis Form (3<sup>rd</sup> page of the KSBA(comm)) allowed one to compare an individual's performance to that of others in long term care facilities. In general, when one is assessing an individual who lives in the community, the community (comm) form should be used; but when assessing an individual in a long term care facility, the KSBA(LTC) should be used. (We feel that the KSBA(LTC) is a superior tool for long term care residents compared to the KSBA(comm).) However, if one is assessing an individual who has just recently been transferred to a long term care facility or retirement home from the community, the community form (KSBA(comm)) would best apply at first.

Another difference seen in the "LTC" form (vs. the "comm" form) is in the "Total Score Descriptions" on the Analysis Form (the far right column). Whereas on the "comm" form under the "INST" column the descriptions are **CRISIS CONSULT/ CONCERN**, on the "LTC" form, they are **CONSULT, CONCERN, FREQUENTLY REPORTED**. This change reflects the belief that long term care facilities are able to correct or manage behavioural problems before a crisis develops.

Note that at the end of the Glossary is a list of the new items found in the KSBA(LTC) with more detailed descriptions of the behaviours (page 27).

The following statistics are drawn from a sample of patients hospitalized in a geriatric psychiatry assessment ward. All were suffering from dementia (mostly Alzheimer's disease).

| n = 47           | Mean  | sd    | Min  | Max  |               | Mean | sd   | Min | Max |
|------------------|-------|-------|------|------|---------------|------|------|-----|-----|
| AGE              | 75.9  | 10.89 | 51.2 | 95.7 |               |      |      |     |     |
| Daily Activities | 4.89  | 2.31  | 1.0  | 9.0  | Judgement     | 1.18 | 1.4  | 0.0 | 5.0 |
| Atten/Conc/Mem   | 1.23  | 1.12  | 0.0  | 4.0  | Perseveration | 0.66 | 1.16 | 0.0 | 5.0 |
| Emotional        | 0.82  | 0.84  | 0.0  | 3.0  | Motor Rest    | 0.5  | 0.79 | 0.0 | 3.0 |
| Aggressive       | 1.25  | 1.24  | 0.0  | 4.0  | Sleep         | 0.95 | 1.08 | 0.0 | 4.0 |
| Misperceptions   | 0.73  | 0.85  | 0.0  | 3.0  | Motor Spatial | 1.64 | 1.28 | 0.0 | 4.0 |
| Paranoid         | 0.32  | 0.64  | 0.0  | 2.0  | Language      | 1.59 | 1.82 | 0.0 | 6.0 |
| NPL Total        | 10.3  | 5.34  | 2    | 21.0 |               |      |      |     |     |
| NPT Total        | 5.45  | 3.81  | 0.0  | 19.0 |               |      |      |     |     |
| TOTAL SCORE      | 15.75 | 7.54  | 2.0  | 33.0 |               |      |      |     |     |

Neuropsychological Behaviours (NPL) [blue]

Neuropsychiatric Behaviours (NPT) [red]

|                   | Tota | ıl Sc | ore Pe | rcentil | les |    |      |     |     |
|-------------------|------|-------|--------|---------|-----|----|------|-----|-----|
| Percentile        | 90   | 80    | 70     | 60      | 50  | 40 | 30   | 20  | 10  |
| Approximate Score | 25   | 24    | 20.5   | 80.7    | 17  | 13 | 11.7 | 9.5 | 5.7 |

#### Items Removed and Added to the Community Form to Create the Long Term Care KSBA(LTC)

| Item # | KSBA(comm) Items Removed                          | Item # | New Items Added to the KSBA(LTC)         |
|--------|---|--------|--|
| 2      | Reduced personal hygiene                          | 2      | Resistant to bathing.                    |
| 3      | If left on his/her own, doesn't eat properly.     | 3      | Refuses to leave own room.               |
| 4      | Unsafe in daily activities, if left unsupervised. | 5      | Does not like being touched.             |
| 6      | Unable to handle personal finances.               | 6      | Combines foods not usually eaten         |
| 7      | Is unable to perform usual household tasks.       | 7      | Refuses to eat.                          |
| 8      | Gets confused in places other than home.          | 8      | Drools on self, clothing.                |
| 10     | Trouble appreciating subtleties in conversations  | 10     | Eats other's food at meal time.          |
| 20     | Has difficulty organizing his/her time            | 18     | Smears faeces.                           |
| 21     | Forgets activities, conversations of only a       | 21     | Easily distracted by surrounding noises. |
| 22     | Forgets important everyday information.           | 22     | Places things in inappropriate places.   |
| 39     | Shows poor judgement in social situations.        | 27     | Expresses suicidal feelings, threatens   |
| 40     | Shows poor judgement about driving.               | 30     | Throws things at, or pinches others.     |
| 41     | Shows uncharacteristic change in his or her       | 36     | Sees or hears things that are not there. |
| 42     | Poor choices in dressing.                         | 37     | Talks to pictures or mirrors.            |
| 44     | Shows less self control than usual.               | 43     | Seeks constant attention.                |
| 59     | Has trouble dressing, especially with buttons     | 44     | Eats non-food items.                     |
| 61     | Reads far less frequently than previously.        | 45     | Grabs others nearby.                     |
| 63     | Does not watch or follow television.              | 46     | Shows increased sexual drive, interest.  |
| 68     | Does not produce meaningful speech.               | 48     | Accident prone, gets hurt a lot.         |
|        |   | 50     | Invades personal space.                  |
|        |   | 53     | Talks about same topic over and over     |
|        |   | 55     | Clapping/noise making.                   |
|        |   | 59     | Repeatedly rearranges furniture.         |
|        |   | 60     | Bangs head deliberately.                 |
|        |   | 74     | Speaks in meaningless phrases, or        |

#### RESEARCH

Currently, there are a number of ongoing research projects with the KSBA (in a variety of settings). These projects explore the statistical properties of the scale, along with a number of clinical applications. The KSBA(comm) is being, and has been (see Kilik et al., 2008), used to explore the behavioural dimensions of Alzheimer's disease, and other neurological conditions. Some of the studies are looking at the relationship between the KSBA(comm) and other Kingston Scales, such as the Kingston Caregiver Stress Scale (KCSS). The two scales are highly correlated (r=.84), suggesting that the KSBA(comm) can reflect caregiver stress. A list of the Kingston scales is found on page 29. If you are interested in participating in these, or other projects, or contributing data, please contact the authors at kscales@queensu.ca.

