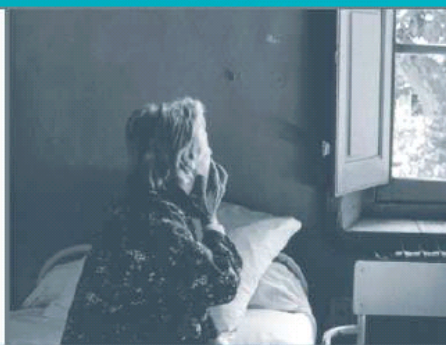


## CHARTRE ALZHEIMER ÉTHIQUE & SOCIÉTÉ 2010



### Références bibliographiques<sup>1</sup> : ARTICLES SCIENTIFIQUES

préparé par Grégory Emery, *Interne de Santé Publique, Espace Ethique/ AP-HP*

#### → ALZHEIMER 2010 : LES SOIGNANTS S'ENGAGENT

Tous ceux, professionnels, proches et bénévoles, qui prennent soin des personnes atteintes d'une maladie d'Alzheimer ou d'une maladie apparentée, s'engagent à :

- 1/ Reconnaître le droit de la personne malade à être, ressentir, désirer, refuser >>> p.2
- 2/ Respecter le choix de la personne malade >>> p.3
- 3/ Respecter la personne malade, ses biens et ses choix matériels >>> p.4
- 4/ Respecter les liens affectifs de la personne malade >>> p.5
- 5/ Respecter la liberté de conscience de la personne malade et valoriser ses activités >>> p.6
- 6/ Assurer à la personne malade l'accès aux soins, la compensation des handicaps et à la prévention des facteurs aggravants >>> pp.7-9
- 7/ Développer et garantir les compétences professionnelles par les formations initiale et continue ainsi que par le travail en équipe >>> p.10
- 8/ Soigner, respecter et accompagner la personne malade jusqu'au terme de sa vie >>> pp.11-12
- 9/ Faire bénéficier la personne malade de la recherche et de ses progrès >>> pp.13-14
- 10/ Contribuer largement à la diffusion d'une approche éthique >>> pp.15-16

<sup>1</sup> La base de données bibliographique MEDLINE a été utilisée pour préparer le présent document. Les articles référencés sont donc tous des articles scientifiques

## 1/ ...Reconnaître le droit de la personne malade à être, ressentir, désirer, refuser.

Toute personne atteinte d'une maladie d'Alzheimer ou d'une maladie apparentée, et quel que soit le niveau de ses atteintes, conserve des capacités à ressentir des émotions et à réagir en fonction de son vécu, de son environnement matériel et humain, de ses goûts et préférences.

*Mots-clés*<sup>2</sup> : Alzheimer + identité ; autonomie ; relations médecin-patient ; compétence ; prise de décision ; capacité ; concept de soi ; communication

Addis DR, Tippett LJ. Memory of myself: autobiographical memory and identity in Alzheimer's disease. *Memory*. 2004 Jan;12(1):56-74.

Conde-Sala JL, Garre-Olmo J & al. Factors related to perceived quality of life in patients with Alzheimer's disease: the patient's perception compared with that of caregivers. *Int J Geriatr Psychiatry*. 2009 Jun;24(6):585-94.

Gzil F. La question éthique du respect de l'autonomie . *Annales Médico-psychologiques, revue psychiatrique*. Vol 167, Issue 3, April 2009, Pages 230-233

Jaworska A. Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value. *Philosophy and Public Affairs*, 1999, vol 28, n°2, p. 105-168

Macrae H. Managing identity while living with Alzheimer's disease. *Qual Health Res*. 2010 Mar;20(3):293-305. Epub 2009 Nov 25.

Orange JB, Ryan EB. Alzheimer's disease and other dementias. Implications for physician communication. *Clin Geriatr Med*. 2000 Feb;16(1):153-73, xi. Review.

Sorrell J. Struggling to do the right thing: stories from people living with Alzheimer's disease. *J Psychosoc Nurs Ment Health Serv*. 2005 Jul;43(7):13-6.

Tappen RM, Williams C & al. Persistence of self in advanced Alzheimer's disease. *Image J Nurs Sch*. 1999;31(2):121-5.

