

Supplementary Material

# Supplementary Data

**1. Clinical criteria for the diagnosis of different subtypes of dementia pag. 2**

**2. COVIDem and dementia – Survey Form A pag. 5**

**3. COVIDem and dementia – Survey Form B pag. 11**

**The impact of COVID-19 quarantine on patients with dementia and family caregivers: a nation-wide survey**

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**METHODS**

**Centers and participants enrollment**

*Diagnostic criteria*

1. Alzheimer’s disease: National Institute on Aging-Alzheimer's Association Workgroups on Diagnostic Guidelines for Alzheimer's Disease.1
2. Dementia with Lewy Bodies: Fourth Consensus Report of the DLB Consortium.2
3. Frontotemporal dementias: Behavioral Variant Frontotemporal dementia – Frontotemporal Dementia Consensus (FTDC) criteria,3 Semantic Variant Primary Progressive Aphasia and Nonfluent/agrammatic Primary Progressive Aphasia – Gorno-Tempini et al. criteria.4
4. Vascular dementia: Diagnostic Criteria for Vascular Cognitive Disorders: A VASCOG Statement.5

**References**

1. McKhann GM, Knopman DS, Chertkow H, Hyman BT, Jack CR Jr, Kawas CH, Klunk WE, Koroshetz WJ, Manly JJ, Mayeux R, Mohs RC, Morris JC, Rossor MN, Scheltens P, Carrillo MC, Thies B, Weintraub S, Phelps CH.McKhann GM, et al. [The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease.](https://pubmed.ncbi.nlm.nih.gov/21514250/?from_term=Alzheiemr+disease+NIA+criteria&from_exact_term=alzheimer+disease+nia+criteria&from_pos=1) *Alzheimers Dement* 2011;7:263-269.
2. McKeith IG, Boeve BF, Dickson DW, Halliday G, Taylor JP, Weintraub D, Aarsland D, Galvin J, Attems J, Ballard CG, Bayston A, Beach TG, Blanc F, Bohnen N, Bonanni L, Bras J, Brundin P, Burn D, Chen-Plotkin A, Duda JE, El-Agnaf O, Feldman H, Ferman TJ, Ffytche D, Fujishiro H, Galasko D, Goldman JG, Gomperts SN, Graff-Radford NR, Honig LS, Iranzo A, Kantarci K, Kaufer D, Kukull W, Lee VMY, Leverenz JB, Lewis S, Lippa C, Lunde A, Masellis M, Masliah E, McLean P, Mollenhauer B, Montine TJ, Moreno E, Mori E, Murray M, O'Brien JT, Orimo S, Postuma RB, Ramaswamy S, Ross OA, Salmon DP, Singleton A, Taylor A, Thomas A, Tiraboschi P, Toledo JB, Trojanowski JQ, Tsuang D, Walker Z, Yamada M, Kosaka K.McKeith IG, et al. Diagnosis and management of dementia with Lewy bodies: Fourth consensus report of the DLB Consortium. *Neurology* 2017;89:88-100.
3. Rascovsky K, Hodges JR, Knopman D, Mendez MF, Kramer JH, Neuhaus J, van Swieten JC, Seelaar H, Dopper EG, Onyike CU, Hillis AE, Josephs KA, Boeve BF, Kertesz A, Seeley WW, Rankin KP, Johnson JK, Gorno-Tempini ML, Rosen H, Prioleau-Latham CE, Lee A, Kipps CM, Lillo P, Piguet O, Rohrer JD, Rossor MN, Warren JD, Fox NC, Galasko D, Salmon DP, Black SE, Mesulam M, Weintraub S, Dickerson BC, Diehl-Schmid J, Pasquier F, Deramecourt V, Lebert F, Pijnenburg Y, Chow TW, Manes F, Grafman J, Cappa SF, Freedman M, Grossman M, Miller BL. Rascovsky K, et al. Sensitivity of revised diagnostic criteria for the behavioural variant of frontotemporal dementia. *Brain* 2011;134:2456-2477.
4. Gorno-Tempini ML, Hillis AE, Weintraub S, Kertesz A, Mendez M, Cappa SF, Grossman M. Classification of primary progressive aphasia and its variants. *Neurology* 2011;76:1006–1014.
5. Sachdev P, Kalaria R, O'Brien J, Skoog I, Alladi S, Black SE, Blacker D, Blazer DG, Chen C, Chui H, Ganguli M, Jellinger K, Jeste DV, Pasquier F, Paulsen J, Prins N, Rockwood K, Roman G, Scheltens P; Internationlal Society for Vascular Behavioral and Cognitive Disorders, et al. Diagnostic criteria for vascular cognitive disorders: a VASCOG statement. *Alzheimer Dis Assoc Disord* 2014;28(3):206-218.