#### USING THE KSBA(comm) TO TRACK BEHAVIOURAL PROGRESSION OF DEMENTIA

The following chart showing the relative order of appearance of behaviours in Alzheimer's disease comes from Kilik, Hopkins, Day, Prince, Prince, Rows, 2008.

#### How to Use the Following Chart

This chart should be used as a guide to help patients and their families understand what may lie ahead in terms of behaviour changes as dementia progresses. Although a variety of behavioural changes may be encountered, certain behaviours are more commonly reported early in the disorder, while others tend to occur later. The behaviours indicated as "1" are those that are usually seen first, followed by those as "2". Those indicated as "3" are usually seen next, and finally those indicated as "4" tend to be found in the later part of the disorder. While behaviour changes normally seen at later times may occur earlier, they tend not to be very common. The point at which a given behaviour becomes marked with a colour depends upon when it achieved an endorsement rate of 30% or more (i.e. it is reported by at least 30% of surveyed subjects in that group).

The data used in this chart were obtained using the KSBA(comm). Groups 1 to 4 are based on the accumulation of behaviour changes from fewest (group 1) to most (group 4). A sample of 200 cases were ordered by total score and divided into four equal groups. The 4 groups used in this chart are based on total KSBA(comm) score only and not on any theoretical disease stages. Theoretic stages usually lack empirical support, and most research suggests dementia to be a continuum. A coloured square indicates the point at which that behaviour is reported by at least 30% of the sample. Uncoloured items did not reach a 30% response level in any group.

#### Quick Reference Guide to the Progression of Behaviour Change in Dementia

#### BEHAVIOURAL IMPAIRMENT Group at which behaviour first achieves a 30% reporting rate. **DOMAINS** Low > High **ITEMS** No longer takes part in favourite pastimes. Daily Activities Reduced personal hygiene . Doesn't eat properly if left to prepare food. Careless about home (kitchen/workshop) safety. 23456 No longer uses some common objects properly. Unable to handle personal finances Is unable to effect minor household repairs, or meals. Gets confused in places other than home. 7 8 9 Overly dependent, wants more guidance than usual. Trouble appreciating subtleties in conversations Difficulty judging the passing of time. 10 11 12 Wanders aimlessly. 13 Hides things. 14 15 Hoards objects. Fails to recognize family or friends. 16 Incontinence of urine/feces in clothes in daytime. Voids in non-toilet areas. Can't concentrate, pay attention for long. Misplaces things than usual. Has difficulty organizing his/her time or daily activities. Atten /Conc 19 /Memory 20 21 22 Forgets activities, conversations of only a short time before Forgets important everyday information. 23 24 25 26 Shows little or no emotion. **Emotional** Mood changes with no apparent reason. Expresses inappropriate emotions, either type or intensity. Makes pessimistic statements. Verbally abusive at times. Excitable, easy to upset; reacts catastrophically. Attempts to hit/strike out at others. Aggressive Claims an object looks similar to, but is not the real one. Claims a family member looks similar but is not the true one. 30 Misperceptions 31 Thinks present dwelling is not their place of living. 33 Thinks people are present who aren't. Suspicious of family and friends. **Paranoid** Suspicious about money issues. 35 36 Accuses others of stealing his or her things. 37 Accuses spouse of infidelity Expresses suspicion around taking medication. 39 Shows poor judgement in social situations. Judgement 40 Shows poor judgement about driving. 41 Shows uncharacteristic change in concern about money. 42 Poor choices in dressing. Makes inappropriate sexual advances. Shows less self control than usual. 43 45 Unconcerned about personal safety. 46 Repeats same actions over and over. Perseveration Repeats same words or phrases. Repeatedly shouts or calls out. 47 48 Desire to pace or walk almost constantly. 49 Motor Rest 50 Can't sit still, restless, fidgety. 51 Tries doors, windows. Falls asleep at uncharacteristic times. Sleep Gets up and wanders or awakens frequently at night. 54 Sleeps more. Behaviour more agitated or impaired in late afternoon. 56 Poor coordination seen in limb/finger movements. Motor Spatial 57 Slowness of movement 58 Unsteadiness when walking. Has trouble dressing, especially with buttons or shoelaces. Difficulty judging object sizes or how near an object is ... Reads far less frequently than in past. 59 61 Language 62 Substitutes some words for others. Does not watch or follow television. 63 64 Does not speak unless spoken to. 65 Often cannot find the right word. Trouble pronouncing words. Does not understand simple commands, explanations. 67 Does not produce meaningful speech.

