

The Progressive Course of Alzheimer Disease: A Training Tool for Caregivers

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A common theme in dementia is misunderstanding—patients with dementia are confused in their thoughts, about the people around them, and by their environment. Furthermore, the patient's family should not be astounded by the seemingly different viewpoints of professionals. In dementia, understanding is of the utmost importance between professionals and family caregivers, and delivering the facts in a clear manner is essential. Striving for this goal, the training tool presented in this article allows the factual understanding of the natural progression of Alzheimer disease. Clinical data and 13 grades are charted within a single table to allow optimal understanding of this disease.

Key words: Alzheimer disease, caregivers, GDS-FAST, training table, MMSE.

Caring for patients with Alzheimer disease (AD) often involves not only the patient but also the patient's family. Over time, as both patient and family become exposed to the difficulties that inevitably accompany AD, the responsibilities of caregivers become more complicated and demanding. Caregivers and all members of the healthcare team should receive meticulous training on how to handle this disease. This article presents a "training table"—a potentially indispensable tool for all those caring for patients with AD.

General practitioners often are asked the following questions from families of patients with AD: What kind of disease is it? How long does it last? What is going to happen? In what order? How does one deal with the disease?

Scientific knowledge on this subject is widely available. Families can obtain information from a number of sources, such as physicians, occupational therapists, nurses, other health professionals and the Internet (e.g., the Alzheimer Café at www.alzheimer.ca). Volunteer caregivers can also find answers to their questions, but it is easy to become confused when moving through the various sources of information. For example, different sources focus on different parameters/aspects of the disease, and terminology or disease "jargon" will vary among different professionals. Therefore, caregivers may get the impression that the information given by professionals and

other sources is inconsistent. They may feel uneasy and wonder whether these people actually know what they are talking about.

This author has been treating dementia for a long time and has come to realise that, in the case of AD where the patient's ideas become confused, the most desirable course of action is to bring communication down to the lowest common denominator. All members of the care team must be on the same wavelength; in other words, what they say must be standardised and reflect consensus. This author, therefore, suggests a training table, which summarises the many facets of AD while remaining simple and exhaustive. The table plots the natural course of AD, approximates the clinic presentation of mixed dementia with an Alzheimer component, and is of some interest in Lewy body dementia—the three syndromes accounting for approximately 80% of all the dementias. "It should be noted that the progression of symptoms with the mild to moderate stages (i.e., FAST stages 4 and 5) is 'shifting to the right' with the long-term use of cholinesterase inhibitors. These stages may now be longer than three years, but it is unknown whether this will mean less time in the severe to terminal stages for the same length of disease."¹

How to Use the Training Table

The Functional Assessment Staging (FAST) section is a detailed functional

subdivision of the Reisberg Global Deterioration Scale (GDS)^{2,3} that briefly lays out, in numerical sequence, the residual competence of a patient with AD throughout the course of the disease.

The letters on the left below the FAST section refer to characteristic developments over the course of the disease:

A = grading of FAST losses;

B = length of the stages;

C = approximate mental age of patient;

D = length of the disease in years (we know, however, that unforeseen events, such as hip fractures and aspiration pneumonia, frequently occur and that the length will generally be shorter in these cases);

E = score on the Folstein mini-mental state examination (MMSE);

F = the usual terms used by physicians to describe the severity of the condition.

Lines 1 to 8 show the clinical events in chronological order over a period of 20 years. It should be noted that Gauthier, *et al.*^{4,5} have contributed greatly to the concepts presented in this portion of the table.

At the beginning of the disease (line 1), patients often suffer from depression, which has to be treated. Later on, patients with dementia—who no longer understand themselves and risk not being understood by people around them—react in an excited, agitated manner. This culminates in behavioural problems (line 6). The period corresponding to line 6 on the table is when the patient's environment should be adapted to his or her needs. This also is the point when neuroleptic and psychoactive medications are administered. It is recommended that adjustments be made to the physical surroundings (e.g., electronic keypad locks, modulated lighting, paintings with soft, matte colours to avoid overstimulation). Caregivers also should adjust their methods of interacting with the patient (e.g., bathing the patient when suitable to him or her, speaking gently in short sentences while facing the patient). Adjunct medications are a last resort.

