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More: Alternatives to Antipsychotics and erratic behavior

2021 Update, with links on avoiding chemical restraints

Multi Site Breakfast - March 3, 2016
Natick, Peabody, Duxbury, and Westfield, Massachusetts



Antipsychotics and Dementia:

What attorneys and geriatric advocates need to know about the (over) use of antipsychotic medications with memory loss residents in a facility setting.

Nursing homes have for many years used psychotropic medicines to modify the behavior of residents who suffer from Alzheimer's disease, memory loss, and dementia. Medicare surveys in Massachusetts and other states show 20% of nursing residents who are on antipsychotic meds have NOT been diagnosed with a psychotic condition.¹

Clients, and their attorneys, who are aware of the alternatives to behavior modification medication can help protect the quality of life for the memory loss patient. Medicaid planning and efforts to protect assets require an understanding of the progressing needs of the memory loss patient, and the many resources that are available to meet those needs. Without a sound understanding of the services available to the memory loss patient at home or in assisted living, a resident could end up needing a nursing home admission, where chemical and physical restraints are applied.

Each stage of memory loss requires awareness of how to direct the client and family members toward appropriate resources. Severe consequences can result when a family member who has authority to act under power of attorney and health care documents fails to understand and anticipate the needs of the memory loss client.

When family members, attorneys and judges do understand legal planning as part of an appropriate response to each stage of memory loss, the client's dignity and quality of life can be preserved. The client can be protected and redirected from erratic behaviors that would otherwise lead to physical and chemical restraints in a nursing home. This information is a vital part of formulating a plan, and essential in any case where planning involves a [5 year Medicaid look back period](#).

An editorial in the [February, 2009 Lancet](#) concluded that: "High levels of prescription of antipsychotic drugs for neuropsychiatric symptoms in dementia are putting many vulnerable patients at risk of death and other adverse events. . . . The risks and benefits of prescribing antipsychotics to patients with dementia need to be carefully balanced and these drugs should be used only if alternative strategies do not work. To protect the health and dignity of people with dementia and reduce the use of antipsychotic drugs, approaches that make the needs of patients central to decisions about care should be promoted."

¹Statistics for April-June 2010 at MDS Quality Measure/Indicator Report on Psychotropic Drug Use; **Nursing home drug use puts many at risk:** [Boston Globe, March 8, 2010](#)

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Examples of Antipsychotic medications administered to Massachusetts nursing home residents

These medications, with Black Box warnings, are listed in the Physicians Desk Reference, pdrhealth.com

Abilify (aripiprazole)

A medicine used to treat schizophrenia. It is also be used to treat bipolar disorder (alone or in combination with lithium or valproate), major depressive disorder (in combination with other antidepressants), and irritability associated with autism.

More common side effects may include: drowsiness, fatigue, vomiting, fever, drooling, decreased appetite, increased salivation, uncontrolled movements (such as shaking or muscle stiffness), tiredness.

Abilify is not approved to treat mental problems caused by dementia (an illness involving loss of memory and judgment, and confusion) in the elderly. It can be life-threatening when used in elderly people with mental problems caused by dementia.

Haldol (haloperidol)

Haldol decanoate is a medication used to treat schizophrenia when oral therapy is no longer possible. It may cause tardive dyskinesia, a movement disorder characterized by slow or jerky facial or body movements. Older adults, especially women, appear to be at greater risk. It may cause neuroleptic malignant syndrome, a life-threatening brain disorder.

Who should not take Haldol Decanoate?

Elderly patients with dementia-related psychosis, or patients with Parkinson's disease or a condition known as severe toxic central nervous system depression should not receive Haldol decanoate.

Risperdal (risperidone)

The Food and Drug Administration (FDA) first approved Risperdal in 2002 to treat schizophrenia in adults and youths at least 13 years old. Schizophrenia is a mental illness that can cause people to lose interest in life and develop abnormal thoughts and emotions.

Risperdal is not approved to treat mental problems caused by dementia (an illness involving loss of memory and judgment, and confusion) in the elderly. It can be life-threatening when used in elderly people with mental problems caused by dementia.

More common side effects may include: abdominal (stomach area) pain, anxiety, blurred vision, common cold, constipation, diarrhea, dizziness, dry mouth, increased saliva, increased appetite, indigestion, involuntary muscle movements, nausea, rash, shaking, sleepiness, stuffy nose, throat pain, tiredness, upper respiratory infection, vomiting, weight gain.

The manufacturer marketed Risperdal as a treatment for older people with agitation from dementia, which is not an FDA-approved use of the medication. The manufacturer had to pay a fine for misbranding the drug. The combined criminal plea agreement with the Justice Department and a civil settlement totaled more than \$1.67 billion.

Seroquel (quetiapine)

Seroquel is a medicine used to treat schizophrenia. This medication can also be used to treat bipolar disorder alone or in combination with lithium or divalproex. Also, Seroquel XR is used to treat major depressive disorder in combination with other antidepressants.

Seroquel XR is not approved to treat mental problems caused by dementia (an illness involving loss of memory and judgment, and confusion) in the elderly. It can be life-threatening when used in elderly people with mental problems caused by dementia.

Medicare Laws that govern Nursing homes and hospitals

Under Federal Medicare law, patients have the right to be free from:

any physical or chemical restraints imposed for purposes of discipline or convenience and not required to treat the resident's medical symptoms. Restraints may only be imposed—(I) to ensure the physical safety of the resident or other residents, and (II) only upon the written order of a physician that specifies the duration and circumstances under which the restraints are to be used.

42 U.S.C. § 1395i-3(c)(1)(A)(ii) and [42 U.S.C. §1396r\(c\)\(1\)\(A\)\(II\)](#).

Guidance issued to government Surveyors for Long Term Care Facilities lists the serious conditions that justify antipsychotic use, and the inadequate indications for administering antipsychotic medications: They should not be used if the only indication is one or more of the following: 1) wandering; 2) poor self-care; 3) restlessness; 4) impaired memory; 5) mild anxiety; 6) insomnia; 7) unsociability; 8) inattention or indifference to surroundings; 9) fidgeting; 10) nervousness; 11) uncooperativeness; or 12) verbal expressions or behavior that are not due to the conditions listed under "Indications" and do not represent a danger to the resident or others.

[Guidance issued by the Centers for Medicare & Medicaid Services, State Operations Manual, Appendix PP](#) at 387 [PDF document page 434]. When antipsychotics are used without monitoring they may be considered unnecessary medications because of inadequate monitoring. Id. at 389.

Nursing Homes Compliance Program and staffing guidelines

Personal injury attorneys use federal directives as evidence of the standard of care in nursing homes. The Office of Inspector General (OIG) has developed compliance program guidance (CPG) that recommends the steps each facility must take in assessing risk areas. This guidance is based on Medicare and Medicaid nursing facility payment systems and regulations, industry practices, and current enforcement priorities. The OIG guidance is at http://oig.hhs.gov/fraud/docs/complianceguidance/nhg_fr.pdf

Sufficient Staffing, Comprehensive Resident Care Plans, Medication Management, and Appropriate Use of Psychotropic Medications are the top four risk factors for "Nursing facilities that fail to make quality a priority, and consequently fail to deliver quality health care." Based on the OIG's enforcement and compliance monitoring activities, inappropriate use of psychotropic medications is a risk for nursing home residents because of the "prohibition against inappropriate use of chemical restraints and the requirement to avoid unnecessary drug usage."

Facilities have affirmative obligations to ensure appropriate use of psychotropic medications. Specifically, nursing facilities must ensure that psychopharmacological practices comport with Federal regulations and generally accepted professional standards.

The facility is responsible for the quality of drug therapy provided in the facility. Federal law prohibits facilities from using any medication as a means of chemical restraint for “purposes of discipline or convenience, and not required to treat the resident’s medical symptoms.”

In addition, resident drug regimens must be free from unnecessary drugs. For residents who specifically require antipsychotic medications, CMS regulations also require, unless contraindicated, that residents receive gradual dose reductions and behavioral interventions aimed at reducing medication use.

In light of these requirements, nursing facilities should ensure that there is an adequate indication for the use of the medication and should carefully monitor, document, and review the use of each resident’s psychotropic drugs.

Working together, the attending physicians, medical director, consultant pharmacist, and other resident care providers play a critical role in achieving these objectives.

Compliance measures could include educating care providers regarding appropriate monitoring and documentation practices and auditing drug regimen reviews and resident care plans to determine if they incorporate an assessment of the resident’s “medical, nursing, and mental and psychosocial needs,” including the need for psychotropic medications for a specific medical condition.

The attending physicians, the medical director, the consultant pharmacist, and other care providers should collaborate to analyze the outcomes of care using the results of the drug regimen reviews, progress notes, and monitoring of the resident’s behaviors.

Pages 56838 – 39 antipsychotic medications recommended compliance, posted at http://oig.hhs.gov/fraud/docs/complianceguidance/nhg_fr.pdf

Medications that require Notice and Consent under MGL ch. 111, §72BB

The most recent effort to protect for nursing home residents is at [Mass. Gen. Laws ch. 111 §72BB](#). The law requires nursing homes to get consent from a resident, or Health Care Agent or Guardian, before administering psychotropic medication.

Psychotropic (also called psychoactive or psychotherapeutic) drugs contain powerful chemicals that act on the brain to change a person's mood, personality, behavior, and/or level of consciousness.

There are 4 classes of psychotropic drugs: antipsychotic, antidepressant, anti-anxiety, and sedative/hypnotic.

Antipsychotics, listed in the right hand column on page 1 of the *Schedule of Psychotropic Drugs* in Attachment A, have a potentially dangerous, sometimes lethal, impact on the elderly, and have been inappropriately used to control nursing home residents with dementia in Massachusetts and in other states.

Other classes of psychotropic drugs listed on this Schedule of Psychotropic Drugs can also have a serious impact on the elderly.

M.G.L. ch. 111, S 72BB requires informed consent on all of these psychotropic drugs.

As explained in the Department of Public Health Circular Letter: DHCQ 16-2-653, only the *Antipsychotic* drugs require special Probate Court authorization (Rogers) if the patient is under a Guardianship.

Otherwise, a Health Care Agent can authorize any of these medications, including the antipsychotic drugs.

Attachment A
Schedule of Psychotropic Drugs
(Updated August, 2015)

Classes of Medications Frequently Used for Psychiatric Indications (page 1 of 2)

Documentation of Informed Consent is required for any medication that is used in the treatment of a psychiatric diagnosis or symptom, whether or not the medication is included in this list. Refer to physician order for determination of indication for use. (See **Special Considerations Regarding the Use of Antipsychotic Drugs**, discussed on page 2 of Circular Letter DHCQ 16-2-653, above)

Documentation of Informed Consent is still required when a medication on this list is used for an off-label or alternate clinical purpose. Such use does not alter its classification on this list. Note that the generic name is listed first, with the brand name in parentheses.