| Kin                     | gst            | on Standardized Behaviour  | al Asses        | ssm     | ent Example 1   |
|-------------------------|----------------|--|-----------------|---------|---|
| Name                    | _              | Example 1 Case #:  | 12345           |         | ,   |
| Sex: N                  | / I            | = X Age: 75 Education: 12 ym Year  | s of Illness: _ | 1       |   |
| Date:                   | ٨              | lov 17 2004 Informant: Daught  | er              |         |   |
| Pleas<br>are <u>a c</u> | e che<br>chang | mmunity <u>X</u> <u>or</u> Lives in Care Facility<br>eck all of the following behaviours that have<br>ge from your spouse/relative/client's earlier b<br>side the appropriate statement. The Total Score | ehaviour (pri   | or to i | illness). Indicate whether they apply by marking                                |
|                         | 1              | Daily Activities   | X               | 21      | Forgets activities, conversations of only a short time before.                  |
| X                       | 1              | No longer takes part in favourite pastimes (or greatly reduced).   | X               | 22      | Forgets important everyday information.   |
| X                       | 2              | Reduced personal hygiene . (e.g. Would not take a bath unless told to do so, or wears the same clothes for days unless made to change).  | 3               | <       | Total Attention/Concentration/Memory  |
|                         | 3              | If left on his/her own, doesn't eat properly.  |                 | 3       | Emotional Behaviour   |
| X                       | 4              | Unsafe in daily activities, if left unsupervised.  |                 | 23      | Shows little or no emotion.   |
|                         | 5              | No longer uses some common objects properly. (e.g. telephone)  |                 | 24      | Mood changes with no apparent reason.  Expresses inappropriate emotions, either |
| X                       | 6              | Unable to handle personal finances.  |                 | 25      | type or intensity.  |
| X                       | 7              | ls unable to perform usual household tasks.  |                 | 26      | Makes uncharacteristically pessimistic statements.                              |
|                         | 8              | Gets confused in places other than home.   | 0               | <       | Total Emotional Behaviour   |
|                         | 9              | Overly dependent, wants more guidance than usual.  |                 |         |   |
|                         | 10             | Trouble appreciating subtleties in conversations (e.g. recognizing humor).   |                 | 4       | Aggressive Behaviour  |
|                         | 11             | Difficulty judging the passing of time.  | X               | 27      | Verbally abusive at times.  |
|                         | 12             | Wanders aimlessly.   |                 | 28      | Uncharacteristically excitable, easy to upset; reacts catastrophically.         |
| X                       | 13             | Hides things.  |                 | 29      | Attempts to hit/strike out at others.   |
|                         | 14             | Hoards objects.  | 1               | ]       | Total Aggressive Behaviour  |
|                         | 15             | Fails to recognize family or friends.  |                 |         | Total Aggressive Behaviour  |
|                         | 16             | Incontinence of urine/faeces in clothes in daytime.  |                 | 5       | Misperceptions/Misidentif   |
|                         | 17             | Voids in non-toilet areas.   |                 | 30      | Claims an object/possession looks similar to, but is not the real one.          |
| 6                       | <              | Total Daily Activities   |                 | 31      | Claims a family member looks similar but is not the true one.                   |
|                         | 2              | Attention/Concentration/   | ]               | 32      | Thinks present dwelling is not their place of living.                           |
|                         | 18             | Can't concentrate, pay attention for long.   |                 | 33      | Thinks people are present who aren't.   |
|                         | 19             | Misplaces things more than usual.  | 0               | <       | Total Misperception Behaviour   |
| X                       | 20             | Has difficulty organizing his/her time or daily activities.  |                 |         |   |

|   | 6               | Paranoid Behaviour  |
|---|-----------------|---|
|   | 34              | Suspicious of family and friends.   |
|   | 35              | Suspicious about money issues.  |
|   | 36              | Accuses others of stealing his or her things.   |
|   | 37              | Accuses spouse of infidelity.   |
|   | 38              | Expresses suspicion around taking medication.   |
| 0 | <               | Total Paranoid Behaviour  |
|   | 7               | Judgement/Insight   |
|   | 39              | Shows poor judgement in social situations.  |
|   | 40              | Shows poor judgement about driving.   |
|   | 41              | Shows uncharacteristic change in his or her concern about money.  |
|   | 42              | Poor choices in dressing. (e.g. wears clothes that are inappropriate for season or temperature, wears the same clothes for days). |
|   | 43              | Makes inappropriate sexual advances.  |
|   | 44              | Shows less self control than usual.   |
|   | 45              | Unable to identify personal safety risks.   |
| 0 | <               | Total Judgement/Insight   |
|   | 8               | Perseveration   |
|   | ] <sub>46</sub> | Repeats same actions over and over.   |
|   | 47              | Repeats same words or phrases.  |
|   | 48              | Repeatedly shouts or calls out.   |
| 0 |                 | Total Perseveration   |
|   | <u> </u>        |   |
|   | 9               | Motor Restlessness  |
|   | 49              | Desire to pace or walk almost constantly.   |
|   | 50              | Can't sit still, restless, fidgety.   |
|   | 51              | Tries doors, windows.   |
| 0 | <               | Total Motor Restlessness  |
|   |                 |   |

| Falls asleep at uncharacteristic times.  Gets up and wanders or awakens frequently at night, more than usual.  Sleeps more.  Behaviour more agitated or impaired in late afternoon.  Total Sleep/Activity/Sundowning  Motor/Spatial Problems  Poor coordination seen in limb/finger movements.  Slowness of movement |
|--|
| at night, more than usual.  Sleeps more.  Behaviour more agitated or impaired in late afternoon.  Total Sleep/Activity/Sundowning  Motor/Spatial Problems  Poor coordination seen in limb/finger movements.  |
| Behaviour more agitated or impaired in late afternoon.  Total Sleep/Activity/Sundowning  Motor/Spatial Problems  Poor coordination seen in limb/finger movements.  |
| afternoon.  Total Sleep/Activity/Sundowning  Motor/Spatial Problems  Poor coordination seen in limb/finger movements.  |
| Motor/Spatial Problems Poor coordination seen in limb/finger movements.  |
| Poor coordination seen in limb/finger movements.   |
| Poor coordination seen in limb/finger movements.   |
| movements.   |
| Slowness of movement   |
|  |
| Unsteadiness when walking.   |
| Has trouble dressing, especially with buttons or shoelaces.  |
| Difficulty judging object sizes or how near an object is from themselves.  |
| Total Motor Spatial Problems   |
|  |

|   | 12 | Language Difficulties  |
|---|----|--|
|   | 61 | Reads far less frequently than previously.                                     |
|   | 62 | Substitutes some words for others.   |
|   | 63 | Does not watch or follow television.   |
|   | 64 | Does not speak unless spoken to. (e.g. Does not participate in conversations.) |
| X | 65 | Often cannot find the right word.  |
|   | 66 | Trouble pronouncing words.   |
|   | 67 | Does not understand simple commands, explanations.                             |
|   | 68 | Does not produce meaningful speech.  |
| 1 | <  | Total Language Difficulties  |