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<sup>2</sup> Les mots clés correspondent aux Mesh Terms , utilisés pour l'indexation des articles dans MEDLINE

## 2/ ...Respecter le choix de la personne malade

Toute personne atteinte d'une maladie d'Alzheimer ou d'une maladie apparentée, doit pouvoir bénéficier d'espaces de liberté. S'impose à tous l'exigence de rechercher ses souhaits et d'en faciliter l'expression, de rechercher et privilégier son autonomie d'action et de décision tout en tenant compte de ses capacités à réévaluer régulièrement.

*Mots-clés* : Alzheimer + personal autonomy ; self concept; decision making ; mental competency ; freedom

Defanti CA, Tiezzi A & al. Ethical questions in the treatment of subjects with dementia. Part I. Respecting autonomy: awareness, competence and behavioural disorders. *Neurol Sci*. 2007 Aug;28(4):216-31.

Feinberg LF, Whitlatch CJ. Are persons with cognitive impairment able to state consistent choices? *Gerontologist*. 2001 Jun;41(3):374-82.

Fisher CB. A goodness-of-fit ethic for informed consent. *Fordham Urban Law J*. 2002 Nov;30(1):159-71.

Holm S. Autonomy, authenticity, or best interest: everyday decision-making and persons with dementia. *Med Health Care Philos*. 2001;4(2):153-9.

Jaworska A. Respecting the margins of agency: Alzheimer's patients and the capacity to value. *Philos Public Aff*. 1999 Spring;28(2):105-38.

Koppelman ER. Dementia and dignity: towards a new method of surrogate decision making. *J Med Philos*. 2002 Feb;27(1):65-85.

Sabat SR. Capacity for decision-making in Alzheimer's disease: selfhood, positioning and semiotic people. *Aust N Z J Psychiatry*. 2005 Nov-Dec;39(11-12):1030-5.

Sailors PR. Autonomy, benevolence, and Alzheimer's disease. *Camb Q Healthc Ethics*. 2001 Spring;10(2):184-93.

Stewart R. Mental health legislation and decision making capacity: autonomy in Alzheimer's disease is ignored and neglected. *BMJ*. 2006 Jan 14;332(7533):118-9.

Whitney SN, McCullough LB. Physicians' silent decisions: because patient autonomy does not always come first. *Am J Bioeth*. 2007 Jul;7(7):33-8.

### 3/ ...Respecter la personne malade, ses biens et ses choix matériels

Toute personne atteinte d'une maladie d'Alzheimer ou d'une maladie apparentée, bénéficie de la protection de la loi pour sa personne et ses biens. Sa vulnérabilité doit être évaluée par des professionnels compétents, afin de lui préserver le plus d'espaces possibles de liberté dans ses choix matériels de vie et ses engagements financiers.

*Mots-clés* : Alzheimer + protection ; Legal Guardians ; Financial Management; Mental Competency/legislation & jurisprudence; Patient Advocacy

Baker FM. Legal issues affecting the older patient. *Hosp Community Psychiatry*. 1986 Nov;37(11):1091-3.

Chan TC, Luk JK & al. Financial abuse in a mentally incapacitated old man. *Hong Kong Med J*. 2009 Jun;15(3):213-6.

Gove D, Georges J. Perspectives on legislation relating to the rights and protection of people with dementia in Europe. *Aging Ment Health*. 2001 Nov;5(4):316-21.

Panknin HT. Violence against Alzheimer patients--causes, effects and solutions. *Krankenpfl J*. 1999 Dec;37(12):498-9.

Lallouët J. Practical considerations on the legal and social assistance of patients with Alzheimer's disease. *Rev Prat*. 1989 Feb 23;39(6):489-91.

Leger-Krall S. When restraints become abusive. *Nursing*. 1994 Mar;24(3):54-6.

Mauduit M. Are legal measures for the protection of patients with Alzheimer disease useful for the caregivers? *Psychol Neuropsychiatr Vieil*. 2004 Jun;2(2):141-6.

Raivio MM, Mäki-Petäjä-Leinonen AP & al. The use of legal guardians and financial powers of attorney among home-dwellers with Alzheimer's disease living with their spousal caregivers. *J Med Ethics*. 2008 Dec;34(12):882-6.

Ruggieri RM, Piccoli F. Legal and assistance aspects of Alzheimer's disease: analysis of 100 cases. *Neurol Sci*. 2003 Oct;24(3):125-9.

Silver HM. Alzheimer's disease: ethical and legal decisions. *Med Law*. 1987;6(6):537-51.