Teaching Table on the Course of Alzheimer's Disease

FAST Stages

- 3 Hold employment
- 4 Perform simple calculations
- 5 Select appropriate clothing
- 6a Dress without assistance

- 6b Shower without assistance
- 6c Use the toilet without assistance
- 6d Urinary continence
- 6e Fecal continence
- 7a Language: five or six words

- 7b Language: one word only
- 7c Walking
- 7d Sitting
- 7e Smiling
- 7f Holding head up

A	FAST	3	4	5	6a	b	c	d	e	7a	7b	7c	7d	7e	7f
B	Length of stage	7 years	2 years	18 months	5 months	5 months	5 months	4 months	10 months	12 months	18 months	12 months	12 months	18 months	12+ months
C	Approximate mental age of patient	12+ years	12 to 8 years	7 to 5 years	5 years	4 years	4 years	3 years	2 to 4 1/2 years	15 months	12 months	12 months	8 months	2 to 4 months	1 to 3 months
D	Length of the disease (in years)	0	7	9	10.5	13									19
E	Score on MMSE	29	25	20	19	14	10	5	0						
F		Mild disease			Moderate			Severe				Terminal			
1		Depressed affect			Agitated affect			Flat affect							
2		Cognitive symptoms			Cognitive void										
3		Diagnosis													
4		Loss of functional autonomy													
5						Loss of motor skills									
6		Behavioural problems													
7		Placement in extended-care facility													
8		Death													

It should be mentioned that at stage 7a, line 1, affect becomes flat. At the beginning of stage 7a, line 2, cognitive life can no longer be evaluated. At line 5, there is a loss of motor skills. At this point (where line 6 ends), behavioural problems no longer occur. The beginning of stage 7 is therefore the time to reduce medication administered for the prevention or control of behavioural or psychological problems (e.g., cholinesterase inhibitors, neuroleptics, anticonvulsants, antidepressants). At the end of line 6 and

the beginning of stage 7a, the approach becomes palliative.

The true importance of the table becomes evident at line 6. Correctly grading the FAST section and bearing in mind the patient's approximate mental age (which will diminish from 12+ years to two years over a 10-year period) enables caregivers to adopt the appropriate attitude. They will not stress the patient by overestimating his or her residual capabilities (e.g., when taking a bath, preparing food/eating, or during recreational

activities). An appropriate attitude on the part of the caregiver will prevent aggressive behaviour. Failing to take into account the approximate mental age of a patient with AD means the care approach may be inadequate, and there is a very good chance the patient will react negatively.

When Should the Table be Used?

The table can be used whenever information has to be communicated throughout the course of AD. In a long-term care hospital, for example, the table could be used

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at a multidisciplinary admission meeting (within three months of the patient's admission), and then every six months thereafter and/or whenever an event occurs. This tool enables any deviation from the usual course of AD to be identified.

Where Should the Table be Placed?

The table should be placed wherever all members of the healthcare team meet:

- on the wall at the nurses' station;
- on the walls of the various professionals' offices.

Where Should the FAST Score be Entered?

The FAST score should be recorded and kept in the patient's chart, for easy access. As examples, the score could be jotted down on the inside cover of the file, or added to the record of most recent symptoms/problems (updated every six months).

Who Should be Trained to Use This Table?

All members of the staff should be trained, without exception. A practical example of how the table can be used, along with various aspects/questions of interest to healthcare professionals, is presented as follows:

Jerry is a male patient with stage 7a AD and a mental age of 15 months.

