

# Supplementary Material

## Mental Health of People with Dementia During COVID-19 Pandemic: What Have We Learned from the First Wave?

### Survey

#### CAREGIVER INFORMATION

What is your relationship with your family member suffering from dementia?

- Spouse
- Child
- Grandchild
- Brother or Sister
- Other

You are:

- a man
- a woman

How old are you?

What is your family situation?

- Single
- Married
- In cohabitation

- Divorced
- Separated
- Widowed
- Other

Do you currently have a professional activity?

- Yes
- No

Your family member is:

- a man
- a woman

### **PATIENT INFORMATION**

How old is she/he? \_\_\_\_\_years old

Does your family member suffer from one or more than one of these diseases?

- Alzheimer's disease
- Parkinson's disease
- Lewy body disease
- Frontotemporal disease
- Cerebrovascular disease
- Other: .....

Diagnosis not formulated or unknown

How long ago was the diagnosis announced?

Less than 1 year

Between 1 and 5 years

More than 5 years

No diagnosis

Has your family member ever been hospitalized for behavioral or psychological disorders?

Yes

No

If yes, in which type of department?

Emergency department

Geriatric department

Neurology department

Psychiatry Department

Cognitive-Behavioral Unit (CBU)

## **COVID 19**

Do you think you are at risk of developing a severe form of COVID-19 infection?

Yes

No

I don't know

Do you think your family member is at risk of developing a severe form of COVID-19 infection?

Yes

No

I don't know

Do you know people around you who are suffering or have suffered from COVID-19?

Yes

No

I don't know

Do you know people around you who have been hospitalized due to COVID-19?

Yes in medical department

Yes in intensive care unit

No

Do you know people around you who died due to COVID-19?

Yes

No

I don't know

Does your family member express concerns about COVID-19?

- Yes
- No
- Not concerned

## **YOUR NETWORK BEFORE LOCKDOWN**

### **PATIENTS' FAMILY ASSOCIATION**

Have you ever contacted a family association and / or are you a member of a family association?

- Yes
- No

If yes which one (s): \_\_\_\_\_

Have you benefited from training interventions for caregivers provided by an association? (France Alzheimer for example)?

- Yes
- No

Have you ever participated in support groups for caregivers or memory coffee?

- Yes
- No

During lockdown, did you receive any contact from families association?

- Yes, for the first time
- Yes, but I already did it before
- No

### **IMPACT OF LOCKDOWN ON THE PATIENT**

Does your family member live:

- with his/her spouse / partner
- with his/her children
- with another person
- alone

Do you live with your family member?

- Yes
- No

The living conditions of your family member:

• Housing type

- Individual house
- Apartment

• Does he/she feel cramped in his/her accommodation?

Yes

No

• Has he/she got an exterior (garden or courtyard)?

Yes

No

• Has he an internet connection and computer tools?

Yes

No

## **HELP AND PROFESIONAL SUPPORTS FOR PATIENTS**

• Before lockdown, which home help or supports were initiated?

Portage of meals

Daycare help

Day hospital

Senior club

Home nurse visit

Home medical visit

Life assistant

Housekeeper

Physiotherapist

Speech therapist

Not concerned

Since lockdown, help or home supports were initiated:

Portage of meals

Daycare help

Day hospital

Senior club

Home nurse visit

Home medical visit

Life assistant

Housekeeper

Physiotherapist

Speech therapist

Not concerned

## **FAMILY CONTACTS**

• Preservation of a remote family contact

Yes

No

• Preservation of a physical family contact



Yes

No

• Total lockdown (no exit at all)

Yes

No

### **I DO NOT LIVE WITH THE PATIENT**

The following questions only concern caregivers who do not live with your family member.

• If you do not live with your family member every day of the week, have you changed the frequency of your visits to their home during lockdown?

Yes, my visits are more frequent

Yes, my visits are less frequent

No, I have the same number of visits

Not concerned

• If you do not live with your family member every day of the week, have you changed the frequency of your electronic contacts (phone, text, video call, social networks) during lockdown?

Yes, my contacts are more frequent

Yes, my contacts are less frequent

No, I have the same number of contacts

Not concerned

• Did the lockdown context make visits more complex to carry out?

Yes

No

Not concerned

• Do you communicate by videophone or other tools with your family member (Skype, Whatsapp etc ...)?

Yes

No

Not concerned

### **MY PRESENCE AND HELP I PROVIDE TO THE PATIENT**

• Since the start of the lockdown, do you help your family member even more

Yes

No

• Since the start of the lockdown do you feel more isolated by accompanying your family member?