#### 4/ ...Respecter les liens affectifs de la personne malade

Toute personne atteinte d'une maladie d'Alzheimer ou d'une maladie apparentée conserve la liberté de communiquer et de participer à la vie en société. Les relations familiales, les liens affectifs et amicaux dans toutes leurs diversités, anciens et nouveaux, doivent être préservés et respectés.

*Mots-clés* : Alzheimer + social relation ; Social Behavior ; Interpersonal Relations ; love, marriage ; sexuality ; Family Relations

Beard RL, Fox PJ. Resisting social disenfranchisement: negotiating collective identities and everyday life with memory loss. *Soc Sci Med*. 2008 Apr;66(7):1509-20. Epub 2008 Jan 28.

Bosch-Domènech A, Nagel R & al. Prosocial capabilities in Alzheimer's patients. *J Gerontol B Psychol Sci Soc Sci*. 2010 Jan;65B(1):119-28. Epub 2009 May 25.

Burns R. A piece of my mind. Rubbing against the late day. *JAMA*. 2010 Jun 23;303(24):2449-50.

Creasey GL, Myers BJ & al. Couples with an elderly parent with Alzheimer's disease: perceptions of familial relationships. *Psychiatry*. 1990 Feb;53(1):44-51.

McIntyre M, Cole A. Love stories about caregiving and Alzheimer's disease: a performative methodology. *J Health Psychol*. 2008 Mar;13(2):213-25.

Moore I. Living with Alzheimer's: understanding the family's and patient's perspective. *Geriatrics*. 1997 Sep;52 Suppl 2:S33-6.

Ocaña GG, Robles RG & al. Family repercussions due to Alzheimer disease. *Rev Enferm*. 2007 Mar;30(3):59-64.

Poveda AM. An anthropological perspective of Alzheimer disease. *Geriatr Nurs*. 2003 Jan-Feb;24(1):26-31.

Schlögl A. Why Oma can become "peculiar" and still remain "Oma". *Children's books on the topic of dementia. Kinderkrankenschwester*. 2010 Jul;29(7):271-2.

Tabak N, Shemesh-Kigli R. Sexuality and Alzheimer's disease: can the two go together? *Nurs Forum*. 2006 Oct-Dec;41(4):158-66.

Wald HS. A piece of my mind. In the here and now. *JAMA*. 2008 Feb 13;299(6):613-4.

Wright LK. The impact of Alzheimer's disease on the marital relationship. *Gerontologist*. 1991 Apr;31(2):224-37.

## 5/ ...Respecter la liberté de conscience de la personne malade et valoriser ses activités

Toute personne atteinte d'une maladie d'Alzheimer ou d'une maladie apparentée conserve sa liberté de conscience, ses droits de citoyen et doit pouvoir exercer les activités qu'elle souhaite, même lorsqu'elle présente une altération intellectuelle et physique sévère.

*Mots-clés* : Alzheimer + vote ; Civil Rights, Mental Competency ; religious ; spirituality ; freedom of conscience

Appelbaum PS, Bonnie RJ, Karlawish JH. The capacity to vote of persons with Alzheimer's disease. *Am J Psychiatry*. 2005 Nov;162(11):2094-100.

Beuscher L, Grando VT. Using spirituality to cope with early-stage Alzheimer's disease. *West J Nurs Res*. 2009 Aug;31(5):583-98. Epub 2009 Mar 11.

Haarhaus F. Spiritual care for demented patients: religious responsibility with social nursing value. *Pflege Z*. 2006 Feb;59(2):96-8. German.

Dopson L. Spirituality and Alzheimer's. *Nurs Older People*. 2005 Jun;17(4):39.

Elliot H. Religion, spirituality and dementia: pastoring to sufferers of Alzheimer's disease and other associated forms of dementia. *Disabil Rehabil*. 1997 Oct;19(10):435-41.

Irastorza LJ, Corujo P & al. The competence to vote in patients with dementia. *Rev Neurol*. 2007 Mar 16-31;44(6):321-5.

Mensdorf B. Spiritual impulses in the everyday routine of demented residents--educational project: breathing room for the soul. *Pflege Z*. 2007 Sep;60(9):510-2.

Post SG, Whitehouse PJ. Spirituality, religion, and Alzheimer's disease. *J Health Care Chaplain*. 1999;8(1-2):45-57.