14 TOTAL SCORE

#### **BEHAVIOURAL PROFILE**

#### TOTAL SCORE ANALYSIS

|                  | 1                | 2                              | 3                   | 4                    | 5              | 6                  | 7                 | 8             | 9                  | 10                        | 11                     | 12                    | C              | DMM                      | INS               | ST                       |
|------------------|------------------|--------------------------------|---------------------|----------------------|----------------|--------------------|-------------------|---------------|--------------------|---------------------------|------------------------|-----------------------|----------------|--------------------------|-------------------|--------------------------|
| COMPARISON SCALE | Daily Activities | Attention/Concentration/Memory | Emotional Behaviour | Aggressive Behaviour | Misperceptions | Paranoid Behaviour | Judgement/Insight | Perseveration | Motor Restlessness | Sleep/Activity/Sundowning | Motor/Spatial Problems | Language Difficulties | Total Score    | Total Score Descriptions | Total Score       | Total Score Descriptions |
| 10               | 17               | 5                              | 4                   | 3                    | 4              | 5                  | 7                 | 3             | 3                  | 4                         | 5                      | 8                     | 68<br>67       | 0                        | 67<br>66          | С                        |
| 9.5              | 16               |                                |                     |                      |                |                    |                   |               |                    |                           |                        |                       | 66<br>64       | 0<br>Z                   | 65<br>64          | R<br>-                   |
| 9                | 15               |                                |                     |                      |                |                    | 6                 |               |                    |                           |                        | 7                     | 63<br>62       | S                        | 63<br>62          | S I S                    |
| 8.5<br>8         | 14               | 4                              |                     |                      |                | 4                  |                   |               |                    |                           | 4                      |                       | 61<br>60<br>58 | DER                      | 61<br>60<br>58    | 0,                       |
| 7.5              | 13               | 4                              | 3                   |                      | 3              | 4                  | 5                 |               |                    | 3                         | 4                      | 6                     | 56             | ק<br>ס                   | 56<br>54          |                          |
| 7                | 12               |                                | J                   |                      | J              |                    | J                 |               |                    | J                         |                        | O                     | 54<br>52<br>50 | LA                       | 52<br>50          |                          |
| 6.5              | 11               |                                |                     | 2                    |                |                    |                   | 2             | 2                  |                           |                        |                       | 48<br>46       | CE                       | 48<br>46          |                          |
| 6                | 10               | 0                              |                     |                      |                | 3                  | 4                 |               |                    |                           | 3                      | 5                     | 44<br>42       | M H                      | 44<br>42          |                          |
| 5.5              | 9                | $\chi$                         |                     |                      |                |                    |                   |               |                    |                           |                        |                       | 40<br>38       | Z<br>H                   | 40<br>38          | CON                      |
| 5                | 8                | / \                            | 2                   |                      | 2              |                    |                   |               |                    | 2                         |                        | 4                     | 36<br>34<br>32 |                          | 36<br>34<br>32    | _                        |
| 4.5              | 7                |                                |                     |                      |                |                    | 3                 |               |                    |                           |                        |                       | 30<br>28       | C 0                      | 30<br>28          | LT                       |
| 4                |                  | 2                              |                     |                      |                | 2                  |                   |               |                    |                           | Ø                      | 3                     | 26<br>24       | z<br>v                   | 26<br>24<br>22    | / co                     |
| 3.5              | <u> </u>         |                                |                     | Ø                    |                |                    |                   | 1             | 1                  |                           | $/ \setminus$          |                       | 22<br>20       | U L                      | 20                | ONC                      |
| 3                | 5                |                                | 4                   | /                    | 1              |                    | 2                 |               |                    |                           | \                      | 0                     | 19<br>17       | Т / с                    | 18<br>16          | ш                        |
| 2.5              | 4<br>3           | 1                              | 1                   | /\                   | 1              | 1                  |                   |               |                    | 9                         | 1                      | 2                     | 16<br>14<br>11 | 0 2                      | 14<br>12          | R<br>Z                   |
| 2<br>1.5         | 2                | l                              |                     | / \                  |                | ı                  | 1                 |               |                    |                           | 1                      | \1                    | 90 6           | CE                       | 10<br>8<br>6<br>5 |                          |
| 1.5              | _                |                                | \ /                 |                      | \              |                    |                   |               |                    |                           |                        | 9                     | 5<br>4         | η<br>Z                   |                   |                          |
| 0.5              | 1                |                                | \                   |                      | \              |                    |                   |               |                    |                           |                        |                       | 3 2            |                          | 4<br>3<br>2       |                          |
| 0                | 0                | 0                              |                     | 0                    |                | A                  | <u>A</u>          | A             |                    | 0                         | 0                      | 0                     | 1              |                          | 1 0               |                          |