Caregiver: "When giving him a bath, I run warm water and then heat it up while he is in the bath. I watch over him. There will be splashing about. I give him something to keep him busy and distract him, like a toy. Bathtime should be playtime, if possible, rather than hell on earth."

Dietitian: "He handles his utensils clumsily; soon he won't be able to use them. Should I opt for chopped food? Should I give him one dish at a time?"

Occupational therapist: "He is still talking, but only five or six words at most. I won't try to reeducate him with respect to fecal continence. I have to assess the risk of falls, because he's beginning to lose his motor skills."

Recreational specialist: "What recreational activity can be targeted to an approximate mental age of 15 months?

What music would he like? Should I look into animal-assisted therapy?"

Nurse: "Would a security blanket or doll in bed comfort him enough, so that his sleep is more restorative, rather than using a sleeping pill?"

Physician: "It's time to decrease the dosage of atypical antipsychotic drugs and cholinesterase inhibitors given to prevent the onset of behavioural problems, because at this particular stage there is a cognitive and affective void. He also is beginning to lose functional activity. He will likely no longer show any aggressiveness."

Patient's daughter: "The caregivers all agree with respect to my father. He speaks very little and it soon will be just one word. At least I know I have to treat him like a baby. At that 'age', it's normal to wear diapers and have dolls. I am less anxious now, because I know what's coming next and can prepare myself for it."

Members of a patient's family should be trained to use the table, as they are considered part of the team. At home, they deal with the patient and with community workers. In long-term care facilities, they must harmoniously push the wheels in the same direction as professionals in the best interest of the loved one.

Individuals close to the patient will also benefit from the table because they will be able to understand the disease progression and explain it to others. Therefore, they will hopefully be less strained by the situation and avoid communicating disarray.

Other Applications of the Training Table

FAST scores for all patients in the care unit can be compiled, and an average calculated. The table can then be posted in a private part of the nurses' station, where all caregivers can consult it. This will help to organise and structure recreational time, to decorate and arrange the common and dining rooms, and to arrange sub-groups for specific activities.

Benefits of Using the Training Table

Patients with AD who are properly stimulated function better in their environ-

ment. Among other things, this results in less disturbance within the patient group. The table also enables family and other caregivers to follow the course of the disease itself and the care provided. They understand more and feel less guilty.

The table gives caregivers more—and better—information, which increases their confidence and competence. There are fewer cases of professional distress. There is greater stability among the care-unit staff, and they direct their energies more efficiently.

Caring for patients with AD often involves not only the patient, but also the patient's family. As the disease takes its course, caregivers, in effect, are accompanying the family on a journey across a long, rugged, unpredictable terrain. Unfortunately, this journey moves steadily towards depersonalisation and eventual loss of the power of thought—the characteristic that differentiates humans from other species. Healthcare professionals are exposed to this reality on a daily basis and, therefore, should receive meticulous training on how to handle this disease, particularly because what is happening to their patients could just as easily happen to them or someone close to them. In short, training caregivers enhances treatment of patients with AD.

The training table is a teaching tool that helps take an overall approach to AD, regardless of what stage the patient has reached. It is very user-friendly and is simple to learn and apply on a daily basis. Even families of those with AD should be taught how to use it. ♦

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References

1. Gauthier S. Alzheimer's disease: Earlier diagnosis and better management. *The Canadian Alzheimer Disease Review* 2002;5:3.
2. Reisberg B. Functional assessment staging (FAST). *Psychopharmacol (bulletin)* 1988;24:653-9.
3. Reisberg B, Ferris SH, Franssen EH, et al. Mortality and temporal course of probable Alzheimer's disease: a 5-year prospective study. *International Psychogeriatrics* 1996;8:291-311.
4. Groulx B. Nonpharmacologic treatment of behavioral disorders in dementia. *The Canadian Alzheimer Disease Review*. 1998;2:6-8.
5. Gauthier S. *Alzheimer's disease in primary care*, 2nd edition. London: Martin Dunitz Ltd., 1999.