Swerdloff MA. Do persons with dementia vote? *Neurology*. 2002 Jul 9;59(1):149; author reply 149.

Tompkins C, Sorrell JM. Older adults with Alzheimer's disease in a faith community. *J Psychosoc Nurs Ment Health Serv*. 2008 Jan;46(1):22-5.

## 6/ ...Assurer à la personne malade l'accès aux soins, la compensation des handicaps et à la prévention des facteurs aggravants

Toute personne atteinte d'une maladie d'Alzheimer ou d'une maladie apparentée doit bénéficier des aides, soins et conseils qui lui sont nécessaires, dispensés par des personnes compétentes. Les discriminations liées à l'âge ou à la maladie d'Alzheimer sont contraires à la loi et à l'éthique professionnelle.

*Mots-clés* : Alzheimer + discrimination behaviour ; stigma ; prejudice ; quality of life ; well being ; health care disparities ; equity of access ; support ; prevention of complications ; consent

Baquero M, Peset V & al. Quality of life in Alzheimer's disease. *Rev Neurol*. 2009 Oct 1-15;49(7):337-42. Spanish.

Baskin SA, Morris J & al. Barriers to obtaining consent in dementia research: implications for surrogate decision-making. *J Am Geriatr Soc*. 1998 Mar;46(3):287-90.

Becker D, Kahana Z. Informed consent in demented patients: a question of hours. *Med Law*. 1993;12(3-5):271-6.

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Blay SL, Toledo Pisa Peluso E. Public stigma: the community's tolerance of Alzheimer disease. *Am J Geriatr Psychiatry*. 2010 Feb;18(2):163-71.

Constantin-Vuignier N, Anchisi A. Reflections on everyday ordinariness . *Krankenpfl Soins Infirm*. 2010;103(3):40-3. French.

Fisher CB. A goodness-of-fit ethic for informed consent. *Fordham Urban Law J*. 2002 Nov;30(1):159-71.

Gailliedreau J, Schlecht P & al. Alzheimer's disease and informed consent of incapacitated people: propositions aimed at improving the procedure . *Encephale*. 1996 Nov-Dec;22(6):409-13. French.

Gwyther LP. Overcoming barriers. Home care for dementia patients. *Caring*. 1989 Aug;8(8):12-6.

Harris J. It's not NICE to discriminate. *J Med Ethics*. 2005 Jul;31(7):373-5.

Hirschman KB, Joyce CM & al. Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? *Gerontologist*. 2005 Jun;45(3):381-8.

Inouye K, Pedrazzani ES & al . Quality of life of elderly with Alzheimer's disease: a comparative study between the patients and the caregivers report. *Rev Lat Am Enfermagem*. 2010 Jan-Feb;18(1):26-32.

Parker LS. Ethical concerns in the research and treatment of complex disease. *Trends Genet*. 1995 Dec;11(12):520-3. Review.

Post SG, Whitehouse PJ. Fairhill guidelines on ethics of the care of people with Alzheimer's disease: a clinical summary. Center for Biomedical Ethics, Case Western Reserve University and the Alzheimer's Association. *J Am Geriatr Soc*. 1995 Dec;43(12):1423-9.

Jolley DJ, Benbow SM. Stigma and Alzheimer's disease: causes, consequences and a constructive approach. *Int J Clin Pract*. 2000 Mar;54(2):117-9.

Josipovic-Jelic Z, Soljan I. Alzheimer's disease patients: quality of life in the Republic of Croatia. *Bratisl Lek Listy*. 2009;110(11):705-9.

Kaduszkiewicz H, Röntgen I & al . Stigma and taboo in dementia care - does continuing education for GPs and nurses contribute to destigmatisation. *Z Gerontol Geriatr*. 2009 Apr;42(2):155-62. Epub 2008 Sep 8. German.

Karlawish JH, Casarett DJ & al. The ability of persons with Alzheimer disease (AD) to make a decision about taking an AD treatment. *Neurology*. 2005 May 10;64(9):1514-9.

Kay CJ, Licari FW. Managing patients with Alzheimer's. *J Am Dent Assoc*. 1993 Oct ;124(10):12, 14, 16.

Kendrick K. A freedom to choose. The ethics of informed consent. *Prof Nurse*. 1994 Aug;9(11):739-42.

Kim SY, Caine ED & al. Assessing the competence of persons with Alzheimer's disease in providing informed consent for participation in research. *Am J Psychiatry*. 2001 May;158(5):712-7.