Yes

No

• Before lockdown, did you help your family member with:

(Indicate on a scale from 0 (I do not take care of him at all) - 1 (we take care of each other as much as I do) to 2 (I completely take care of him/her))

- |   |                            |                            |                            |
|---|----------------------------|----------------------------|----------------------------|
| Groceries                               | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| Administrative management               | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| Housework                               | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| His/her therapeutic and drug management | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |

• From lockdown, did you help your family member with:

(Indicate on a scale from 0 (I do not take care of him at all) - 1 (we take care of each other) to 2 (I take care of him completely))

- |   |                            |                            |                            |
|---|----------------------------|----------------------------|----------------------------|
| Groceries                               | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| Administrative procedures               | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| Housework                               | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| His/her therapeutic and drug management | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| The use of travel certificates          | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| Respect for barrier gestures            | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |

• Since the beginning of lockdown, do you feel the need to benefit from:

- |                    |                              |                             |
|--------------------|------------------------------|-----------------------------|
| Psychological help | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Material aid       | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Periods of respite | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

• Has confinement created specific needs or difficulties for your family member:

Yes                      If yes, which ones ?

No

## **RELATIONSHIP WITH THE PATIENT**

• During confinement, relations with my closed one became:

Easier

Unchanged

More difficult

• Has the period of confinement changed your level of worry about your closed one?

I am less worried than before

My level of worry has not changed

I am more worried than before

## **IMPACT OF LOCKDOWN ON PATIENTS**

Alzheimer's disease and related disorders are sometimes accompanied by behavioral and psychological symptoms. Lockdown can generate changes in this symptomatology.

Before lockdown, have you noticed behavioural changes in your family member?

Yes

No

I don't know

Since lockdown, have you noticed behavioural changes in your family member?

No

Yes, although he/she did not present any one before

Yes, but these manifestations are not more important than before

Yes, these manifestations are more important than before

If yes, what are the behavioural symptoms that have increased in intensity

Anxiety

Depression

Irritability or aggressiveness

Insomnia

Hallucinations

Delusions

Loss of energy, unusual decrease in motivation or activities

Since the beginning of lockdown, has your family member been hospitalized because of recent emergence or worsening of his/her psychological and/or behavioral difficulties?

In emergency department

In geriatrics

In neurology unit

In psychiatric unit

- In Cognitive-Behavioral unit (CBU)
- None of the mentioned departments

Do you encounter other specific needs or difficulties caused by lockdown on your family member?

- Yes
- No

If yes, which ones: \_\_\_\_\_

## **IMPACT OF LOCKDOWN ON PATIENT IN NURSING-HOME**

### **CAREGIVERS INFORMATION**

Do you accompany a family member residing in nursing-home?

- Yes  No

What is your relationship your family member?

- Spouse
- Child
- Grandchildren
- Brother or Sister
- Mother
- Father

Other: .....

You are:

a man

a woman

How old are you: \_\_\_\_\_years old

What is your family situation?

Single

Married

Cohabiting

Divorced

Separated

Widowed

Other

Currently do you have a professional activity?

Yes / no / not concerned

If yes: Are you teleworking during the lockdown?

Yes

No

Before this pandemic, had you ever personally experienced depression / burnout? Yes No

## THE PATIENT

Your family member:

a man

a woman

How old is your family member? .....years old

Does your family member suffer from one or more than one of these diseases?

Alzheimer's disease

Parkinson's disease

Lewy body disease

Frontotemporal disease

cerebro-vascular disease

Diagnosis not formulated or not known to you

Other: .....

How long ago did the first signs of the disease appear?

Less than 1 year

Between 1 and 5 years

More than 5 years



How long ago was the diagnosis announced?

- Less than 1 year
- Between 1 and 5 years
- More than 5 years
- No diagnosis

Has your family member ever been hospitalized for behavioral or psychological troubles in one of the following departments?

- Yes
- No

If yes, in what type of department?

- Emergency department
- Geriatric department
- Department of neurology
- Department of psychiatry
- Cognitive-Behavioral Unit (CCU)

## **COVID-19**

Do you think you are at risk of developing a severe form of COVID-19 infection?

- Yes
- No

I don't know

Do you think your family member is at risk of developing a severe form of COVID-19 infection?

Yes

No

I don't know

Do you think you have been affected by COVID-19?

Yes

No

Do you think your family member has been affected by COVID-19?

Yes

No

### **IMPACT OF LOCKDOWN ON THE WAY TO ACCOMPANY THE PATIENT**

Before lockdown, how often did you visit your family member?

Daily

Several times a week

Once a week

Between 2 to 3 times a month

once a month

Less than once a month

Before lockdown, how often did you have call contact with your family member?

- Daily
- Several times a week
- Once a week
- Between 2 to 3 times a month
- Once per month
- Less than once a month

Since lockdown, can you communicate with your family member by phone?

- Never
- As many times as you want
- At least once a day
- At least once a week

Since lockdown, do you have the possibility to communicate with your family member by videoconference?

- YES
- NO

Since lockdown, do you think that information provided by the healthcare team concerning physical and psychological state of your family member is:

- Sufficient
- Insufficient

No answer

Since the end of lockdown measures, have you been able to visit your family member?

YES

NO

If yes, how many times?