



# COVID-19 and clients of long-term care in Finland - impact and measures to control the virus

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## 1. Key points

- Finland has succeeded in protecting people aged 70 years and over from coronavirus in general, but almost half of the 318 deaths in the country have occurred in care homes for older people (situation on 1<sup>st</sup> June). However, it is likely that all deaths from COVID-19 have not been recognised and classified similarly.
- There are remarkable regional differences in the spread of the infection. However, the national guidelines for restrictions are similar throughout the country.
- The national level guidelines have been more detailed and clearer for care homes than for home care.
- The implementation of the measures to prevent the infection has varied between municipalities, however, most of the municipalities have acted vigorously regarding the prevention of the virus and followed the given instructions.
- Family caregivers and their disabled family members living at private homes face more mental, physical and social problems the longer the isolation continues. The need for support services in isolation will not disappear and may even increase.
- In care homes, visiting restrictions have in some cases led to anxiety concerning family members. In exposure cases, some of the residents have had relatively long periods of isolation, during which mobility within the care unit is limited. Therefore, attempts have been made to prevent a possible deterioration in mental well-being, for example by providing video calls and photographs to the residents.

## 2. Introduction

World Health Organisation (WHO) announced on 11<sup>th</sup> March 2020 that COVID-19 can be characterised as a pandemic. On 16<sup>th</sup> March, the Finnish Government announced a state of emergency. The aim of the state of emergency is to protect the population and to safeguard the function of society and the economy [1].

The first coronavirus case in Finland was confirmed in the University Hospital of Lapland, but rapidly the cases concentrated into the Uusimaa region (the capital city Helsinki and the surrounding county). The district was isolated from the rest of the country from 27<sup>th</sup> March to 15<sup>th</sup> April. Now the virus has spread all over the country, although the incidence varies widely between the regions [2].

As older people are at risk of a serious form of COVID-19 and mortality is higher among them than among younger people, the Government recommended on 16<sup>th</sup> March that people aged 70 years or older should live in quarantine-like conditions. This means minimizing physical contacts with other people. Visits of family and relatives to care homes were forbidden. The recommendations have been followed quite well, but now, after two months in state of emergency, critical voices are arising and there is concern about a loss of physical and social functional ability among older people [3].

On 22<sup>nd</sup> May, restrictions were beginning to be cancelled, but these cancellations do not concern older people. They are advised to continue avoiding physical contacts. However, older people may meet their

families and friends outside with a 2-metre distance between them. [4] Visits to care homes are still forbidden, however, optional ways to meet family member living in care homes have been developed.

The Government has suggested moving to a 'hybrid strategy', i.e., moving from extensive restrictions to enhanced management of the epidemic. The strategy focuses on testing, tracing, isolating and treating. The Government has called together a science panel to provide advice on exit strategy measures and mitigation of impacts. A wide range of experts have been invited, but it has been noted that the panel lacks expertise of aging and gerontology. [4]

Testing capacity in Finland has been restricted and the Finnish institute for health and welfare (THL) issued guidance that testing should focus on patients with severe respiratory tract infection symptoms and health care and social welfare personnel. Later, the criteria have been broadened to include people with mild symptoms, those returning from abroad and risk groups, e.g., older people. However, only people suspected to be infected are tested, and a physician's referral is required. [4]

Thousands of elective surgeries and appointments in outpatient health care have been cancelled, to guarantee care for people with COVID-19 [5]. In addition, many people have cancelled their appointments themselves, resulting in a tens of percents drop in admissions. There has been concern that 1) people who need care do not seek it and 2) the need for care will cumulate and after the immediate crisis, there will be a massive need for care. It has been assessed that shortening the queue will take at least several months or even a couple of years [5].

In this report, we describe the number of positive cases and deaths in the population and among older people in round-the-clock long-term care (LTC). We describe the restrictions and their effects on older people, the public discussion and the ways in which municipalities have implemented the national level guidelines in home care and round-the-clock LTC. We use the statistics of THL and Statistics Finland, and figures provided by municipalities and news reported in media. In addition, we use interview data and information provided by NGO's, the Association of Local and Regional Authorities and one case municipality.