| BEHAVIOURAL PROFILE |                   |                                |                     |                      |                |                    |                   |               |                    |                           |                        | TOTA                  | L SCO         | RE /           | <u>ANALY</u>             | 'SIS                       |                          |
|---------------------|-------------------|--------------------------------|---------------------|----------------------|----------------|--------------------|-------------------|---------------|--------------------|---------------------------|------------------------|-----------------------|---------------|----------------|--------------------------|----------------------------|--------------------------|
|                     | 1 2 3 4 5 6 7 8 9 |                                |                     |                      |                |                    |                   |               | 10                 | 11                        | INS                    | T                     |               |                |                          |                            |                          |
| COMPARISON SCALE    | Daily Activities  | Attention/Concentration/Memory | Emotional Behaviour | Aggressive Behaviour | Misperceptions | Paranoid Behaviour | Judgement/Insight | Perseveration | Motor Restlessness | Sleep/Activity/Sundowning | Motor/Spatial Problems | Language Difficulties |               | Total Score    | Total Score Descriptions | Total Score                | Total Score Descriptions |
| 10                  | 17                | Ó                              | 4                   | Ô                    | 4              | 5                  | Ø                 | 3             | 3                  | 4                         | Ø                      | 8                     |               | 68<br>67       | 0                        | 67<br>66                   | 0                        |
| 9.5                 | 16                | $\int \int$                    |                     | $\prod$              |                |                    | $\Lambda$         |               |                    |                           | /                      |                       |               | 66<br>64       | 0 2                      | 65<br>64                   | R -                      |
| 9                   | 15                | / \                            |                     |                      |                |                    | 6                 |               |                    |                           | / \                    | 7                     |               | 63<br>62       | s –                      | 63<br>62                   | S –                      |
| 8.5                 | 14                | \                              |                     |                      |                |                    | / \               |               |                    |                           |                        |                       |               | 61<br>60       | DE                       | 61<br>60                   | S                        |
| 8                   | 13                | 4                              |                     |                      |                | 4                  |                   | \             |                    | /                         | 4                      |                       |               | 58<br>56       | R                        | 58<br>56                   |                          |
| 7.5                 | 12                |                                | 3                   |                      | 3              |                    | 5                 | \             |                    | Ø                         |                        | 6                     |               | 54<br>52       | P L                      | 54<br>52                   |                          |
| 7                   | 11                |                                | \                   | 2                    |                |                    |                   |               | کے                 |                           |                        |                       | $\rightarrow$ | 50<br>48<br>46 | A C I                    | 50<br>48                   |                          |
| 6.5                 | 10                |                                | \                   |                      |                |                    |                   | <u></u>       | J                  |                           |                        | 5                     |               | 44             | EME                      | 46<br>44                   |                          |
| 6                   | 9                 | 3                              |                     |                      |                | Ø                  | 4                 |               |                    |                           | 3                      |                       |               | 42<br>40       | Z                        | 42<br>40                   | 00                       |
| 5.5<br>5            | 8                 |                                | V                   |                      | 2              |                    |                   |               |                    | 2                         |                        | 4                     |               | 38<br>36       |                          | 38<br>36<br>34             | O N S                    |
| 4.5                 | 7                 |                                | 0                   |                      |                |                    | 3                 |               |                    | 2                         |                        | \                     |               | 34<br>32<br>30 | C                        | 32<br>30                   | ) U                      |
| 4                   | ,                 | 2                              |                     |                      |                | 2                  | Ŭ                 |               |                    |                           | 2                      |                       |               | 28<br>26       | 0<br>Z                   |                            | Τ,                       |
| 3.5                 | 6                 |                                |                     | 1                    |                |                    |                   | 1             | 1                  |                           |                        | Ò                     |               | 24<br>22       | S U                      | 28<br>26<br>24<br>22       | 0 0                      |
| 3                   | 5                 |                                |                     |                      |                |                    | 2                 |               |                    |                           |                        |                       |               | 20<br>19       | LΤ                       | 20<br>18                   | N C                      |
| 2.5                 | 4                 |                                | 1                   |                      | 1              |                    |                   |               |                    | 1                         |                        | 2                     |               | 17<br>16       | / c                      | 16<br>14                   | E R                      |
| 2                   | 3                 | 1                              |                     |                      |                | 1                  |                   |               |                    |                           | 1                      |                       |               | 14<br>11       | 0 2                      | 12<br>10                   | Z                        |
| 1.5                 | 2                 |                                |                     |                      | 1              |                    | 1                 |               |                    |                           |                        |                       |               | 9              | CEI                      | 8<br>6                     |                          |
| 1                   | _                 |                                |                     |                      |                |                    |                   |               |                    |                           |                        | 1                     |               | 5<br>4         | R<br>Z                   | 8<br>6<br>5<br>4<br>3<br>2 |                          |
| 0.5                 | 1                 |                                |                     |                      | $\mathbf{I}$   |                    |                   |               |                    |                           |                        |                       |               | 3 2            |                          | 3 2                        |                          |
| 0                   | 0                 | 0                              | 0                   | 0                    | 9              | 0                  | 0                 | 0             | 0                  | 0                         | 0                      | 0                     |               | 1<br>0         |                          | 1 0                        |                          |

|                  | BEHAVIOURAL PROFILE 1 2 3 4 5 6 7 8 9 10 1 |                                |                     |                      |                |                    |                   |               |                    |                           |                        |                       |          | TOTAL SCORE ANALYSIS  11 12 COMM INST |                          |                            |                          |  |  |
|------------------|--|--------------------------------|---------------------|----------------------|----------------|--------------------|-------------------|---------------|--------------------|---------------------------|------------------------|-----------------------|----------|---------------------------------------|--------------------------|----------------------------|--------------------------|--|--|
|                  | 1  | 2                              | 3                   | 4                    | 5              | 6                  | 7                 | 10            | 11                 | 12                        | INS                    |                       |          |                                       |                          |                            |                          |  |  |
| COMPARISON SCALE | Daily Activities                           | Attention/Concentration/Memory | Emotional Behaviour | Aggressive Behaviour | Misperceptions | Paranoid Behaviour | Judgement/Insight | Perseveration | Motor Restlessness | Sleep/Activity/Sundowning | Motor/Spatial Problems | Language Difficulties |          | Total Score                           | Total Score Descriptions | Total Score                | Total Score Descriptions |  |  |
| 10               | 17   | 5                              | 4                   | 3                    | 4              | 5                  | 7                 | 3             | 3                  | 4                         | Ø                      | 8                     |          | 68<br>67                              | С                        | 67<br>66                   | 0                        |  |  |
| 9.5              | 16   |                                |                     |                      |                |                    |                   |               |                    |                           | $I \setminus$          |                       |          | 66<br>64                              | 0 2                      | 65<br>64                   | R I                      |  |  |
| 9                | 15   |                                |                     |                      |                |                    | 6                 |               |                    |                           | / \                    | 7                     |          | 63<br>62                              | S                        | 63<br>62                   | S I S                    |  |  |
| 8.5<br>8         | 14   | 4                              |                     |                      |                | 4                  |                   |               |                    |                           | 4                      |                       |          | 61<br>60<br>58                        | D E R                    | 61<br>60<br>58             | 0,                       |  |  |
| 7.5              | 13   | 4                              | 3                   |                      | 3              | 4                  | 5                 |               |                    | 3                         |                        | 6                     |          | 56<br>54                              | P                        | 56<br>54                   |                          |  |  |
| 7.3              | 12   |                                | J                   |                      | J              |                    | J                 |               |                    |                           |                        | Ŭ                     |          | 52<br>50                              | LA                       | 52<br>50                   |                          |  |  |
| 6.5              | 11   |                                |                     | 2                    |                |                    |                   | 2             | 2                  |                           |                        | \                     |          | 48<br>46                              | CE                       | 48<br>46                   |                          |  |  |
| 6                | 10   | ര                              |                     |                      |                | 3                  | 4                 |               |                    |                           | 3                      | 5                     |          | 44<br>42                              | M                        | 44<br>42                   |                          |  |  |
| 5.5              | 9  | χ                              |                     |                      |                |                    |                   |               |                    |                           |                        |                       |          | 40<br>38                              | Z<br>T                   | 40<br>38<br>36             | CON                      |  |  |
| 5                | 0  | /\                             | 2                   |                      | 2              |                    |                   |               |                    | 2                         |                        | 9                     |          | 36<br>34<br>32                        |                          | 34<br>32                   | ΠSΙ                      |  |  |
| 4.5              | 7  | / \                            |                     |                      |                |                    | 3                 |               |                    |                           |                        |                       |          | 30<br>28                              | c 0                      | 30<br>28<br>26             | ΙТ                       |  |  |
| 4                | 6  | 2                              |                     |                      |                | 2                  |                   |               |                    |                           | 2                      | 3                     |          | 26<br>24                              | O N S                    | 26<br>24<br>22             | / C                      |  |  |
| 3.5              |  |                                | \                   | 1                    |                |                    | _                 | 1             | 1                  |                           |                        |                       |          | 22<br>20                              | U L                      | 20                         | 0 N 0                    |  |  |
| 3                | <b>Ø</b>                                   |                                |                     |                      | 4              |                    | 2                 |               |                    |                           |                        | ·                     | <b>*</b> | <b>6</b>                              | Т / С                    | 18<br>16                   | CEF                      |  |  |
| 2.5<br>2         | 3  | 1                              | Q                   |                      | 1              | 1                  |                   |               |                    | 9                         | 1                      | 2                     |          | 16<br>14<br>11                        | 0<br>N                   | 14<br>12<br>10             | R<br>Z                   |  |  |
| 1.5              | 2  | 1                              | \                   |                      |                | 1                  | 1                 |               |                    |                           | 1                      |                       |          | 9                                     | CE                       |                            |                          |  |  |
| 1                | _  |                                | \                   |                      |                |                    |                   |               |                    |                           |                        | 1                     |          | 5<br>4                                | R<br>Z                   | 5<br>4                     |                          |  |  |
| 0.5              | 1  |                                |                     | \                    |                |                    |                   |               |                    |                           |                        |                       |          | 3                                     |                          | 8<br>6<br>5<br>4<br>3<br>2 |                          |  |  |
| 0                | 0  | 0                              | 0                   |                      | <b>A</b>       | À                  | A                 | Â             |                    | 0                         | 0                      | 0                     |          | 1<br>0                                |                          | 1<br>0                     |                          |  |  |