Kruse A. Quality of life and satisfaction of patients with dementia. "We can prove the value of good nursing care" (interview by Katrin Balzer). *Pflege Z*. 2008 Feb;61(2):74-5. German.

Lui VW, Lam LC & al. Capacity to make treatment decisions in Chinese older persons with very mild dementia and mild Alzheimer disease. *Am J Geriatr Psychiatry*. 2009 May;17(5):428-36.

Marson DC, Ingram KK & al. Assessing the competency of patients with Alzheimer's disease under different legal standards. A prototype instrument. *Arch Neurol*. 1995 Oct;52(10):949-54.

Marson DC, Schmitt FA & al. Determining the competency of Alzheimer patients to consent to treatment and research. *Alzheimer Dis Assoc Disord*. 1994;8 Suppl 4:5-18. Review.

McQuillen MP, Tariot P. Who can say yes (or no) to a physician--and how does the physician know they can? *Neurology*. 2005 May 10;64(9):1494-5.

Murray LM, Boyd S. Protecting personhood and achieving quality of life for older adults with dementia in the U.S. health care system. *Aging Health*. 2009 Mar;21(2):350-73. Epub 2008 Dec 29.

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Rosenfeld B. The psychology of competence and informed consent: understanding decision-making with regard to clinical practice. *Fordham Urban Law J*. 2002 Nov;30(1):173-85.

Umegaki H, Suzuki Y & al. Changes in the perception of dementia in Japan. *Int Psychogeriatr*. 2009 Aug;21(4):793-5. Epub 2009 May 11.

Vandeweerd C, Paveza GJ & al. Abuse and neglect in older adults with Alzheimer's disease. *Nurs Clin North Am*. 2006 Mar;41(1):43-55, v-vi. Review.

Werner P. Discriminatory behavior towards a person with Alzheimer's disease: examining the effects of being in a nursing home. *Aging Ment Health*. 2008 Nov;12(6):786-94.

Werner P, Goldstein D, Buchbinder E. Subjective experience of family stigma as reported by children of Alzheimer's disease patients. *Qual Health Res*. 2010 Feb;20(2):159-69.

Zank S, Leipold B. The relationship between severity of dementia and subjective well-being. *Aging Ment Health*. 2001 May;5(2):191-6.

## **7/ ...Développer et garantir les compétences professionnelles par les formations initiale et continue ainsi que par le travail en équipe**

Toute personne atteinte d'une maladie d'Alzheimer ou d'une maladie apparentée, doit bénéficier des soins et des aides spécifiques que requiert son état de santé. Ces soins et aides doivent être dispensés par des intervenants formés, en nombre suffisant, que ce soit à domicile, en institution ou à l'hôpital.

*Mots-clés : Alzheimer + professional competence; teaching; patient care; multidisciplinary care*

Eayrs P. Snapshot: Alzheimer's Australia pilot of an innovative approach to consumer education and training. *Int Psychogeriatr*. 2009 Apr;21 Suppl 1:S69-71. Epub 2009 Mar 17.

Erlanger A. Experiences in the training of personnel in homes for the aged. *Soz Praventivmed*. 1987;32(3):164-7. German.

Furåker C, Nilsson A. The competence of certified nurse assistants caring for persons with dementia diseases in residential facilities. *J Psychiatr Ment Health Nurs*. 2009 Mar;16(2):146-52.

James IA, McClintock K & al. Are staff reliable informants? Identifying the triggers to challenging behaviours in dementia. *Int J Geriatr Psychiatry*. 2007 Jun;22(6):598-600.

Kemeny B, Boettcher IF & al. Using experiential techniques for staff development: liking, learning, and doing. *J Gerontol Nurs*. 2006 Aug;32(8):9-14.

Klostermann J. Nursing care of patients with dementia in the hospital: interaction requires competence and time. *Pflege Z*. 2004 Dec;57(12):841-4. German.

Smith GB. Case management guideline: Alzheimer disease and other dementias. *Lippincotts Case Manag*. 2002 Mar-Apr;7(2):77-84.

Spiegel W. Measuring general practitioners' mental health competencies. *Int J Geriatr Psychiatry*. 2007 May;22(5):499.

Otero ME, Drasković I & al. Professionals' shared competences in multidisciplinary dementia care: validation of a self-appraisal instrument. *J Am Geriatr Soc*. 2009 Sep;57(9):1719-21.