### **3. Impact of COVID-19 on the whole population so far**

#### **3.1. Number of positive cases in whole population and deaths**

Situation on 7<sup>th</sup> June 2020

Total samples tested: approximately 201,000 (+500 \*)

Total number of cases reported: 6,981 (+ 17 \*)

323 (+ 1\*) COVID-19-related deaths have been reported.

\* Amount changed from previous day.

In relation to the Finnish population (5,543,233), the total incidence is 126 cases per 100,000 inhabitants. [6]

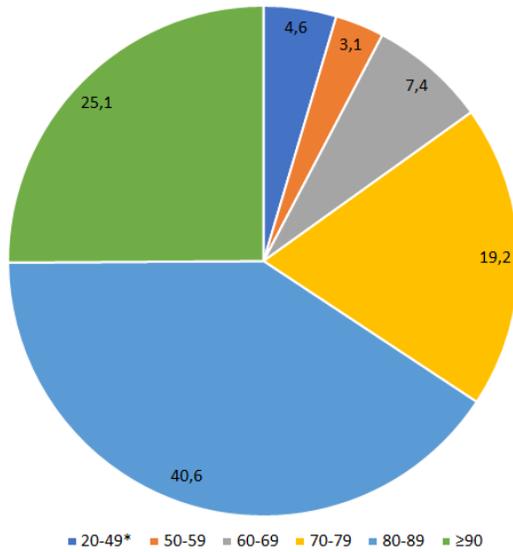
#### **3.2. Age and gender distribution of COVIDS-19-related deaths**

The number of COVID-19-related deaths is the highest among people aged 80-89 years, and the second highest among people aged 90 or older (Figure 1). Based on statistics on 7<sup>th</sup> June, 48% of COVID-19-related deaths are men and 52% are women. The median age of the deceased is 84 years. [6]

Preliminary mortality statistics by Statistics Finland do not show extensive differences in the number of all deaths between spring 2020 and earlier years. Figure 2. shows the numbers of deaths among the age group in which COVID-19-related deaths are the highest, i.e. men and women aged 80-89 years, during