|                  |                  |                                | В                   | EHAV                 | IOUR/          | AL PR              |                   | TOTA          | L SCO              |                           |                        | /SI                   | IS       |                |                          |  |                            |                          |
|------------------|------------------|--------------------------------|---------------------|----------------------|----------------|--------------------|-------------------|---------------|--------------------|---------------------------|------------------------|-----------------------|----------|----------------|--------------------------|--|----------------------------|--------------------------|
|                  | 1                | 2                              |                     |                      |                |                    |                   |               |                    |                           |                        |                       |          |                |                          |  |                            |                          |
| COMPARISON SCALE | Daily Activities | Attention/Concentration/Memory | Emotional Behaviour | Aggressive Behaviour | Misperceptions | Paranoid Behaviour | Judgement/Insight | Perseveration | Motor Restlessness | Sleep/Activity/Sundowning | Motor/Spatial Problems | Language Difficulties |          | Total Score    | Total Score Descriptions |  | Total Score                | Total Score Descriptions |
| 10               | 17               | 5                              | 4                   | 3                    | 4              | 5                  | 7                 | 3             | 3                  | 4                         | 5                      | 8                     |          | 68<br>67       | С                        |  | 67<br>66                   | 0                        |
| 9.5              | 16               |                                |                     |                      |                |                    |                   |               |                    |                           |                        |                       |          | 66<br>64       | 0 2                      |  | 65<br>64                   | R I                      |
| 9                | 15               |                                |                     |                      |                |                    | 6                 |               |                    |                           |                        | 7                     |          | 63<br>62       | S   I                    |  | 63<br>62                   | SIS                      |
| 8.5<br>8         | 14               | 4                              |                     |                      |                | 4                  |                   |               |                    |                           | 4                      |                       |          | 61<br>60<br>58 | DER                      |  | 61<br>60<br>58             | 0,                       |
| o<br>7.5         | 13               | 4                              | 3                   |                      | 3              | 4                  | 5                 |               |                    | 3                         | 4                      | 6                     |          | 56<br>54       | P                        |  | 56<br>54                   |                          |
| 7.3              | 12               |                                | J                   |                      | J              |                    | J                 |               |                    |                           |                        | 0                     |          | 52<br>50       | LA                       |  | 52<br>50                   |                          |
| 6.5              | 11               |                                |                     | 2                    |                |                    |                   | 2             | 2                  |                           |                        |                       |          | 48<br>46       | CE                       |  | 48<br>46                   |                          |
| 6                | 10               | A                              |                     |                      |                | 3                  | 4                 |               |                    |                           | 3                      | 5                     |          | 44<br>42       | ME                       |  | 44<br>42                   |                          |
| 5.5              | Ò                | ۲                              |                     |                      |                |                    |                   |               |                    |                           |                        |                       |          | 40<br>38       | N<br>H                   |  | 40<br>38                   | 0 0                      |
| 5                | 8                |                                | 2                   |                      | 2              |                    |                   |               |                    | 2                         |                        | 4                     |          | 36<br>34       |                          |  | 36<br>34                   | N S N                    |
| 4.5              | 7                |                                |                     |                      |                |                    | Ø                 |               |                    |                           |                        |                       |          | 32<br>30<br>28 | c c                      |  | 32<br>30<br>28             | ΙЛ                       |
| 4                | 6                | 2                              |                     |                      |                | 2                  | $\bigwedge$       |               |                    |                           | 2                      | 3                     |          | 26<br>24       | ONS                      |  | 28<br>26<br>24<br>22<br>20 | ) C                      |
| 3.5              | J                |                                |                     | 1                    |                |                    | /\                | 1             | 1                  |                           |                        | Ö                     |          | 22<br>20       | SUL                      |  | 22<br>20                   | 0 N                      |
| 3                | 5                |                                |                     |                      |                |                    | 2                 |               |                    |                           |                        |                       | <b>→</b> | ٥              |                          |  | 18<br>16                   | CE                       |
| 2.5              | 4                |                                | 1                   |                      | 1              |                    | \                 |               |                    | P                         |                        | P                     |          | 16<br>14       | T / CONC                 |  | 14<br>12                   | R<br>N                   |
| 2                | 3                | 1                              | \                   |                      |                | Ø                  | _ \               |               |                    | /\                        | 1                      |                       |          | 11<br>9        |                          |  | 10<br>8                    |                          |
| 1.5              | 2                |                                |                     |                      |                | /                  | 1 \               |               |                    | \                         |                        | 1                     |          | 6<br>5         | M<br>N<br>Z              |  | 8 6 5 4 3 2 1              |                          |
| 1<br>0.5         | 1                |                                |                     |                      | /              |                    |                   | \             | /                  | \                         | /                      |                       |          | 4<br>3<br>2    |                          |  | 3                          |                          |
| 0.5              | 0                | 0                              |                     | <u>~</u>             |                | 0                  | 0                 |               |                    | 0                         | $\bigvee_{\mathbf{a}}$ | 0                     |          | 1 0            |                          |  | 1 0                        |                          |