Antidepressants

amitriptyline (Elavil)
amoxapine (Asendin)
bupropion (Wellbutrin, Wellbutrin SR)
bupropion (Wellbutrin XL)
citalopram (Celexa)
desipramine (Norpramin)
desvenlafaxine (Pristiq, Khedezla)
doxepin (Sinequan)
duloxetine (Cymbalta)
escitalopram (Lexapro)
fluoxetine (Prozac)
imipramine (Tofranil)
maprotiline (Ludiomil)
mirtazapine (Remeron, Remeron SolTab)
nefazodone (Serzone)
nortriptyline (Pamelor, Aventyl)
paroxetine (Paxil, Paxil CR)
protriptyline (Vivactil)
sertraline (Zoloft)
trazodone (Desyrel)
trimipramine (Surmontil)
venlafaxine (Effexor, Effexor XR)
vilazodone (Viibryd)
vortioxetine (Brintellix)

Anxiolytics/Sedatives/Hypnotics

alprazolam (Xanax, Xanax XR)
buspirone (BuSpar)
chlordiazepoxide (Librium)
clonazepam (Klonopin)
clorazepate (Tranxene)
diazepam (Valium)
diphenhydramine (Benadryl)
eszopiclone (Lunesta)
flurazepam (Dalmane)
hydroxyzine (Atarax, Vistaril)
lorazepam (Ativan)
oxazepam (Serax)
pentobarbital (Nembutal)
ramelteon (Rozerem)
temazepam (Restoril)
triazolam (Halcion)
zaleplon (Sonata)

zolpidem (Ambien)

Antipsychotics

aripiprazole (Abilify, Abilify Discmelt)
Aripiprazole (AbilifyMaintena)
asenapine (Saphris)
chlorpromazine (Thorazine)
clozapine (Clozaril, Fazaclor, Versacloz)
Reserve droperidol (Inapsine)
fluphenazine (Prolixin)
fluphenazine decanoate (Prolixin D)
haloperidol (Haldol)
haloperidol decanoate (Haldol D)
iloperidone (Fanapt)
Reserve loxapine (Loxitane)
loxapine inhalant (Adasuve)
lurasidone (Latuda)
olanzapine (Zyprexa, Zyprexa Zydis)
olanzapine pamoate (Zyprexa Relprevv)
Reserve paliperidone (Invega)
paliperidone palmitate (Invega Sustenna)
perphenazine (Trilafon)
pimozide (Orap)
quetiapine (Seroquel)
quetiapine (Seroquel XR)
risperidone (Risperdal, RisperdalM-Tab)
risperidone (Risperdal Consta)
thioridazine (Mellaril)
thiothixene (Navane)
trifluoperazine (Stelazine)
ziprasidone (Geodon)

Stimulants

amphetamine/dextroamphetamine mixture
(Adderall, Adderall XR)
dexmethylphenidate (Focalin, Focalin XR)
dextroamphetamine (Dexedrine)
lisdexamfetamine (Vyvanse)
methamphetamine (Desoxyn)
methylphenidate (Ritalin, Ritalin SR, Concerta, Metadate, Metadate CD)
methylphenidate patch (Daytrana)
methylphenidate soln (Quillivant XR)

Attachment A
Schedule of Psychotropic Drugs
(Updated August, 2015)

Classes of Medications Frequently Used for Psychiatric Indications (page 2 of 2)

Chemical Dependency Adjuncts

acamprosate (Campral)
disulfiram (Antabuse)
naltrexone (ReVia, Vivitrol)
topiramate (Topamax)

Monoamine Oxidase Inhibitors

isocarboxazid (Marplan)
phenelzine (Nardil)
selegiline (Emsam)
tranylcypromine (Parnate)

Miscellaneous Drugs

atomoxetine (Strattera)
atenolol (Tenormin)
clomipramine (Anafranil)
clonidine (Catapres)
clonidine ER (Kapvay)
fluvoxamine (Luvox)
gabapentin (Neurontin)
guanfacine (Tenex)
guanfacine ER (Intuniv)
metoprolol (Lopressor)
nadolol (Corgard)
propranolol (Inderal)
reserpine (Serpasil)
naltrexone (ReVia)
olanzapine/fluoxetine (Symbyax)
pindolol (Visken)
prazosin (Minipress)

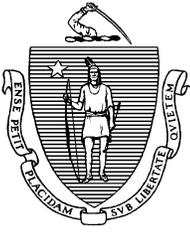
§72BB and Dep't of Public Health February 1, 2016 Circular Letter

Section 72BB says that the nursing home must disclose (i) the purpose for administering a psychotropic drug, (ii) dosage, and (iii) effects or side effects of the medication.

The Department of Public Health issued a Circular Letter on February 1, 2016 explaining how nursing homes and rest home will comply with the statute.

The Department of Public Health Circular also explains how the *Rogers* procedures established in [*Rogers v. Commissioner of Mental Health*](#), 390 Mass. 489, 508 - 509, 458 N.E.2d 308, 320 (1983) (convenience of facility staff is not an acceptable reason for using restraints) are now codified in the Massachusetts Uniform Probate Code, Mass. Gen. Laws ch. 190B, § 5-306A.

The requirements established in *Rogers* were intended to provide patients in Massachusetts with even greater protection than the protections afforded under Federal laws and regulations. See: Smith, "*Just Say No!*" *The Right to Refuse Psychotropic Medication in Long-Term Care Facilities* **13 Annals Health L** 1, 17 – 18 (2004). Do Massachusetts Courts meet the standards in the federal law and regulations?



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Circular Letter: DHCQ 16-2-653

TO: Long-Term Care Facility Administrators

FROM: Eric Sheehan, J.D. Interim Bureau Director
 Bureau of Health Care Safety and Quality

Sherman Lohnes, J.D. Director, Division of Health Care Facility Licensure and Certification

Jonathan M. Mundy, R.Ph, MBA, Director of the Office of Prescription Monitoring and Drug Control

DATE: February 1, 2016

SUBJECT: Informed Consent for Use of Psychotropic Medications in Long-term Care Facilities.

Section 72BB of chapter 111 of the General Laws (Section 72BB) was enacted by section 140 of chapter 165 of the acts of 2014 (FY2015 General Appropriations Act), becoming effective July 1, 2014. This section relates to documentation of informed consent prior to the administration of psychotropic medications, including antipsychotic medications, in Massachusetts-licensed long-term care facilities.

As a Medicare condition of participation, federal law requires that long-term care facilities document informed consent to the extent provided by state law, and Massachusetts long-term care regulations, 105 CMR 150.008(A)(4), require facilities to “comply with all Federal and State laws and regulations relating to the procurement, storage, dispensing, administration, recording and disposal of drugs.”

This circular letter outlines the requirements for long-term care facilities under section 72BB, including guidance for the documentation of informed consent and the provision of a schedule of medications for which these procedures must be completed.

Section 72BB states as follows:

- (a) For the purposes of this section, the term 'facility' shall mean a nursing home, rest home or other long-term care facility.*
- (b) The department shall establish a schedule of psychotropic medications that shall not be administered to a resident by a facility without informed written consent.*
- (c) Prior to administering psychotropic medication listed on the schedule created under subsection (b), a facility shall obtain the informed written consent of the resident, the resident's health care proxy or the resident's guardian. Informed written consent shall be obtained on a form approved by the department, which shall include, at a minimum, the following information: (i) the purpose for administering the listed psychotropic drug; (ii) the prescribed dosage; and (iii) any known effect or side effect of the psychotropic medication. The written consent form shall be kept in the resident's medical record.*

The Department will consider a long term care facility to be in compliance with Section 72BB if the facility has policies and procedures that document the following:

1. Documentation of informed consent for prescribing psychotropic medications (as specified below), including but not limited to, drugs that treat depression, anxiety disorders, or attention deficit/hyperactivity disorder (official Department list included as Attachment A);
2. Appropriate training of staff regarding the *Rogers* requirements (discussed below), including the acknowledgment that, consistent with *Rogers*, guardians may not consent to the administration of antipsychotic medications.

In order to meet Section 72BB's requirements for documentation of informed consent, upon administration of any drug included on the Schedule of Psychotropic Medications (Attachment A), long term care facilities must complete the Department's prescribed form (Attachment B), and include the completed form in the resident's medical record. This form will demonstrate that the following were discussed with the resident or the resident's representative:

- (i) the purpose for administering the listed psychotropic drug;
- (ii) the prescribed dosage; and
- (iii) any known effect or side effect of the psychotropic medication.

While prescribers are not required to complete this process each and every time a resident is administered a dose of psychotropic medication, such procedures are required each time a new or renewed prescription falls outside the dosage range to which the resident or the resident's representative previously consented, or once a year, whichever is shorter.

Special Considerations Regarding the Use of Antipsychotic Drugs

The Department previously issued guidance on the consent requirements for the use of antipsychotic drugs. See Circular Letter DHCQ 03-04-433, issued in 2003, which is available at <http://www.mass.gov/eohhs/docs/dph/quality/hcq-circular-letters/ltc-facilities-0304433.pdf>. As noted, a valid health care proxy (HCP) (see M.G.L. c. 201D), also referred to as a Health Care

Agent, can consent to antipsychotic drugs without having to obtain a court-approved treatment plan required under *Rogers v. Commissioner of the Department of Mental Health*, 390 Mass. 489, 458 N.E.2d 308, (1983), if the following three conditions are met:

- (1) the health care proxy is activated by a physician after a determination that the resident is incompetent;
- (2) the resident has not limited the HCP agent's authority to consent to treatment with antipsychotic medications on the HCP form; and
- (3) the resident has not revoked or indicated an intent to revoke the HCP, for example, the resident has not refused to accept antipsychotic medication.

Please note that the above applies only to antipsychotic medications; a guardian or health care proxy can consent to other psychotropic medications. Antipsychotic medications are indicated separately on the Schedule of Psychotropic Medications (Attachment A). Please note that documentation of informed consent must be completed prior to administration of any medication appearing on the list.

In *Rogers*, the court established new rights relative to informed consent for individuals being treated with antipsychotic medications. Among these are that an individual has a constitutional right to refuse treatment with antipsychotic medications; that a guardian must be appointed for an individual following a determination that he or she is incompetent to consent to treatment; that the court must use a substituted judgment test comprised of six factors before authorizing a treatment plan; and that a guardian cannot make decisions about the use of antipsychotics because use of such medications is considered extraordinary treatment, but rather can monitor the implementation of the court-ordered treatment plan. In using the substituted judgment analysis, the court tries to recreate what an incompetent individual would choose if he or she were competent. The substituted judgment standard is now codified in the Massachusetts Uniform Probate Code, at M.G.L. c. 190B, § 5-306A. The court relies on a medical affidavit from the treating psychiatrist, or his or her testimony, as evidence in determining an individual's substituted judgment and treatment plan. Each *Rogers* treatment plan must be reviewed annually.