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2. COVID-19 and dementia – Form A

Form A

**A.1 Caregiver**

Sex: Male \_\_\_ Female \_\_\_

Age \_\_\_\_\_\_\_\_ Education (years)\_\_\_\_\_\_\_\_

Relative of the person with dementia (type):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

* Do you live with the person suffering from dementia?

YES\_\_\_\_\_

NO\_\_\_\_\_

* If so, were you already living together before quarantine?

YES\_\_\_\_\_

 NO\_\_\_\_\_

* If not, is the patient institutionalized?

YES\_\_\_\_\_

NO\_\_\_\_\_

 Have you the possibility to see him regularly

YES\_\_\_\_

NO\_\_\_\_

* Are there other people in the house?

YES\_\_\_\_\_

NO\_\_\_\_\_

* Are you working during quarentine?

YES\_\_\_\_\_

NO\_\_\_\_\_

* Has your life changed with quarentine?

NO

YES, I have less time to devote to myself.

YES, I have relationship problems with other family members.

 7) Has the relationship with your relative changed?

NO

YES, increase of conflicts

YES, improvement of the relationship

 8) Are you concerned about possible consequences of COVID 19 on the patient's health?

YES\_\_\_\_\_

NO\_\_\_\_\_

9) Do you think that specific guidance on the prevention of COVID 19 infection in patients with dementia may be useful?

YES\_\_\_\_\_

NO\_\_\_\_\_

10) In general, are you experiencing problems in care/therapeutic continuity?

YES\_\_\_\_\_

NO\_\_\_\_\_

 11) Have you been in the situation to search first aid services (out-of-hours service doctor/ emergency medical care) for yourself or the patient due to the lack of assistance on the territory by the medical practitioner (family doctor) or specialist consultant?

YES\_\_\_\_\_

NO\_\_\_\_\_

 12) Would you be in favour of the use of tools such as telephones and computers, and use of remote psychological support for outpatient visits in suspended services?

YES\_\_\_\_\_

NO\_\_\_\_\_

 13) Did you receive any help or support during the COVID emergency?

NO

Yes, by the family

Yes, from the neighbours/friends

Yes, from the Municipality

Yes, from volunteering (associations, parishes, red cross, others)

 14) Did you feel isolated or abandoned during the COVID emergency?

YES\_\_\_\_\_

NO\_\_\_\_\_

 15 Did you feel overwhelmed or helpless?

YES\_\_\_\_\_

NO\_\_\_\_\_

 16 Did you present

anguish Yes \_\_\_No\_\_\_

 depression Yes \_\_\_No\_\_\_

anxiety Yes \_\_\_No\_\_\_

 irritability Yes \_\_\_No\_\_\_

**A.2 Patient**

Age\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Sex: Male \_\_\_ Female \_\_\_

Type of dementia: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Year of dementia onset\_\_\_\_\_\_\_\_\_\_\_\_

Quarantine start date: \_\_\_ / \_\_\_ / \_\_\_

1. Before quarantine the patient was used to get out of the house

Yes, independently \_\_\_

Yes, accompanied, \_\_\_

No \_\_\_

2) What is the stage of the disease?

Mild

Moderate

Severe

Bedridden

3) Have you noticed patient’s behavioural changes since the beginning of the quarantine?