**GLOSSARY** 

#### **Further Description of Behaviours**

#### 1 Daily Activities

- 1 No longer takes part in favourite pastimes (or greatly reduced).
  - no longer participates in hobbies or previously preferred activities like playing the piano, or card games
  - reduction in self-directed leisure activities
- 2 Reduced personal hygiene.
  - would not take a bath unless told to do so, or wears the same clothes for days unless prompted to change
  - reduction in individual's normal self-directed hygiene
  - care done by nursing staff
- 3 If left on his/her own, doesn't eat properly.
  - will not independently eat adequate meals or will miss meals, even if provided
  - weight loss may be apparent
- 4 Unsafe in daily activities, if left unsupervised.
  - may leave stove on, water running, choking, unsafe with hot liquids, unsafe getting into bath, etc.
- 5 No longer uses some common objects properly.
  - now seems to have difficultly handling common household objects such as telephones, microwaves, etc.
  - difficulty with kitchen utensils knowing what to use
- 6 Unable to handle personal finances.
  - gets confused paying bills may not pay at all, or pays twice
  - now someone else has to handle finances
- 7 Is unable to perform usual household tasks
  - such as cleaning, minor repairs, or prepare meals.
  - gets confused while trying to fix something,
  - or unable to organize oneself to prepare meals
- 8 Gets confused in places other than home.
  - gets confused in other people's homes or other familiar places such as shopping centres, neighbourhood, etc.
  - if taken off unit for activities/appointments could not find their way back to unit alone.
- 9 Overly dependent, wants more guidance than usual.
  - asks for more help, or approval from caregiver than in past; relies on caregiver to initiate activities
  - often described as "shadowing"
- 10 Trouble appreciating subtleties in conversations
  - now has trouble recognizing humour does not get jokes
- 11 Difficulty judging the passing of time.
  - may keep asking time of day, etc.
  - may prepare for appointments etc., several hours before necessary
- 12 Wanders aimlessly.
  - walks around looking lost
  - not rapid pacing as in Motor Restlessness
- 13 Hides things.
  - hides things away that do not need to be hidden, e.g. dentures
  - stores things in inappropriate places such putting a purse or wallet in freezer
- 14 Hoards objects.
  - more extreme version of hiding; collecting excessive quantity of things
- 15 Fails to recognize family or friends.
  - does not know them or thinks they are someone else
- 16 Incontinence of urine/faeces in clothes in daytime.
  - clothes include "Depends" etc.
- 17 Voids in non-toilet areas.
  - plant pots, hall corners, etc.
  - not the same as incontinence in clothes or incontinence briefs

#### 2 Attention/Concentration/Memory

- 18 Can't concentrate, pay attention for as long as they used to.
  - attention span reduced, thinking is more muddled, often slower
- 19 Misplaces things more than usual.

- like normal failures of memory/forgetfulness, only much more frequent
- forgets where they put something down e.g. book, glasses, etc.
- 20 Has difficulty organizing his/her time or daily activities.
  - seems to be busy but accomplishes very little
  - activities are organized by someone else
- 21 Forgets activities, conversations of only a short time before.
  - within that day
- 22 Forgets important everyday information.
  - such as scheduled appointments and activities, phone numbers, addresses, etc.

#### 3 Emotional Behaviour

- 23 Shows little or no emotion.
  - reduction of normal emotional range
- 24 Mood changes for no apparent reason.
- 25 Expresses inappropriate emotions, either type or intensity.
  - e.g. laughing at news of a death, or crying at mild disappointment
- 26 Makes uncharacteristically pessimistic statements.

#### 4 Aggressive Behaviour

- 27 Verbally abusive at times.
  - must be directed at someone or something
- 28 Uncharacteristically excitable, easy to upset; reacts catastrophically.
  - reactions to change are exaggerated
  - intensity of emotional reaction is excessive for the situation
- 29 Physically aggressive.
  - hitting, biting, pinching, spitting, pushing, hair pulling, etc.

#### 5 Misperceptions/Misidentifications Behaviour

- 30 Claims an object or possession looks similar to, but is not the real one.
  - e.g. the family car in driveway is not recognized as own car, or a piece of jewelry/glasses is identified as looking similar to but not their own
- 31 Claims a family member looks similar (to that person) but is not the true one.
- 32 Thinks present dwelling is not their place of living.
  - e.g. the person in the nursing home does not recognize that they live in that facility
  - or, the person who lives in their own home but states they want to, or is packing to, "go home"
- 33 Thinks people are present who aren't.
  - thinks people are present in the room or somewhere in the house when in fact they are not e.g. believes that people on TV are real and in the room, a deceased family member is living elsewhere in the house, misinterprets own image in mirror as another person

#### 6 Paranoid Behaviour

- 34 Suspicious of family and friends.
  - accuses family or staff of putting poison in food or drinks
- 35 Suspicious about money issues.
  - suspects people around them are trying to steal their money
  - suspects people around them are taking unusual interest in their financial affairs
- 36 Accuses others of stealing his or her things.
- 37 Accuses spouse of infidelity.
  - refers to current behaviour not some incident from long past.
- 38 Expresses suspicion around taking medication.
  - suggests that the contents of the medicine bottle is not what it says on the label
  - believes that the medicine is poison
  - NOT questions re the value of the medication

#### 7 Judgement/Insight

- 39 Shows poor judgement in social situations.
  - e.g. Making inappropriate comments
  - off-coloured jokes
  - no longer respects the social decorum required in a given situation e.g. unwanted comments on physical appearance
- 40 Shows poor judgement about driving.