Rest Home Compliance

Facilities are reminded that 105 CMR 150.008 sets forth detailed requirements for the record-keeping, supervision, administration, labeling, and storage of all medication. Notwithstanding the language in Section 72BB that purports to treat rest homes and skilled nursing facilities in the same manner, Level IV facilities should refer to 105 CMR 150.008(C)(2) for the limited circumstances in which medications may be administered in a rest home, while complying with relevant procedures set forth in this letter.

Contact

If you have any questions about this guidance, please contact the Bureau of Health Care Safety and Quality, Division of Health Care Facilities Licensure and Certification, at sherman.lohnes@state.ma.us.

§72BB Notification Form

The Informed Consent Form promulgated on February 1, 2016 includes the statement "*it is possible that little or no adverse consequences may occur if the medication is administered.*" The statement is printed under "Risks" on the notice form, alongside the box where black box warnings should be listed by the facility. Will this statement detract from patient understanding or comprehending the significance of the black box warnings?

**Attachment B
Informed Consent Form**

This consent form shall be kept in the resident's medical record.

| | |
|---|-----------------------------------|
| [Facility Name] CONSENT FORM FOR PSYCHOTROPIC ADMINISTRATION | (Affix resident information here) |
|---|-----------------------------------|

| | |
|--|--|
| NAME OF RESIDENT | |
| DATE OF DISCUSSION | |
| FACILITY REPRESENTATIVE NAME | |
| FACILITY REPRESENTATIVE TITLE | |
| LAST REVIEWED BY FACILITY | |
| MEDICATION PROPOSED/PRESCRIBED (Only one medication per form) | |
| DOSAGE RANGE | |
| PURPOSE OF MEDICATION | |
| RISKS (These risks may vary; and it is possible that little or no adverse consequences may occur if the medication is administered) | |
| BENEFITS (These benefits may vary; and it is possible that little or no adverse consequences may occur if the medication is not administered) | |

Please indicate if resident or resident's representative refused consent.

By checking here and by my signature below, I give consent for the above named medication and anticipated dosage range. My signature also indicates that I understand the above listed risks and benefits of the medication. If the proposed medication is on the anti-psychotic list, evidence of substituted judgment may be required.

Signature of Resident or Resident's Representative

Date

MGL ch. 201D: Health Care Agent authority to administer antipsychotics.

April, 2003 Department of Public Health Circular with Frequently Asked Questions Concerning the Use of Antipsychotic Medications in Long-term Care Facilities.



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CIRCULAR LETTER: DHCQ 03-04-433

TO: Long Term Care Facility Administrators
FROM: Paul Dreyer, Ph.D., Director
DATE: April 4, 2003
SUBJECT: Frequently Asked Questions Concerning the Use of Antipsychotic Medications in Long-term Care Facilities.

Attached for your information is a series of questions and answers concerning the use of antipsychotic medications in Massachusetts's nursing homes. Please contact Donna Allen at 617-753-8106 or Sondra Korman at (617) 624-5220 if you have questions.

**FREQUENTLY ASKED QUESTIONS: TREATMENT OF LONG-TERM CARE FACILITY
RESIDENTS WITH ANTIPSYCHOTIC MEDICATIONS**

Introduction

Massachusetts's courts recognize a general right of all individuals to control medical treatment decisions, including the right to refuse medical treatment. This right extends to both competent as well as incompetent individuals. The laws governing the administration of anti-psychotic medications are designed to ensure that these legal principles are honored to the greatest extent possible.

Federal and state law governing long-term care facilities specifically prohibit the use of antipsychotic drug therapy for residents without the informed consent of the resident or appropriate legal decision-maker. Further, antipsychotic medication treatment may not be administered unless medically necessary to treat a specific condition and in accordance with a written treatment plan designed to discontinue the medications if possible. Consent to treatment is relatively easy to obtain when the resident is able to understand treatment choices and make an informed decision as to whether to accept antipsychotic medications. The difficult issues and potential legal problems arise when residents lack the ability to provide informed consent due to mental and/or physical impairments and facilities attempt to determine who, if anyone, is the appropriate legal decision-maker for the resident. The following outline addresses commonly asked questions and provides guidance to facilities in resolving these legal issues.

1. Can a resident's health care agent consent to treatment with antipsychotic medications?

Yes. In accordance with an Attorney General's informal opinion, the designated health care agent has the authority to make all health care decisions, including treatment with antipsychotic medications, without court intervention if:

- 1) the resident has signed a valid health care proxy;
- 2) the attending physician has determined that the resident lacks the capacity to make or communicate health care decisions, made an entry in the medical chart of that determination noting the cause and nature and extent and duration of the incapacity, and notified the agent, orally and in writing, of that determination;
- 3) the resident has not limited the agent's authority to consent to treatment with antipsychotic medications on the health care proxy form; and
- 4) the resident has not revoked or indicated a specific intent to revoke the health care proxy

Please note that a refusal to accept antipsychotic medication may indicate an intent to revoke the health care agent's authority. In such situations, the facility should take steps to obtain court authority to treat. See Question No. 5.

The following questions assume that a resident has not executed a valid health care proxy:

2. Under what circumstances can the facility administer antipsychotic medications to a resident if that resident has not been declared "incompetent" by a court of law?

The Attorney General's regulations governing long-term care facilities make it clear that the focus of the inquiry should be on the resident's ability to provide informed consent, not on whether the resident has been "adjudicated incompetent" by a court.

Case 1: If that resident has the ability to make an informed decision as to treatment with antipsychotic medication and the resident has consented to such treatment, the facility can administer antipsychotic medication to the resident in accordance with a written treatment plan.

Case 2: If a clinical determination has been made by a physician or psychiatrist that the resident lacks the ability to provide informed consent, the facility must take the necessary steps to seek court authority to treat with antipsychotic medication (even if the resident is accepting the medication).

3. Can a family member consent to treatment with antipsychotic medications on behalf of a resident who lacks decision-making capacity?

No. A specific probate court proceeding (commonly referred to as a Rogers hearing) is necessary before the facility may legally administer antipsychotic medication to an individual who lacks the ability to give informed consent. As more fully described above, court authority may not be required if the family member is the resident's health care agent. See Question No.1.

4. If the resident has a legal guardian, can the legal guardian consent to treatment with antipsychotic medications?

No. A legal guardian has the authority to consent to routine and customary (as opposed to extraordinary) medical decisions, including admissions to nursing homes and hospitals. In the 1983 Rogers v. Commissioner, Department of Mental Health decision, the Massachusetts Supreme Judicial Court ruled that the administration of antipsychotic medication is "extraordinary treatment" and that consent to such treatment can not be delegated to a resident's legal guardian. Rather, court authorization to treat with antipsychotic medications is required and typically, the court will direct the guardian to monitor such treatment ("the Rogers Monitor"). In order to determine what, if any, court action is required, the guardianship decree should be reviewed to determine whether the court has authorized treatment with antipsychotic medications.

5. How does a facility obtain specific court authority?

If a resident lacks the capacity to give informed consent and does not have a valid health care proxy, the facility must file a probate court guardianship petition seeking specific authorization to treat with antipsychotic medications. Generally, this request is combined with the initial guardianship petition. In cases where a guardian is already in place but there is no court order authorizing treatment with antipsychotic medications, the facility must seek such an order from the court through a General Petition.

The court appoints an attorney to represent the resident in this proceeding. After interested parties receive notice, the court holds a hearing to determine 1) whether the person is incompetent to make treatment decisions and, if so, 2) whether the individual would accept treatment with antipsychotic medications if he/she were competent to so choose (commonly referred to as the "substituted judgment" determination). The facility's physician is required to submit a proposed treatment plan and an affidavit which contains information on the substituted judgment factors: the expressed wishes of the resident; the resident's religious beliefs; the impact of the treatment on the resident's family; the side effects; the risks and benefits of the proposed treatment, and the prognosis with and without the treatment. If the evidence warrants treatment, the court will issue an order specifically authorizing the medical provider to treat the individual with antipsychotic medications in accordance with a written treatment plan. Generally, courts appoint the resident's legal guardian as the "monitor" of the treatment plan. The guardian/monitor has the responsibility to assess the usefulness of the treatment and may be required to report to the court regarding this treatment.

6. How long do treatment orders last?

Because the law views antipsychotic drug therapy as highly invasive treatment, each court-approved treatment order contains a court review date (generally on an annual basis) and an expiration

date. The facility must ensure that the treatment plan reviews are conducted in accordance with the court order. Additionally, the facility must request that the court amend the treatment plan if the medical provider determines that the resident requires an antipsychotic medication not listed as an alternative on the treatment plan.

SUMMARY

Antipsychotic medications may be administered in the following ways:

1. With the informed consent of the resident and in accordance with a written treatment plan; or
2. With the consent of a health care agent under the authority of a valid health care proxy; or
3. In accordance with a court-approved Rogers treatment plan, and appointment of a Rogers Monitor.

References:

Federal Law

42 CFR 483.10(a)(4)

42 CFR 483.75

42 CFR 483.25(l)(1)(2)

State Law

M.G.L.c. 201, §§6 et seq.

M.G.L.c. 201D, §§1 et seq.

105 CMR 150.002(A)(2) (Department of Public Health Licensing)

940 CMR 4.08(18)(19) (Consumer Protection--Governing Long-Term Care Facilities)

Case law

Rogers v. Commissioner of the Department of Mental Health, 390 Mass. 489, 458 N.E.2d 308 (1983)

Guardianship of Weedon, 409 Mass. 196, 565 N.E. 2d 432 (1991)

Letter from Barbara Anthony, Chief, Public Protection Bureau, Office of the Attorney General to Alex Moschella, Esq., July 24, 1997

Attorney General's 1997 Letter on LTC Facility Regs: 940 CMR 4.08 (18)(19)



SCOTT HARSHBARGER
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Office of the Attorney General
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July 24, 1997

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Dear Attorney Moschella:

This letter is in response to the question raised at the National Academy of Elder Law Attorneys Massachusetts Chapter program in April regarding whether, under Rogers v. Commissioner of the Department of Mental Health, the caretaker of an incompetent patient is required to obtain a court order prior to administering prescribed antipsychotic medication, even if: (1) the incompetent patient had previously appointed an authorized health care agent pursuant to G. L. c. 201D [The Health Care Proxy Act]; (2) the agent has consented to the medication on the patient's behalf; and (3) the patient has not objected to or refused the medication. It is our understanding that there has been some confusion among the elder law practitioners as to how to interpret the Attorney General's long term care facility regulations 940 CMR 4.08 (18) and (19), when this issue arises. While this letter does not serve as a formal published opinion of the Attorney General, which may only be issued pursuant to specific statutory authority not applicable here, in the interest of addressing a matter of significant concern to elders and long term health care providers, we offer the following informal clarification.

in Rogers, the Supreme Judicial Court held that before antipsychotic drugs could be administered to an incompetent patient, counsel and a guardian must be appointed for the patient and the court must then determine what the incompetent patient's desires would have been, had he or she been competent to consent on his or her own behalf. If the court determines the patient would have consented to the medication, the court is required to establish a treatment plan and a treatment-monitoring mechanism as well. The underlying purpose of a Rogers hearing is to protect incompetent patients

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from forcible treatment in circumstances where the patient would refuse the treatment were he or she competent to do so.