## 8/ ...Soigner, respecter et accompagner la personne malade jusqu'au terme de sa vie

Toute personne atteinte d'une maladie d'Alzheimer ou d'une maladie apparentée doit bénéficier jusqu'aux ultimes instants de sa vie des soins et attentions appropriés. Les soignants refusent tout autant le fatalisme et l'abandon des soins que l'obstination déraisonnable également inacceptable.

*Mots-clés* : Alzheimer + palliative care ; end of life ;

Berghmans RL. Ethics of end-of-life decisions in cases of dementia: views of the Royal Dutch Medical Association with some critical comments. *Alzheimer Dis Assoc Disord*. 1999 Apr-Jun;13(2):91-5.

Company at the end of life: position of the Suisse Alzheimer Association (summary). [No authors listed]. *Rev Med Suisse Romande*. 2002 Apr;122(4):207-8. French.

Evers MM, Purohit D & al. Palliative and aggressive end-of-life care for patients with dementia. *Psychiatr Serv*. 2002 May;53(5):609-13.

Filley CM, Chapman MM & al. Ethical concerns in the use of palliative drug treatment for Alzheimer's Disease. *J Neuropsychiatry Clin Neurosci*. 1996 Spring;8(2):202-5.

Francis LP. Decisionmaking at the end of life: patients with Alzheimer's or other dementias. *Georgia Law Rev*. 2001 Winter;35(2):539-92.

Freudenberg D. Decision making concerning the end of life in dementia, ethical considerations between paternalism and autonomy. *Nervenarzt*. 1998 Jul;69(7):632-3. German.

Gura C. The ethics of end-of-life care. *Alzheimer Dis Assoc Disord*. 1996 Spring;10(1):57-8.

Harvey M. Advance directives and the severely demented. *J Med Philos*. 2006 Feb;31(1):47-64.

Holmes HM, Sachs GA & al. Integrating palliative medicine into the care of persons with advanced dementia: identifying appropriate medication use. *J Am Geriatr Soc*. 2008 Jul;56(7):1306-11. Epub 2008 May 12.

Hurley AC, Volicer L. Alzheimer Disease: "It's okay, Mama, if you want to go, it's okay". *JAMA*. 2002 Nov 13;288(18):2324-31.

Kane MN, Hamlin ER 2<sup>nd</sup> & al. Perceptions of preparedness to assist elders with end-of-life care preferences. *J Soc Work End Life Palliat Care*. 2005;1(1):49-69.

Karlawish JH, Quill T & al. A consensus-based approach to providing palliative care to patients who lack decision-making capacity. ACP-ASIM End-of-Life Care Consensus Panel. American

College of Physicians-American Society of Internal Medicine. *Ann Intern Med.* 1999 May 18;130(10):835-40.

Kettl P. Helping families with end-of-life care in Alzheimer's disease. *J Clin Psychiatry.* 2007 Mar;68(3):445-50. Review.

Kim KY, Yeaman PA & al. End-of-life care for persons with Alzheimer's disease. *Psychiatr Serv.* 2005 Feb;56(2):139-41.

Kunz R. Palliative care for patients with advanced dementia: Evidence-based practice replaced by values-based practice . *Z Gerontol Geriatr.* 2003 Oct;36(5):355-9. German.

Lamb VL, Sloan FA & al. Dementia and Medicare at life's end. *Health Serv Res.* 2008 Apr;43(2):714-32.

Lopez-Tourres F, Lefebvre-Chapiro S &al. Palliative care and Alzheimer disease. *Rev Med Interne.* 2009 Jun;30(6):501-7. Epub 2008 Nov 1. French.

Mahon MM, Sorrell JM. Palliative care for people with Alzheimer's disease. *Nurs Philos.* 2008 Apr;9(2):110-20.

Mino JC, Frattini MO. Chronic palliative care: specific practices for Alzheimer's disease sufferers. *J Palliat Care.* 2009 Winter;25(4):257-63.

Pancrazi MP, Métais P. Ethical approach to Alzheimer patients at the end of life. *Soins Gerontol.* 2005 Sep-Oct;(55):33-6. French.

Potkins D, Bradley S & al. End of life treatment decisions in people with dementia: carers' views and the factors which influence them. *Int J Geriatr Psychiatry.* 2000 Nov;15(11):1005-8.