- wants to drive when he or she should not
- believes he or she could safely drive despite evidence to the contrary
- 41 Shows uncharacteristic change in his or her concern about money.
  - e.g. very reluctant to pay bills, or may give away money to strangers
- 42 Poor choices in dressing.
  - e.g. wears clothes that are inappropriate for season or temperature.
  - nursing staff picks out clothing
- 43 Makes inappropriate sexual advances.
  - behaviour should be explicit and not vague references that could be interpreted in many ways
- 44 Shows less self control than usual.
  - problems controlling eating, drinking, etc. (not just memory problem)
  - e.g. eating a whole pot of chili at one sitting
  - difficulty denying impulses
- 45 Unable to identify personal safety risks.
  - unable to foresee obviously dangerous outcomes to certain actions
  - unable to take personal safety into account in decision making
  - will eat food even if clearly spoiled

#### 8 Perseveration

- 46 Repeats same actions over and over.
  - such as tapping or rocking in a chair
- 47 Repeats same words or phrases.
  - includes repetition of syllables or sounds
- 48 Repeatedly shouts or calls out.

#### 9 Motor Restlessness

- 49 Desire to pace or walk almost constantly.
  - different from aimless wandering, i.e. faster
- 50 Can't sit still; restless; fidgety.
  - e.g. restlessly moving from chair to chair (or in wheelchair, etc.)
- 51 Tries doors, windows.
  - seems unable to inhibit the tendency to use handles and knobs on things
  - exit seeking behaviour

#### 10 Sleep/Activity/Sundowning

- 52 Falls asleep at uncharacteristic times.
  - during conversations or during meals, or increased daytime sleep
- 53 Gets up and wanders or awakens frequently at night more than usual.
- 54 Sleeps more.
  - more than usual
- 55 Behaviour more agitated or impaired in late afternoon.
  - ADL is more impaired in late afternoon or early evening; exacerbation of already problematic behaviours

#### 11 Motor/Spatial Problems

Score even if due to physical problems e.g. arthritis, vision, etc.

- 56 Poor coordination seen in limb/finger movements.
  - e.g. difficulty using pens or pencils, or moving a cup to one's mouth
  - includes tremor
- 57 Slowness of movement.
- 58 Unsteadiness when walking.
- 59 Has trouble dressing, especially with buttons or shoelaces.
  - struggles to put on clothes the right way lefts and rights frequently mixed up or clothes sometimes on backwards
- 60 Difficulty judging object sizes or how near an object is from themselves.
  - may make exaggerated steps to step over something quite low, such as a crack in the floor, change in carpet colour

#### 12 Language Difficulties

- 61 Reads far less frequently than they used to.
- 62 Substitutes some words for others.
  - substitutes an incorrect term for an object or uses a nonsensical word

- makes substitutions usually without knowing it
- 63 Does not watch or follow television.
- 64 Does not speak unless spoken to. (e.g. Does not participate in conversations.)
- 65 Often cannot find the right word.
  - halted speech while struggling to find the right word
- 66 Trouble pronouncing words.
- 67 Does not understand simple commands, explanations.
- 68 Does not produce meaningful speech.
  - caregiver cannot reliably understand person's requests or responses.

### GLOSSARY OF THE ADDITIONAL ITEMS ON THE LONG TERM CARE FORM

- 2 Resistant to bathing.
  - refuses to bath, or requires substantial persuasion to do so
- 3 Refuses to leave own room.
- 5 Does not like being touched.
- 6 Combines foods not usually eaten together.
- 7 Refuses to eat.
  - or requires considerable effort on part of staff to do so
- 8 Drools on self, clothing.
- 10 Eats other's food at meal time.
  - eats food from other people's trays, etc.
- 18 Smears faeces.
- 21 Easily distracted by surrounding noises.
  - either by other people or machines, etc.
- 22 Places things in inappropriate places.
  - either in body cavity, or in wrong location, such as shoes in refrigerator
- 27 Expresses suicidal feelings, threatens to hurt him/herself.
- 30 Throws things at, or pinches others.
- 36 Sees or hears things that are not there.
  - includes delusions and hallucinations
- 37 Talks to pictures or mirrors.
  - assumes that image of self in mirror is another person, or person in picture is real
- 43 Seeks constant attention.
  - often keeps bothering staff for inconsequential matters
- 44 Eats non-food items.
- 45 Grabs others nearby.
- 46 Shows increased sexual drive, interest.
  - toward either sex
- 48 Accident prone, gets hurt a lot.
- 50 Invades personal space.
  - when carrying on a conversation, comes much closer than is normally considered appropriate
- 53 Talks about same topic over and over again.
  - slightly different from item 53 which refers to words or phrases only
  - this item refers to stories, or topics of conversation e.g. "When will dinner be served?"
- 55 Clapping/noise making.
  - either with hands, feet, or an object.
- 59 Repeatedly rearranges furniture.
  - -either furniture in own room or elsewhere
- 60 Bangs head deliberately
- 74 Speaks in meaningless phrases, or unintelligible language.

#### THE KINGSTON SCALES

#### Cognition

Kingston Standardized Cognitive Assessment - Revised (KSCAr)
BriefKingston Standardized Cognitive Assessment - Revised (BKSCAr)
mini-Kingston Standardized Cognitive Assessment - Rev (mini-KSCAr)

#### **Behaviour**

Kingston Standardized Behavioural Assessment (KSBA(comm) & KSBA(LTC))

#### **Caregiver Stress**

Kingston Caregiver Stress Scale (KCSS)

#### **Behaviour and Cognition**

Kingston Dementia Rating Scale (KDRS)

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#### KINGSTON CAREGIVER STRESS SCALE (KCSS)

- Kingston Caregiver Stress Scale Administration and Interpretation Manual <a href="http://www.kingstonscales.org/caregiver-stress-scale.html">http://www.kingstonscales.org/caregiver-stress-scale.html</a>
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