As you know, the Legislature enacted the Health Care Proxy Act seven years after the Rogers decision as a way of providing individuals with the means for maintaining control over medical decision-making in the event that they should become incapacitated. In cases involving a validly executed health care proxy, the person selects a substitute decision maker who is thereby legally authorized to represent the principal's own health care decision-making rights. The statute lays out specific requirements that must be fulfilled before a health care agent can exercise his or her authority on behalf of the patient. Specifically, the law requires that the health care agent must consult with all of the principal's health care providers and must fully consider all acceptable medical alternatives regarding the principal's diagnosis, treatment and side effects. M.G.L. c. 201D, § 5. The law also requires that the agent consider the principal's wishes, if known – including the principal's religious and moral beliefs – or, if the principal's wishes are unknown, in accordance with the agent's assessment of the principal's best interests. Id. Under the law, every person has the right to exercise informed consent and appoint a health care agent by executing a valid health care proxy while he or she is competent. Moreover, a principal may revoke a health care proxy at any time by any act evidencing a specific intent to revoke the proxy.

We believe Chapter 201D, in all significant respects, establishes standards that are consistent with the Rogers requirements for both informed consent by the patient and for substitution of judgment by the health care agent. As set forth in Rogers, the factors to be considered by a judge in determining whether a judicial "substituted judgment" decision is required include: (1) the patient's expressed preferences regarding treatment; (2) the strength of the patient's religious convictions; (3) the impact of the decision on the patient's family; (4) the probability of adverse side effects; (5) the patient's prognosis without treatment; (6) the patient's prognosis with treatment; and (7) any other factors which appear relevant to the determination. 390 Mass. at 505-506. These factors coincide with the requirements that a health care proxy agent must consider in making health care decisions for a principal pursuant to the Health Care

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Proxy Act. M.G.L. c. 201D, §§ 5 and 6. Because a decision made by an authorized health care agent provides the patient with the same type of protection a Rogers hearing is designed to provide, we conclude that an authorized health care agent may consent on behalf of an incompetent patient to the administration of antipsychotic medication without a Rogers hearing.

We note that, in the Attorney General's view, a consent to antipsychotic drugs on behalf of an incompetent patient made by an authorized health care agent will only eliminate the need for a Rogers hearing if the patient does not in any way indicate a contrary decision. When a patient refuses or objects to the administration of antipsychotic medications, we believe that a court-ordered substituted judgment is required, whether or not the patient has a valid health care proxy. M.G.L. c. 201D, § 7, permits the principal to revoke his or her proxy "by notifying the agent or a health care provider orally or in writing or by any other act evidencing a specific intent to revoke the proxy." Refusal to accept medication may be deemed a revocation of the proxy and would, therefore, void any consent previously given by the agent. Moreover, an incompetent patient without a health care proxy always requires a Rogers hearing, regardless of whether the patient will accept the proffered medication, because he or she is incapable of giving consent and has not previously designated a proxy to do so on his or her behalf.

I hope that this letter offers some assistance in your work. The intent of the Attorney General's long term care regulations is to protect patients covered by Rogers. However, we see no benefit to patients in interpreting the regulations in a way that both effectively deprives an incompetent patient of his or her right to have an authorized health agent chosen by the patient make decisions on the patient's behalf and imposes delay and expense on an incompetent patient without adding any protection to the patient's interests.

In light of this letter, the Attorney General would be very interested in working further with the private bar to (1) encourage the use of health care proxies, especially prior to nursing home admissions; (2) educate the general public about the specific

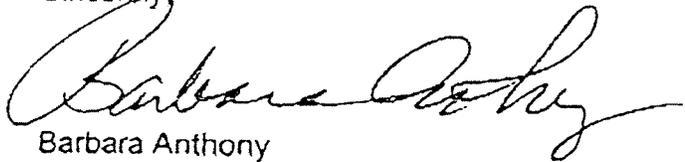
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issues raised by Rogers and the use of antipsychotic drugs; and (3) ensure compliance with the long term care facility regulations. Please do not hesitate to contact me at the number below if you wish to discuss this matter further. Thank you.

Sincerely,



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(617) 727-2200, ext. 2925

cc: Kenneth A. Behar, Esq., Behar & Kalman
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Scott Plumb, Massachusetts Extended Care Federation
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Should your client restrict or limit their Health Care Agent's authority?

The Health Care Proxy form commonly used in Massachusetts includes a section where clients can list exceptions to the authority granted to a Health Care Agent.

Disability Rights of California has prepared an Advance Directive Completion Checklist and an Individual Health Care Instruction Worksheet that lists topics of concern that clients may want to consider.

http://www.disabilityrightsca.org/pubs/540701.htm#_Toc122837747

This worksheet is intended to help clients complete the Advance Health Care Directive form, with questions to help think through some of the decisions you may want to make about your physical and mental health treatment.



Among the topics are: *Medications*. The client could be asked:

1. What are the medications you are currently taking? How often? At what dosages?
2. Do you want to take medication in the hospital? ----- Yes / No
3. What kinds of medication would you prefer if you were hospitalized? Which medications? At what dosages?
4. Are there medications you would not want under any circumstances?
5. What time of day do you prefer to take medication?

But, query: what if antipsychotic medications would benefit a patient who had listed antipsychotics among the medications he/she would not want under any circumstances? Would the listing of specific exceptions force the client/patient into costly and otherwise unnecessary Probate Court proceedings? Does this possibility suggest that the Agent be given general authority without exceptions, so that decisions can be based on what the person would have wanted under the circumstances?

The Alternative to drugging memory loss patients: understand the Symptoms of Memory Loss, and how to respond.

Attorneys who are familiar with stages of memory loss can help families avoid the need for drugs, and better advocate for the client/incapacitated person when filing Rogers guardianships or amending Rogers Orders/treatment plans.

STAGE 1 – EARLY



SYMPTOMS and EXAMPLES

Recent memory loss affects performance: Forgets grocery list, May get lost

Vague complaints: Headache when forgets, “Something is wrong”, “I’m going crazy”

Less tolerant/angry: Upset with family visits, Cannot tolerate children

Less energy: Frequent naps, Sighs often

No initiative: cannot self start, Seems disinterested

No longer does routine tasks: cooking

Slow to learn/react: May not respond to question or request, Forgets what is just told, Asks, “What was I doing again?”

Loss of spontaneity or zest: Seems apathetic or down in the dumps, Seems less outgoing

Mood/personality change: Does not seem like himself

Takes longer with tasks: Especially ADLs, Difficulty following recipes

Poor judgment, Makes poor decision driving, Leaves the stove on

Difficulty with money and calculation: Does not pay bills, Pays bills twice

May become suspicious or paranoid; Accuses people of taking things, Calls the police

Difficulty thinking abstract thoughts: Cannot interpret proverbs, Difficulty balancing the checkbook

STAGE 2 – MIDDLE



SYMPTOMS and EXAMPLES

Needs assistance in many areas: Needs help bathing, Needs help with eating

Difficulty understanding, planning, concentrating, deciding; becomes lost in conversation

Cannot follow through on tasks

Becomes frustrated with choices

Slow to react or overreacts: May look faraway when spoken to

Becomes angry with simple request

Unable to cope with failure Feels hopeless when makes mistakes

Self-absorbed, Lacks empathy

Increased memory loss and confusion, May not recognize family members
 Communication greatly impaired
 Difficulty organizing thoughts: Talks nonsense, Uses made up words
 Has trouble expressing needs: May not be able to state when in pain
 May begin to wander: Looks for something familiar; Disoriented to time/place/self; May not be aware of where is living
 May think it is a different year
 May think is much younger than actual age
 Inappropriate behavior: Wears 3 shirts at once
 Unable to recognize familiar: May wish to go home when already at home
 Repetitive statements or movements: Repeats questions consistently
 Perception/motor difficulties: Difficulty sitting on a chair, Steps over change in flooring pattern
 Less impulse control: Swears, Hits others
 Delusions and hallucinations: Believes he/she is still employed, Sees things that are not there

STAGE 3 – LATE



SYMPTOMS and EXAMPLES

Needs assistance in many areas: Needs help bathing, Needs help with eating
 Difficulty understanding, planning, concentrating, deciding:
 Becomes lost in conversation
 Cannot follow through on tasks
 Becomes frustrated with choices
 Slow to react or overreacts: May look faraway when spoken to
 Becomes angry with simple request: Unable to cope with failure,
 Feels hopeless when makes mistakes
 Self-absorbed: Lacks empathy

Increased memory loss and confusion: May not recognize family members
 Communication greatly impaired
 Difficulty organizing thoughts: Talks nonsense, Uses made up words
 Has trouble expressing needs: May not be able to state when in pain
 May begin to wander: Looks for something familiar, Disoriented to time/place/self, May not be aware of where is living
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 Perception/motor difficulties: Difficulty sitting on a chair, Steps over change in flooring pattern
 Less impulse control: Swears, Hits others
 Delusions and hallucinations: Believes he/she is still employed, Sees things that are not there



Agitation in Older Adults

by Helen H. Kyomen, MD, MS and Theodore H. Whitfield, ScD

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Dr. Whitfield is a biostatistician in the department of psychiatry at Massachusetts General Hospital.

<http://www.psychiatrictimes.com/display/article/10168/1166790>

Agitation in older adults is frequently associated with multiple psychiatric and medical conditions and comorbidities. It commonly occurs in patients with anxiety, affective illness, psychosis, dementia, stroke, brain injury, delirium, or pain, and in those who misuse psychoactive medications or other substances. Optimal treatment strategies to reduce or prevent agitation in older adults encompass a multidisciplinary model that used nonpharmacological and pharmacological/somatic approaches. In this article, we discuss clinical approaches for evaluating and managing agitation in older adults.

Defining and determining causes of agitation



To focus treatments appropriately, it is important to specifically define the target signs or symptoms that are being labeled as “agitation.” Agitation is a nonspecific concept that broadly encompasses various activity disturbances such as those delineated on the next page.

Specifying the actual behavior is especially important so that all treatment team members can be consistent in their understanding and subsequent approach to and treatment of the patient. For example, it is difficult to devise an effective treatment plan for agitation if some staff members refer to a patient’s combativeness as agitation, and other staff members use the term agitation to describe the same patient’s hypersexual behaviors. If each type of agitation is defined, a focused plan to manage, monitor, and evaluate the progress of each unique behavior can be developed.