YES\_\_\_\_\_

NO\_\_\_\_\_

If Yes, what are the behavioral symptoms that have increased in intensity but were already present before quarantine?

o Apathy (reduction of initiative)

o Anxiety

o Depression

o Sleep disorders

o Delusions (i.e. the patient has thoughts that someone wants to hurt him, steal from him, kill him, etc.).

o Hallucinations (the patient sees or hears things or people that are not there)

o Irritability

o Aggressiveness

o Wandering (the patient walks around aimlessly and irrepressibly)

o Agitation

o Change in appetite

4) Did you notice any new behavioral symptoms, which were not present before the quarantine period?

o There were no new symptoms detected

o Apathy (reduction of initiative)

o Anxiety

o Depression

o Sleep disorders

o Delusions (the patient has thoughts that someone wants to hurt him, wants to rob him, kill him etc.)

o Hallucinations (seeing and hearing things or people who are not there)

o Irritability

o Aggressiveness

o Wandering (walking around aimlessly and irrepressibly)

o Agitation

o Change in appetite

5) Because of these disorders, was it necessary to change the medication therapy?

YES\_\_\_\_\_

NO\_\_\_\_\_

 6) Have you noticed any changes in the patient’s motor performances in the last month?

o I think he/she walks better than before

o No

o He/she walks slower

o He/she can't stand up independently from the chair anymore.

o He/she doesn't get up from bed anymore

7) Have you noticed any changes in the patient’s cognitive symptoms that were present before quarantine?

NO\_\_\_\_\_\_\_

YES\_\_\_\_\_\_

o Increased confusion

o Greater forgetfulness

o More difficulty in finding the correct words

o In-door space disorientation and difficulties of house recognition

o Disorientation in time

o Loss of recognition of family members

o Troubles of self-recognition in the mirror

8) Do you think the disease has progressed faster during the quarantine period?

YES\_\_\_\_\_

NO, I think it's taking its natural course\_\_\_\_\_\_

9) Is the patient aware of the COVID emergency?

YES\_\_\_\_\_

PARTIALLY \_\_\_\_

NO\_\_\_\_\_

Date .......................................................................................

3. COVID-19 and dementia – Form B

**FORM B**

A1. DESCRIPTION of CDCD (centres for cognitive decline and dementia)

1. Region of the CDCD \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

2. The centre is: university clinic \_\_\_ hospital clinic \_\_\_ local service\_\_\_

3. On average, how many outpatient visits of patients with dementia per month are made (refer to the period before COVID pandemic)? \_\_\_\_\_\_\_\_

4. Is psychological counselling available for caregivers?

YES\_\_\_\_\_

NO\_\_\_\_\_

5. Is a social worker available?

YES\_\_\_\_\_

NO\_\_\_\_\_

A.2 CHANGE IN SERVICES PROVIDED BY THE CDCD DUE TO QUARANTINE

1. Has normal outpatient activity been suspended?

YES, since\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

NO, the activity has remained unchanged

NO, but the activity has been greatly reduced

2. Has hospitalisation been suspended?

YES, since\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

NO\_\_\_\_\_

3. Has teleconsultation visit been activated? Yes \_\_\_ No \_\_\_

YES\_\_\_\_\_

NO\_\_\_\_\_

4. the deadline of therapeutic schedules have been automatically extended beyond the regulatory rules of the Region?

YES\_\_\_\_\_

NO\_\_\_\_\_

5. Has the caregiver support service been activated?

YES\_\_\_\_\_

NO\_\_\_\_\_

6. Is there a way to renew the therapeutic schedules through e-mail after telephone consultation with caregivers?

YES\_\_\_\_\_

NO\_\_\_\_\_

7. Is there the possibility of urgent visits for cognitive deficit or behavioural disorders?

YES\_\_\_\_\_

NO\_\_\_\_\_

8. Have drug trials (profit and non-profit) been suspended?

YES\_\_\_\_\_

NO\_\_\_\_\_

9. Have the semi-residential and residential services you manage (Day Centre, Alzheimer's Café) been suspended?

YES\_\_\_\_\_

NO\_\_\_\_\_

Date \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_.