Shega JW, Levin A &al. Palliative Excellence in Alzheimer Care Efforts (PEACE): a program description. *J Palliat Med.* 2003 Apr;6(2):315-20.

Schneider-Schelte H. Accompanying patients with dementia in their last stage of life: a challenge for nursing. *Pflege Z.* 2006 Feb;59(2):100-2. German.

Robichaud AJ. Approaches to palliative therapies for Alzheimer's disease. *Curr Top Med Chem.* 2006;6(6):553-68. Review.

Vollmann J. Advance directives in patients with Alzheimer's disease. Ethical and clinical considerations. *Med Health Care Philos.* 2001;4(2):161-7.

Whitehouse PJ, Post SG & al. Dementia care at the end of life: empirical research and international collaboration. *Alzheimer Dis Assoc Disord.* 1996 Spring;10(1):3-4.

## 9/ ...Faire bénéficier la personne malade de la recherche et de ses progrès

Toute personne atteinte d'une maladie d'Alzheimer ou d'une maladie apparentée doit pouvoir bénéficier des progrès des recherches biomédicales et de santé publique, ainsi qu'en matière de sciences humaines et sociales. Ces recherches doivent être reconnues comme une priorité.

*Mots-clés* : Alzheimer + research; informed consent

Beattie BL. Consent in Alzheimer's disease research: risk/benefit factors. *Can J Neurol Sci*. 2007 Mar;34 Suppl 1:S27-31. Review.

Cahill M, Wichman A. Research involving persons with cognitive impairments: results of a survey of Alzheimer disease research centers in the United States. *Alzheimer Dis Assoc Disord*. 2000 Jan-Mar;14(1):20-7.

Cutler NR, Sramek JJ. Scientific and ethical concerns in clinical trials in Alzheimer's patients: the bridging study. *Eur J Clin Pharmacol*. 1995;48(6):421-8.

DeRenzo E. Surrogate decision making for severely cognitively impaired research subjects: the continuing debate. *Camb Q Healthc Ethics*. 1994 Fall;3(4):539-48.

Eth S, Leong GB. Toward revising the ethical boundaries of research with noncompetent subjects. *Am J Psychiatry*. 2009 Feb;166(2):131-4.

Ethical issues concerning research in patients with dementia. Società Italiana di Neurologia (SIN)--Working Group "Bioethics and Neurology". [No authors listed]. *Ital J Neurol Sci*. 1996 Oct;17(5):371-5. No abstract available. Erratum in: *Ital J Neurol Sci* 1997 Feb;18(1):68.

Fry ST. Ethical issues in Alzheimer disease research. *Alzheimer Dis Assoc Disord*. 1999 Apr-Jun;13 Suppl 1:S54-8.

High DM, Whitehouse PJ & al. Guidelines for addressing ethical and legal issues in Alzheimer disease research: a position paper. National Institute on Aging. *Alzheimer Dis Assoc Disord*. 1994;8 Suppl 4:66-74.

High DM. Advancing research with Alzheimer disease subjects: investigators' perceptions and ethical issues. *Alzheimer Dis Assoc Disord*. 1993 Fall;7(3):165-78.

High DM. Research with Alzheimer's disease subjects: informed consent and proxy decision making. *J Am Geriatr Soc*. 1992 Sep;40(9):950-7. Review.

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Lindahl C. Patients must have right to test available therapy. *akartidningen*. 1996 Mar 27;93(13):1203-4.

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Peterson G, Wallin A. Alzheimer disease ethics--informed consent and related issues in clinical trials: results of a survey among the members of the Research Ethics Committees in Sweden. *Int Psychogeriatr*. 2003 Jun;15(2):157-70.

Saks ER, Dunn LB & al. Proxy consent to research: the legal landscape. *Yale J Health Policy Law Ethics*. 2008 Winter;8(1):37-92.

Schenk DB, Gilman S. What do people at risk for Alzheimer disease think about surrogate consent for research? *Neurology*. 2006 Jun 13;66(11):1785-6.

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## 10/ ...Contribuer largement à la diffusion d'une approche éthique

Les soignants s'engagent à mieux faire reconnaître l'humanité, la dignité et les droits des personnes atteintes d'une maladie d'Alzheimer ou d'une maladie apparentée.

*Mots-clés* : Alzheimer + ethical approach ; ethic ; principle-based Ethics; dignity; humanity

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