Once the behavioral target signs and symptoms are identified, the next step is to determine their causes in order to formulate appropriate multidisciplinary interventions. A clinically relevant way to categorize causes is to first identify the circumstances antecedent to the behavioral target signs and symptoms that trigger the agitation and then to identify the illnesses or pathological conditions that exacerbate the agitation.

Types of activity disturbances often referred to as agitation in the elderly

Purposeless hyperactivity (intrusive pacing or restless repetitive demands and behaviors)

Wandering away from home or other protected environments

Exhibiting socially and functionally inappropriate or aggressive behaviors (eg, disinhibited screaming, grabbing, throwing, sexual advances, or suicidal gestures)

Resistance to care (such as combativeness with personal or other nursing care; refusal of needed medications, food, or fluids); or declining to participate in necessary diagnostic procedures, such as blood draws, urine collection, or radiological studies)

Sleep-wake cycle disturbances

Circumstances antecedent to episodes of agitation

Is there Overstimulation?

Does the patient have a roommate who intrudes into the patient's personal space excessively?

Is the patient's space overly noisy because of equipment (such as oxygen concentrators or ventilators) or individuals who call out incessantly?

Are staff members rushing in and out of the patient's area as they change shifts?

Are the day programming, activities, and structure appropriate to the patient's functional capabilities?

Understimulation?

Is the patient occupied with appropriately challenging tasks that encourage interest and a sense of mastery?

Is the patient exposed to adequate amounts of sensorimotor stimulation?

Do people or objects trigger stressful memories, drives, or feelings?

Does the patient believe that a family member is responsible for the patient's placement in an extended-care facility?

Does the patient think that a friend who comes to visit at the hospital is able to take him or her home?

Is the patient troubled by a roll belt or other safety restraint?

Are there unmet needs?

Is the patient hungry or thirsty?

Does the patient need to be oriented to the facilities or be toileted?

Does the patient need glasses, hearing aids, or similar sensory enhancers?

Overlooked causes of pain and discomfort that may exacerbate agitation

Psychiatric disorders (such as anxiety, mania, depression, psychosis, and dementia) and somatic conditions (such as stroke, brain injury, delirium, pain, discomfort, and adverse effects of medications) have all been implicated in exacerbating agitation. Common disorders, separately or in combination, that may co-occur with psychiatric conditions and cause acute pain and discomfort, and may contribute to delirium, are:



Arthritis
Constipation
Diarrhea
Urinary Tract Infection
Vaginal yeast infections
Decubitus ulcer
Tinea

Gastro esophageal reflux disease
Headaches
Muscle Aches
Dental problems
Podiatric conditions
Low vision
Hearing Loss

These conditions are more likely to contribute to agitated behaviors in patients with underlying dementia, partly because such persons have an impaired ability to obtain help for pain or discomfort through coherent conversation.

Common disorders (eg, arthritis, hearing loss) are often overlooked because of their chronic nature or because of difficulties in the patient evaluation (eg, difficulty of obtaining a clean-catch urine specimen for cultures and sensitivities from a resistant patient). Iatrogenic causes, such as diuretics given at bedtime rather than early in the day, a rebound effect from a sedative or hypnotic dose reduction or discontinuation, and paradoxical disinhibiting reactions from benzodiazepine use can also exacerbate agitation.

Thorough evaluation of the patient's physical condition is essential so that agitation exacerbated by such disorders is not mistakenly attributed entirely to psychiatric illness and treated primarily with psychotropic medication.

Psychiatric Conditions Associated With Agitation In The Elderly

Here are some psychiatric conditions that may contribute to agitation.

- Psychosis (paranoia, hallucinations)
- Affective illness (especially mania)
- Anxiety
- Delirium
- Psychotic Or Mood Disorder Related To A General Medical Condition
- Dementia



with dogs was found to decrease agitated behaviors and enhance socialization in patients with dementia.⁹⁻¹¹ A preliminary study showed that interacting with a therapeutic robotic cat decreased agitation and increased pleasure and interest in nursing home residents with dementia.¹² Although the effects of animal-assisted activities and therapy on agitated behaviors in the elderly are promising, the duration of beneficial effect, the relative benefits of dogs residing on a special care unit for patients with Alzheimer disease versus visiting the patients, and the confounding effects of animals on caregivers are unclear.⁹

Preliminary studies suggest that tender touch, hand, and slow-stroke massage may help reduce agitation and improve well-being in older adults with dementia.^{4,13-16} Although limited, the available information is in favor of touch and massage therapy for behavioral disturbances in patients with dementia; however, definitive evidence about their benefits and adverse effects is lacking.¹⁷

Simulated presence therapy is an individualized therapy that uses voice recordings to suggest the presence of meaningful persons and evoke associated positive emotional experiences in patients with memory loss. Simulated presence therapy seems to decrease overall agitation and withdrawn behavior in patients with dementia, but the number and quality of studies evaluating this therapy are limited.¹⁸⁻²⁰ One recent small study compared simulated family presence therapy with preferred music therapy and found that both were effective in reducing the frequency of physical agitation, that simulated presence but not preferred music decreased the frequency of verbal agitation, and that although behavioral incidents fell by one-half or more in many patients, others became more agitated.²¹

Light therapy uses time-limited, daytime-specific exposure to daylight, certain wavelengths of light, or full-spectrum light to treat various conditions including depression, seasonal affective disorder, and sleep disturbances. Agitated behaviors and sleep disturbances in older adults with dementia have been linked to abnormal circadian rhythms caused, in part, by a lack of exposure to light. Light therapy has been used to treat disruptive behaviors in dementia patients with variable short-term success, and it may be more effective in those with milder dementia.²²⁻²⁵

Multisensory stimulation or Snoezelen is an approach that “actively stimulates the senses of hearing, touch, vision, and smell in a resident-oriented, nonthreatening environment. It is intended to provide individualized, gentle sensory stimulation without the need for higher cognitive processes, such as memory or learning, in order to achieve or maintain a state of well-being.”^{26,27} When integrated as part of 24-hour care in nursing home residents with dementia, it was found to be effective in reducing agitated behaviors over an 18-month period.^{26,28} However, a session-based Snoezelen program did not show any effects on behavior disturbances during or just after the sessions or at a 1-month postintervention evaluation.²⁹

Validation therapy was developed for the elderly with cognitive impairments and is based on the concept of validation, the acceptance of the patient's reality and personal experience. Preliminary studies suggest that validation therapy helps decrease behavioral disturbances and depression in older adults with dementia.³⁰ A recent case-control study suggests that validation therapy reduces the severity and frequency of behavioral and psychological symptoms of dementia.³¹ However, there is inadequate evidence from randomized trials to allow definitive conclusions about the efficacy of validation therapy.³⁰

Behavioral and milieu management skills for caregivers emphasize respectful redirection, positive expressions of concern, and an appropriate approach to the patient. Such programs have been shown to effectively reduce patient agitation.³²⁻³⁴ When compared to information and support-oriented interventions for caregivers, skill-building interventions reduced caregiver emotional distress more over 18 months.³⁵ The available data suggest that caregiver-skills training may be an effective way to prevent and reduce agitated behaviors in elderly patients and improve the caregivers' sense of mastery while decreasing stress.

Pharmacological interventions: understanding some of the antipsychotic medications that are commonly prescribed

When nonpharmacological strategies fail to effectively manage agitation, pharmacological treatment may be indicated. If there are clear psychiatric conditions, and target symptoms that accompany the agitation, patients are likely to be responsive to psychotropic medication. Benefit-to-risk ratio should be evaluated in choosing pharmacological interventions, and informed consent from the patient and/or legal surrogate should be obtained and documented.



Agitated behaviors have been commonly treated with typical and atypical antipsychotics, mood stabilizers, sedative/hypnotics, and/or nootropic agents; other pharmacological interventions include serotonergic agents, b-adrenergic blockers, and hormonal therapies.^{36,37} Antipsychotics are the best studied and have been shown to modestly impact agitation. However, recent studies have questioned their effectiveness and demonstrated an increased risk of death with the use of both typical and atypical antipsychotics.

Current FDA black box warnings that caution against the use of atypical antipsychotics in older patients, especially those with dementia, may have diminished the enthusiasm for their use, even in patients who exhibit clear psychotic signs and symptoms in addition to agitation.³⁸⁻⁴¹ The use of nootropic agents, promoted as a first-line treatment for agitation in dementia, also came under greater scrutiny as recent evidence showed limited efficacy of donepezil for the treatment of agitation in patients with Alzheimer disease.⁴²

There is little evidence for the efficacy of anticonvulsants, lithium, or b-blockers for treating agitation in dementia. Because these medications have significant adverse effects, they are not recommended except for patients in whom other treatments have failed.⁴³ Trazodone and serotonergic agents have not been well studied, except for treatment of depression. However, they may be appropriate for nonpsychotic, mildly agitated patients.⁴³ Benzodiazepines may be helpful, as needed, for agitation. Those with short half-lives and no active metabolites, such as lorazepam or oxazepam, are preferred.⁴³



In the light of limited evidence-based literature to support the use of psychotropic medications in the treatment of agitation, the decision about which medication to use should be determined largely by the patient's unique needs and characteristics, the adverse-effect profile of the medication, and the benefit-to-risk ratio of treating versus not treating with a given medication.⁴³

Conclusions

Agitation in older adults is a complex syndrome associated with multiple psychiatric and medical conditions and comorbidities. Despite its impact on elderly patients, caregivers, and health care costs, there is much that is unclear about the causes, prevention, and treatment of agitation. Yet, clinical interventions that use individualized, multidisciplinary best-practice approaches are routine. Further investigation to develop new interventions and more rigorously test existing ones is needed.

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Managing Behaviors By Meeting Basic Human Needs

What quality of life issues should an attorney be looking for when reviewing a proposed treatment plan? In *Dementia Reconsidered: The Person Comes First*, Tom Kitwood defines five basic human needs.

The goal of care partners for people with Alzheimer's Disease is to create an environment where the basic human needs are met, and many of the common behaviors of the dementia process can be managed.

These 5 Basic Human Needs are:

Inclusion: need to be part of a larger group, such as being members of a church, community club or workplace.

Occupation: Being occupied, or having a task, is meaningful and draws on a person's abilities and strengths, such as succeeding at a career, providing for a family or being a homemaker all satisfy this need.

Attachment: The need to bond with another person is an innate need, it helps one feel safe.

Comfort: The need to feel tenderness, closeness, soothing of pain and sorrow, and feeling of security.

Identity: Each person creates and presents a unique identity and is then affirmed by others when they connect about interests, hobbies and life stories.

<http://www.amazon.com/Dementia-Reconsidered-Person-Comes-First/dp/0335198554>

Habilitation Therapy by Paul Raia, Ph.D.

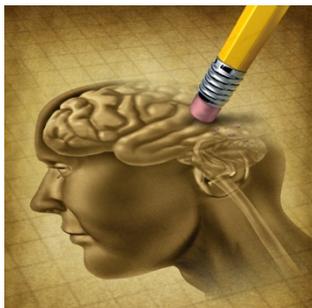


Vice President, Clinical Services, Alzheimer's Association, MA/NH Chapter. First published in *Enhancing the Quality of Life in Advanced Dementia* (1998).

Knowledge often depends on how we define what we want to know. Before Galileo, astronomers claimed the sun revolved around the Earth, defining Earth, and man, as the center of the cosmos.

Old world view of the disease: inevitable loss

Until recently, it could be said that the life of the person with Alzheimer's disease was defined as revolving entirely around inevitable loss—sun around Earth. This shortsightedness permeates several common, broad “definitions” of Alzheimer's disease. It has led not only to different response to the disease, but to dramatically different approaches to care.



The first view is essentially no definition at all. Memory loss, confusion, and disorientation occurring later in life are considered just facets of normal aging. And because these symptoms are “normal,” no specific approach to care is needed.

A second, and equally disturbing, definition tends to see Alzheimer care as a backwater, a low-technology area of medicine and professional caregiving with minimal challenges and scant rewards. The emphasis here is on palliative care—that is, providing basic comfort as patients wait to die.

The third definition emphasizes that Alzheimer's disease is a disease for which there is no cure and no treatment. Hence, our only hope to alleviate the pain and suffering associated with the disease process is to devote all of our resources to biomedical research. The violable quest for the “magic pill” obscures the need for new ways to better manage symptoms of the disease in those who are presently afflicted. Although a cure is nowhere in sight, the paradigm holds enormous power among professionals and the public at large.

A new way to look at the disease: progressive disability.

In contrast, another view of Alzheimer's disease and related disorders has emerged, in which these diseases are defined more as disabilities, albeit caused by progressive and fatal neurological illness. In this view, individuals respond to their

disease according to how supportive their environments are. Here, the emphasis is on active treatment of the symptoms of the dementia through a careful focus on the utilization of those capacities that remain, particularly the person's psychological capacity.



Developing a better understanding of the psychology of dementia—how a person thinks, feels, communicates, compensates, and responds to change, to emotion, to love—may bring some of the biggest breakthroughs in treatment.

This new paradigm has led to a radically different orientation to dementia care—a called habilitation, first discussed by Raia and Koenig-Coste in 1996. Drawn for the most part from the common experiences of professional and family caregivers, habilitation is more a disposition, or a way of thinking, than a complete therapeutic model. It reflects the humanistic perspective of psychologist Abraham Maslow (1968), meaning that habilitation starts with premise that there is an innate drive in all people to maximize their potential, even, as we would apply it, if the person is afflicted with a dementing illness.

The aim of habilitation therapy is not to restore people with a dementia such as Alzheimer's disease to what they once were (i.e. rehabilitation), but to maximize their functional independence and morale. This approach also allows minimization or elimination of many difficult symptoms of the dementia in spite of the person's progressive physical, cognitive, and emotional illness.

For caregivers, the primary learning task becomes how to value what is still there and not dwell on functions the person has lost. To borrow from the philosopher Erich Fromm (1976), family and professional caregivers need to emphasize "being" rather than "having." This model is no cure. But it is a system of treating symptoms that can benefit both the person with Alzheimer's disease and the caregiver.

Realigning the Planets: maintain positive emotional state.

The goal of habilitation is deceptively simple—to bring about a positive emotion and to maintain that emotional state over the course of the day. Clinically, however, it presents a challenge. If cognitive capacities involving memory, logic reason, decision making, judgment, language, attention, perception, and motor control all are being gradually lost to the disease, what remains? What cognitive capacity can we then use as a channel to the brain?



The collective experience of caregivers tells us that the capacity to feel and exhibit emotions persists among people with Alzheimer's disease far into the disease process. What is lost is the insight into what may have triggered a particular emotion, or how to control it. The ability to feel emotions, then, may be our best inroad to the mind of the person with Alzheimer's disease.

That said, habilitation can be defined as a proactive environmental therapy characterized by what we refer to as “domains,” six critical areas in which positive emotions can be created and maintained (see Table below, listing the Six Domains). This therapeutic intervention supports the person’s remaining cognitive capacities, respects his or her adult needs, and emphasizes meaningful activity. It can be established in the home, day center, assisted-living, or long-term care setting.

The challenge, of course, is for family and professional caregivers to recognize, within the six-domain construct, what will evoke—and what will inhibit—positive emotions, and then to address those positive emotions over the course of the day.

The Six Domains of Habilitation. Understanding how attorneys can better advocate for the client/incapacitated person.

| TABLE: The six domains | | |
|-------------------------------|--|--|
| | Goal | Outcome |
| Physical Environment | To create a physical environment that directs cognition without the patient’s awareness. | Positive emotions because of greater mastery of environment. |
| Communication | To enhance the patient’s capacity to understand language as well as to make him- or herself better understood. | Positive emotions because of less frustration. |
| Functional Assistance | To reduce excess disability | Positive emotions because of greater perception of independence. |
| Social | To help the patient hold on to cognitive and social skills longer via practice | Positive emotions because of meaningful activity and sense of purpose |
| Perceptual | To make sensory cues more easily perceived | Positive emotions because of less confusion |
| Behavioral | To reduce unsafe as well as annoying behavior | Positive emotions because of fewer negative interactions with staff and other patients |

The Physical Domain

Even a once-familiar environment can become frightening and confusing to someone with Alzheimer’s disease. Within the physical domain, the habilitation model attempts to reduce the potential for fear and disorientation by “directing” cognition, often

without the person's awareness. In this way, the manipulated environment becomes a prosthetic for the brain.

A well-designed prosthetic environment, like all the other domains in this model, has as a goal to bring about a positive emotion and to maintain that emotion. To illustrate, I was asked to consult on a case in which a 73-year old woman with Alzheimer's disease, living at home with her husband, was having difficulty dressing herself in the morning. When I arrived at the home I asked the husband to show me how he assisted her in the morning. He took me to the bedroom, where there was an enormous walk-in closet. He indicated that he simply would say to his wife that it was time to get dressed and he would leave. When he would return 20 minutes later he would find his wife still standing in the closet in her nightgown.



Because it is well known that Alzheimer's patients have problems making decisions, the environment had to be altered in such a way as to reduce the number of choices. I instructed the husband to remove all but two or three outfits from the closet and begin the morning by taking two outfits from the closet. I suggested that he say something like: "We have two very pretty outfits here, a blue one and a red one. I like the blue one because it matches your eyes. Which one would you like to wear today?"

Once we limited the number of choices, she was able to get dressed on her own. With her environment structured so that she can use her remaining skills, chances are that she will hold on to these skills longer. It also serves to bring about a positive emotion, because she feels more independent.

Perhaps the single most important adaptation to an environment is enhanced lighting. Experience indicates that by increasing artificial light from approximately 45-foot-candle power (typical lighting in a home). To 80-foot-candle power and controlling the glare and shadows from outside, ambient light we can improve independence, reduce late afternoon and early evening agitation, and stabilize mood.

Another principle of habilitative design is that we use color and textural contrast to draw attention to important features of the environment, and we camouflage or hide dangerous or distracting elements of the environment. Again, to illustrate, I was called to a caregiver's apartment because her husband, a mid-stage Alzheimer's patient, was urinating in a closet.



The problem as I saw it was that the couple had recently moved to a new apartment and he more often than not chose the wrong door when he felt he needed to use the bathroom. In fact, the bathroom and closet doors were adjacent to one another. By painting the bathroom door red, the color automatically drew the gentlemen's attention and he reliably chose the correct door.

However, once in the bathroom he was confronted by white walls and floor, a white sink, toilet, and bathtub. He often would urinate in the bathtub. I instructed the caregiver to purchase a red toilet seat. The problem was solved.





These are just some of the physical enhancements that can reduce the environmental demands on the person's already challenged perception. They, in combination with the other domains of this model, can increase dramatically levels of functioning. More importantly, they lessen the frustration, which often results in behavioral outbursts, and promote feelings of accomplishment, security, and belonging.

The Social Domain

Structured activities are the engine that drives the social domain.

Understandably, people with Alzheimer's disease who spend significant amounts of time doing nothing experience more psychiatric symptoms, such as depression, anxiety, paranoia, delusions, and hallucinations, than people who are occupied by a meaningful activity; however, the increased amounts of leisure time with which these people find themselves can be addressed successfully through enriching activities that promote feelings of purpose and accomplishment. See *activities at home brochure*, in the Appendix.

By developing a failure-free activities plan, we can avoid cognitive skill areas that have been lost. This plan may require that the person's cognitive strengths and weaknesses be assessed through a battery of neuropsychological tests. A cautionary note should be mentioned here: For some patients, these tests can cause frustration and bring about negative emotions. In these instances our knowledge of the patient and observation of his or her skill level are better indicators of how to design failure-free activities. Practice with remaining skills with these failure-free activities can help slow the rate of decline of those skills.

In the social domain, time is filled with opportunities for reminiscence (e.g., cooking classes, word games, and holiday reflections), for fun (dancing, sing-a-longs), and for creativity (herb gardening, jigsaw puzzles, and art projects). However, these activities are not "time fillers"; rather, they are carefully and individually selected cognitive enhancers that maintain healthy neural connections and promote branching or arborization of neurons.



Branching of neuronal axons allows an electrical impulse in the brain to bypass damaged areas of the brain and make connections with healthy cells. So, failure-free activities help individuals hold on to the capacities longer and maintain positive emotions. Another benefit of activities, especially musical activities, is that they very quickly change emotions. Thus, activities can be used prophylactically to avoid anticipated swings in mood or increased confusion. An activity cannot be introduced once the person is already agitated. At the same time, therapeutic activities facilitate orientation, maintain interests and strengths, and minimize isolation.

Again, activities should be commensurate with the person's cognitive level. They should offer opportunities for success and interaction and be based on previous interests expressed throughout the person's lifetime. If the person is especially uncooperative in a particular activity, one can try it again later on or forget it for that day. One should avoid jeopardizing a positive emotion in order to adhere to a schedule.

Activities also should have an adult focus and not be childish. In this way they can provide a medium for caregivers to interact with the person in new ways, or to connect with aspects of that person's character, personality, and experience that appear to have been lost to the disease. One caregiver, for example, to address his wife's "sundowning" behavior (late-day confusion), began ballroom dancing with her late every afternoon. She enjoys it, she does not experience sundowning, and they are able to relive some previously inaccessible intimate emotions of their youth.



There is an unfortunate but persistent myth that people with Alzheimer's disease, because they may not remember friends or be able to contribute to a relationship, no longer have a need for social experience and interaction.

In fact, they have an increasing need for all of the social benefits that derive from relationships. Victims of Alzheimer's disease may lose the ability to initiate social interaction, but not their need for it.

In the social domain, the caregiver's aim should be to build the person's social competence by fostering opportunities for mutual support. One way to do that is to create social groupings in which the person's feelings of alienation and isolation can be countered by feelings of belonging, mutual respect, and purpose. Groups can be formed for people in the early through the middle stages of the disease and may focus on the general activities or on very specific therapeutic goals.

The Functional Domain

All too frequently in Alzheimer's care we note an inability to perform routine tasks even before the person has reached the point in the downward trajectory of the disease process at which that degree of dysfunction would be expected. Dysfunction caused by the person's emotional reaction to the disease (e.g. depression) or to physical or care factors in the environment is said to be an "excess disability." But depression, like many other psychiatric symptoms seen in Alzheimer's disease, usually can be treated by the judicious use of medication.

Excess disabilities with environmental causes can be avoided by creating supports that encourage independence in the person's activities of daily living, such as eating, walking, toileting, dressing, grooming, and bathing. As in the activity domain,

previous routines become the cornerstones here, as caregivers struggle to keep one step ahead of dependence.



The key is to continue for as long as possible with the person's normal, customary routines. From which side of the bed does she get up in the morning? This information becomes significant, for example, if she were to move to a new setting in which the side of the bed she arose from for the past 50 years now abuts a wall. When he dresses, in what order does he like to put on the articles of clothing? They should be laid out for him accordingly. Did she usually shower, or bathe in a tub? Use a face cloth or sponge?

Is the fact that he has so much difficulty removing his pants the real cause of his apparent incontinence? If she fails at more complicated chores, can she instead help by shredding lettuce or setting the table? No matter how simple the task, we must sustain the person at an appropriate functional level for as long as possible.

Caregivers also can change the task to fit the person and prioritize which activities for daily living (or parts of an activity) are important and which are not. Bathing, for example, may be the most difficult activity asked of the person. Once should begin by spending at least 5 minutes just talking and building rapport. This is called the "spend 5 and save 20" rule.

Proposing an activity as a question ("Would you like to take a bath?") too often leads to a resounding "no." Assist the person with verbal cues, using a technique called chunking: a series of short, simple, calmly stated commands, such as "come with me," "unbutton your shirt," "take out your arm," "unbuckle your belt," and so on. Schedule bathing when the person is in the best frame of mind, most alert and cooperative. If necessary, provide hands-on assistance, mindful not to let water pour over the person's face and eyes, which can be frightening. Wash the hair and the face at a different time. Showering for a patient with Alzheimer's disease is best done from the feet, stopping at the neck, rather than the standard practice of working from the head down.

Remember, the goal of habilitation is to bring about a positive emotion and to maintain that emotion over the course of the day. If we start the day, say, with a negative emotion caused by a bad experience with bathing or showering, the person will forget the context for that negative emotion but will be left with the emotion without any idea about how it was established. The patient will carry that negative emotion to his or her next interaction, causing it to result in a more intense emotion. By the end of the day the person is agitated, confused, and disruptive.

How to abide by a treatment plan.

It is important not to start the day on a slippery slope of escalation negative emotion. As illustration of this point, Tom, a 53-year old patient with Alzheimer's

disease had great difficulty with his morning shower. Not only was he combative during the ordeal of the shower, but his behaviors dramatically worsened in the afternoon. Under habilitation therapy it is imperative to intervene and prevent the development of the negative emotion.

The first step is triage. If showering is so difficult for him, how many times per week are willing to risk starting off the day with a negative emotion? In this case we said four times per week. We then determined after talking with this man's family that there were four things that calmed him—backrubs, blue sports cars, women in short skirts, and the music of the Beach Boys. So, we developed an intervention that employed these calming agents.

To begin with, only one nursing assistant was involved with assisting with this man's shower rather than three aides, as was used before. The aide would come into the man's room and just chat with him for a few minutes—the spend 5 to save 20 rule. She then gave the man a backrub to create a relaxed mood. Once he was relaxed she simply said, "Come with me," and led him down the hall to the shower.

On the walls between the "young" patient's room and the shower we had taped pictures of blue sports cars and tasteful pictures of women in short skirts to distract him and avoid any anticipatory anxiety. Once in the shower room the music of the Beach Boys was playing; the room was warm and well illuminated. While singing with the young man the aide undressed him. We had determined that it might be important to put a bathrobe on the man to reduce any modesty problems. Using a handheld shower nozzle, the aide started washing at the man's feet and quickly moved up the body, stopping at the neck.



The actual washing took less than 3 minutes. He was not at all resistant or combative during this procedure, and he actually participated in the washing. It also was noted that this behavior did not worsen in the late afternoon as it had under the previous method of showering. Thus, great lengths are taken not to start off the day with a negative emotion, and to make the experience one that brings about a positive emotion.

Focus more on advocacy and less on procedure – but of course procedure may overlap

Habilitation is only successful if we are willing to capitalize on—and discover—remaining skills, to break tasks into simple, easily sequenced steps, to go slowly, and always to provide only the level of support that the person with Alzheimer's disease needs. Then the person derives meaning and purpose as he or she participates in the task as much as he or she is able. Perhaps the best illustration of these principles involves assisting patients with eating.

Many factors can contribute to a patient not eating, and it is entirely too easy for caregivers to take over the task to ensure proper nutritional intake. Some patients can be overwhelmed by too many decisions involved in eating. Consider the typical tray of food in a nursing home. We might have a white tray with a white covered plate, a packet of utensils wrapped in a napkin, a small teapot, a teacup, a salad bowl wrapped in plastic, a dessert, and condiments.



The patient, because of problems with executive functioning—planning and implementing a task—does not know where to begin. Some patients may be able to feed themselves if we just get them started; others may need to have only dish and one utensil presented to them in order to simplify the task. Still other patients may require finger foods to continue feeding themselves.

It may take only 10 minutes to feed a patient, and an hour if he or she feeds himself or herself. But if caregivers prematurely take over the task, the patient will lose the ability and thus fall more dependent.

The Communication Domain

Nowhere in the habilitation model is the process of eliciting positive emotions more critical than in the communication domain. As surely as our language system sets us apart from other animals, our loss of communication skills profoundly dismays and unnerves us. In our highly verbal world, expressive and receptive language deficits are catastrophic losses for someone with Alzheimer's disease.

In the communication domain, habilitation calls for increased use of body language, encouraging the use of gestures, demonstrations, signs, and pictures. A drawing of a cup and saucer may better communicate what is in the kitchen cabinet than anything verbal or written.

Habilitation underscores listening techniques related to emotions, directing us to listen not so much to the often mis-used words and muddled sentences, but to the driving emotion behind them.

For example, if the person is experiencing symptoms of suspiciousness and accuses the caregiver of taking her pocketbook, the caregiver can say something like, “I know how you feel. When I lose my pocketbook [or wallet] I feel panicky. Let me help you find it.” Once this offer of assistance is communicated, the outcome is likely to be a change in the person's emotional state.

Within the communication domain there are rules of communication, straightforward techniques, and the strategies of communication that are more abstract principles of interaction. The following are some of the basic rules of communication.

- Always approach the patient from the front
- Always indicate your name and say the patient's name every time you have an exchange, even if it is several times in the course of a day.



- Be aware of body language, making sure you are smiling and using a positive tone of voice.
- Always say something positive about the person, such as, "I love your hat," or, "That is a beautiful dress," each time you interact with the patient.
- Try to maintain eye contact with the patient even though the patient may be looking at your mouth. As patients lose the ability to understand language they become inadvertent lip

readers. Female staff and family members can wear lipstick, which can be easily seen and facilitate lip reading.

- If the patient is seated you should be at the same level. If the patient is standing you should be standing.
- Never position patients so that a light source (a window or lamp) is behind you as you face them. They will not be able to see the details of your face with the light source in their eyes.



- Always "chunk" information into short, explicit communications. For example, avoid saying, "please set the table," because this may be too abstract. Try a series of short commands such as "come with me"; "take a dish from the shelf"; "put the dish on the table"; and so on.
- Be careful about using metaphors or abstract phrases.

- If the patient loses her or his train of thought, reorient her or him. If she or he is struggling to find a lost work, offer it. If the patient cannot remember something she or he wanted to say, often a reassuring pat on the hand and the comment, "It's OK, it will come back to you later," are helpful.

The less people with Alzheimer's disease are frustrated by their verbal errors, the longer they will continue to interact with others, and the longer they will maintain feelings of personal value.

The more abstract strategies of communication suggest how different habilitation therapy is from everyday methods of communication with cognitively intact elders. The first strategy of habilitative communication is that one can never change behavior with words, only by changing what one does, the approach to the patient, or the environment. The rationale for this strategy is obvious.

Because the patient has no short-term memory and limited capacity to learn, we cannot tell the patient to do something or not to do something and expect him or her to do it the next time. This point can be illustrated in the following true story.

The daughter of a patient with Alzheimer's disease had the custom of taking her mother to a restaurant every Thursday evening. This particular Thursday, the daughter arrived at her mother's home to find her mother standing on the porch wearing her mink coat, matching shoes, and pocketbooks, ready for an evening out. When they arrived at the restaurant, Mom took off her coat to reveal her slip. She had forgotten to put her dress on. The daughter, realizing that the goal of all habilitative communication is to bring about a positive emotion and that pointing out to her mother forgot to put on her dress only would cause embarrassment, merely said to her mother, "It is a bit chilly. I'm going to put my coat back on." Mom did the same, and they then were able to have a wonderful meal together.

The second strategy is never to use the word "no." If the patient wakes up at 4 am and wants to take a walk outside in a rainstorm, one should say: "Sure, let's do it." If one says "no," muscles tense up, tone of voice changes, and the patient sees the caregiver as limiting his or her independence. Because of this the situation becomes highly emotional—and emotions are what the patient is good at. Even if the patient is given the most logical, eloquent argument why he or she should not go outside, there is nothing in his or her brain that can appreciate the reasoning. Rather than logic, one should use distraction.

Two techniques, refocusing and redirecting, help distract the patient long enough so that his or her faulty memory will work to the caregiver's advantage. For example, one might say, "Sure, let's go, but before we go I need to have a cup of tea and a sandwich. My favorite kind of sandwich is turkey. What's yours?" The caregiver is refocusing the person's attention. He or she then might go on to say, "Help me make the sandwich." Such dialogue redirects behavior. By using these techniques, enough time passes so that the person forgets his or her original intention. Saying "no" at the outset only makes the person more likely to leave.

A third strategy, perhaps the hardest to learn and apply, is that one never brings a mid-stage patient back to our sense of reality; rather, the caregiver must go to where she or he is. Reality orientation as a therapeutic technique works just fine for cognitively intact elders, but it is not at all useful for mid-stage patients with Alzheimer's disease.

Consider this: A 91-year old lady with Alzheimer's disease becomes increasingly confused in the late afternoon and early evening, a condition referred to as "sundowning." During this period the lady might approach a caregiver and say that she just saw her mother. Using reality orientation, the caregiver would tell the lady that her mother is dead and that she did not really see her. This would propel the patient into mourning because it is the first time she has heard that her mother has died. Two minutes later the patient forgets that her mother is dead, but she is left the mourning

with absolutely no context for it. She carries the negative emotion to her next interaction, and the emotion affects that interaction. And, again because she is feeling anxious and insecure, she says to the caregiver that she saw her mother, thus starting the cycle over.

Within habilitation, rather than tell the patient that her mother is dead, we would say: "Tell me about your mother, I hear that she is a wonderful person." Or, if this happens frequently and predictably, the caregiver could have a picture of the patient and her mother taken many years earlier and use the picture to create a story, which may or may not be true, to bring about a positive emotion.

Still another example emphasizes the creativity required in habilitative communication. An 80-year old woman in mid-stage Alzheimer's disease was admitted to a nursing home, and for the first several days there she refused to eat anything. The nursing assistant, having read the patient's social history, learned that she had been a fan of the Boston Pops Orchestra and that she had a crush on Arthur Fiedler, the renowned conductor of the Pops, for many years.

Armed with this information, the aide went down into the kitchen and brought up a tray of food. The aide told the patient that while in the lobby she saw Arthur Fiedler and she mentioned to him that the patient was not eating. The aide went on to say that when Mr. Fiedler heard that the patient was not eating, he went into the kitchen and prepared this meal especially for her (keep in mind that this took place many years after Arthur Fiedler had died). The patient then was given the tray of food and she ate every bite, and every meal thereafter Arthur Fiedler prepared.

This sounds as if we are lying to our patients, but these are not lies, these are what I call "therapeutic fiblettes"—inroads into the patient's reality. It is only if we become comfortable and creative in the use of fiblettes that we become effective practitioners of habilitation therapy.

A fourth communication strategy emphasizes our roles in reducing fear for the patients and acknowledging underlying emotions. Patients with Alzheimer's disease experience fear throughout their disease course. As they decline and lose capacities, part of what is also lost is the ability to articulate their fears and cope with them. Essentially, what is lost is the person's ability to self-soothe if fears become overwhelming. This is akin to behavior seen in infants who don't have neurological and cognitive capacities to overcome their unrealistic fears. The focus of our communications is to make the person feel loved and safe. They need to hear from us what it is that they should be doing, because they live with this nagging feeling that they are supposed to be doing something important, but they do not know what it is. Our communications give them purpose and direction. We also need to attend to underlying feelings behind the inarticulate communications, even if they are difficult emotions.

In a previous example, a patient accused a caregiver of taking her pocketbook. The caregiver's natural reaction was to indicate that she did not take it, and then to offer

her assistance in finding the misplaced item. This, however, is only a partial intervention. First, telling the patient that one did not take the item will go nowhere. In fact, it may make things worse. Offering assistance to find the item is appropriate but it still leaves the underlying emotion, in this case panic, ignored and unresolved. It might be better to say, "I know you must be very upset. I get panicky when I lose my pocketbook because all my important stuff is in there. Let's go look for it together."

One must look beneath the words to what the patient's basic emotions are and try to address them in a simple, direct way. If these emotions are ignored, they fester and lead to catastrophic behavior.

The Perceptual Domain

It seems likely that part of the faulty communication system among people with Alzheimer's disease is the result of some sensory deprivation. We have long recognized the link between memory stimulation and odors, sights, and sounds. But how is the person with Alzheimer's to communicate if sensory messages to the brain are not fully captured or are no longer recognizable?

Sensory modalities blend together, meaning that senses like sight and sound may not be completely separate experiences. As William James (1890) observed about infants: "Sensory input is a blooming, buzzing confusion." In some cases, the person may lose what is called proprioceptive memory; that is, memory related to muscle function. A person in mid to late-stage Alzheimer's disease, for example, may forget how to open a door, or how to bend the knees in order to sit. If this loss occurs, caregivers can use hand gestures indicating that the person should sit or might even apply some gentle pressure behind the knees to initiate the sitting action.

Caregivers also need to heighten the person's sensory experience, as well as their own reading of what messages the environment may be giving the person with Alzheimer's disease. Most importantly, we need to be aware of what the person may be connecting to (often the past) as a result of a current sense interaction but may be unable to articulate.



The rose's thorny stem, for example, may signal discomfort to the person who is unable to perceive the blooming flower atop it. Or consider the person with Alzheimer's disease whose frustration approaches panic as he rummages for the keys in his pocket because he does not recognize their shape, their feel. When we provide a visual cue by removing the "lost" keys from his pocket and showing them to him, he simply says, "Oh, there they are."



Knowing that the disease process alters perception should prompt caregivers to supply the person with more visual, tactile, and auditory cues.

The Behavioral Domain

Although structured activities drive the social domain, properly focused behavior-management techniques are what drive the behavioral domain. To manage problematic (i.e., reactive) behaviors successfully, the habilitation model requires that caregivers adopt a dementia-centered perspective. As stated previously, it accepts that we cannot change the person's behavior directly, but only indirectly by changing either our approach technique or the person's physical environment.

Certainly, by the middle stages of the disease we must assume that patients have no short-term memory and only very limited capacity to learn. (See examples of behaviors in Stages of Memory Loss) We cannot say to a patient, "Don't do that," and expect that the command will be remembered and followed in the future. For this reason, traditional forms of behavior modification, that is, new connections between rewards and behaviors, cannot be formed. Likewise, conventional reality-orientation methods have little chance of anchoring the patient to the present or of changing behavior.

So how do family and professional caregivers insinuate themselves into this Alzheimer's reality in order to manage the person's behavior?

Difficult behaviors in people with Alzheimer's disease are most often defensive in nature—a compensation for the confoundedness of an increasingly unfamiliar world. Physical or verbal aggression, for example, is less an arbitrary acting out than a reaction to fear caused by the person's altered perceptions. An important point to stress here is that rarely is behavior a random act; all behavior has a cause or a triggering event. Sometimes these events are obvious because they are external, we can see them, and sometimes triggers are more difficult to see because they are internal, cause by delusions, hallucinations, paranoia, or misunderstood events and motives. Caregivers must assess several possible causes for each challenging behavior. In the habilitation model, these evaluations are ongoing, adjusted, and prophetic.

Assessments should include the physical, medical, and emotional well-being of the person. Is the person hot, cold, hungry, thirsty, ill, in pain, emotionally distressed, in need of toileting? Through a behavioral log that records what happened, when it happened, where it happened, and who was around when it happened, in time patterns begin to emerge. Once a pattern is observed, we can hypothesize about its origin and plan an intervention. Are there too many steps to a given project? Has the person forgotten the sequence of steps? Was this the cause of the outburst that resulted in his or her angrily tossing the project aside?

Try simplifying the task. If setting the table is causing dismay, have the person first put down all of the placements, then only the plates, then just the glasses, allowing

time to process each chore. Assess your communication techniques, carefully evaluating the person's comprehension and your own body language.

Most importantly, try to look at the environment through the person's altered lens of perception. Has a shadow on the wall suddenly taken the shape of an intruder in the room? Are pools of light on a glossy floor perceived as spilled water, which might make the person slip? Has the aroma of baking cookies induced hunger pangs?

Screaming is a good behavior with which to illustrate the last several points. There are at least three different types of screaming that we see with patients with Alzheimer's disease, each with different causes and different interventions.

The first type is a rhythmic sound; it often takes the form of "help me, help me." This is most likely caused by minimal brain stimulation. Too little information is coming into the brain from the senses, so the person creates a form of autostimulation. One can identify this form of screaming by the rhythmic nature and also by the fact that if one approaches the patient it generally does not stop. There are several interventions that work to reduce or eliminate this behavior. One intervention is to replace the stimulation and the rhythm with a more acceptable form. For example, for Catholic patients the rosary recorded on an audiotape creates a kind of rhythmic mantra; a rocking chair or a glider chair does the same. I used an electronic drum pad connected to earphones to reduce screaming in several patients.

Another form of screaming is identified by its low-pitched and constant sound. When one approaches the patient it does not stop. Often this form is caused by pain. The intervention is to assess the patient for pain and address its source.

Still another form is a loud, shrill, continuous sound that stops when one approaches the patient. This form is often a sign of panic in the patient and sometimes a sign of boredom. The interventions are to make the patient feel safe and secure, such as more one-on-one care, backrubs, or more stimulation.

Family and professional caregivers must be aware of the ongoing need to modify things in the environment—lights, mirrors, plants, electronic equipment, and so many other objects we all take for granted. By manipulating the environment, and with education, patience and practice, caregivers can learn to manage reactive behaviors without, in some cases, resorting to psychoactive medications, or at least with lessened amounts of medication.

Take, for example, the patient with Alzheimer's disease living in a nursing home who occasionally would calmly get up from his chair, walk across the room, and hit another resident. By keeping a log, we began to see that he would only hit someone if he was in the activities room, but not every time he was in that room. There did not appear to be any pattern to whom he hit. Later, we saw that he would only hit people on sunny days, but not on every sunny day on which he was in the activities room.

Then, we saw that he only hit people on sunny days if he was sitting on one side of the room. With the log we were able to eventually determine that he would hit people if he sat in the activities room and the sun was shining in his eyes. The intervention was simply to make sure that the blinds were closed on sunny days if this particular man was in the activities room. Thus, with patience and careful analysis of the situation we were able to avoid the use of a psychoactive medication.



However, it may be dangerous to allow repeated episodes of assaults to occur in order to gather data to determine the cause of the triggering behavior. Judgment should be exercised to ensure a safe environment for all residents.

Conclusion - How a person who is suffering from memory loss would benefit from the alternatives to antipsychotic meds

Through its multiple and interconnected domains, habilitation seeks to create a proactive therapeutic milieu for understanding the needs of people with Alzheimer's disease into the 21st century. It is distinguished from rehabilitation, which seeks to restore external function, by its emphasis on the internal: emotion. It is as much a positive attitude about Alzheimer's disease and related disorders as it is a therapeutic method.

Habilitation's most poignant definition may have been the observation of neurologist A.R. Luria, which appears in a letter written some years ago to Dr. Oliver Sacks, which Sacks (1970) quotes in his book *The Man Who Mistook His Wife for a Hat, and Other Clinical Tales*. "Man," Luria wrote, "does not consist of memory alone. He has feeling, will, sensibility, moral being. It is here you may touch him, and see a profound change." If we choose to see symptoms associated with Alzheimer's disease as potentially treatable, rather than part of inevitable decline, a new starscape materializes before us, as it did for the ancient astronomers.

alzheimer's  association

activities at home

Planning the day for a person
with moderate or severe dementia



Appendix - *Activities at Home: Planning the Day for the Person with Dementia*

Ideal for distribution to clients and family members.

<http://masshealthhelp.com/pdf/Activities at Home Alz Assoc.pdf>

Return to: MassHealthHelp.com

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