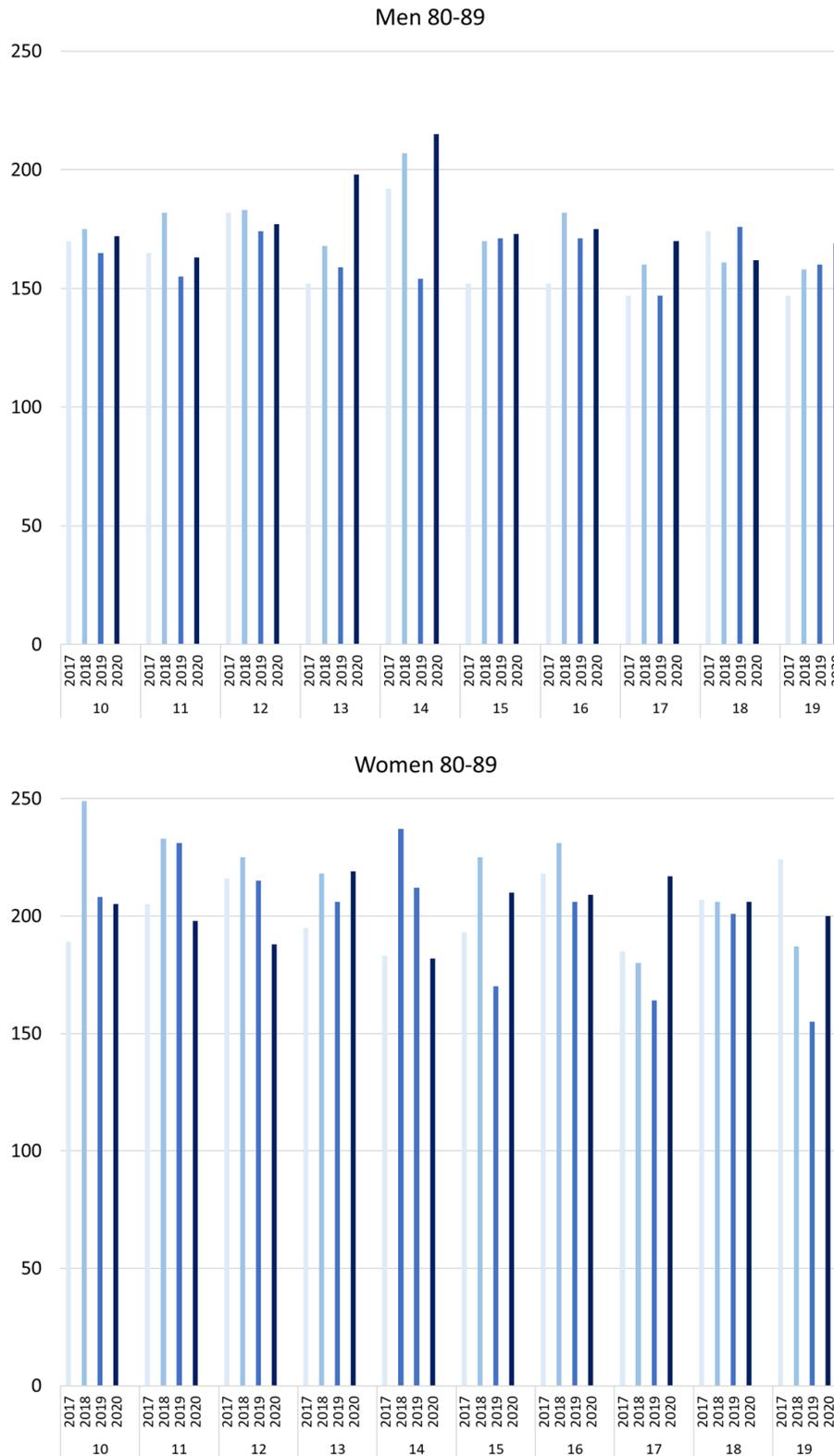
weeks no. 10-19 in 2017, 2018, 2019 and 2020. Weeks no. 10-19 in 2020 include time period 1<sup>st</sup> March – 10<sup>th</sup> May. The only slightly higher peaks in 2020 are in men aged 80-89 years during weeks 13-14 that cover dates from 23<sup>rd</sup> March to 5<sup>th</sup> April, and in women during weeks 17 and 19. [7]

**Figure 1. Age distribution of COVID-19-related deaths. Percentages.**



\* In the three age groups 20-29, 30-39 and 40-49, there are <5 COVID-19-related deaths per age group. [5]

**Figure 2. Number of all deaths in weeks 10-19 among men and women aged 80-89. The years 2017-2020 (2020 preliminary data). [6]**



### 3.3. Regional differences in the spread of COVID-19

The coronavirus has been most prevalent in the Uusimaa region, which is the area with the highest population density in Finland. The hospital district in Uusimaa has cared for most of the intensive care patients in Finland. On 8<sup>th</sup> June, there were 5,128 coronavirus cases in Helsinki and Uusimaa region. The incidence ratio was 304 / 100 000 inhabitants. (Source: Finnish Institute for Health and Welfare / National Infectious Disease Register)

In all, the incidence rate based on confirmed coronavirus cases varies notably within the country from the high rates in Helsinki to the lowest incidence rate in North Karelia (14.6). [8]

## 4. Impact of COVID-19 on long-term care users so far

### 4.1. Brief background to the long-term care system

In Finland municipalities are responsible for organising health and social services for their residents. Municipalities may provide services themselves or jointly with other municipalities or purchase the services from private for-profit or not-for-profit actors. [9]

Care for older people (usually aged 75 years or older) is primarily offered at home (Table 1). Family caregiving is supported and home care (help and nursing) and support services (meals-on-wheels, bathing, cleaning etc.) are provided for those in need. Clients of home care use outpatient and inpatient services in health centres (primary care) and hospitals (secondary and tertiary care). Home care clients had, on average, 29 inpatient hospital care days in Tampere in 2018 [10].

Round-the-clock LTC is allocated for those with the highest need of care, and home care is emphasised [11]. Most of the older people in round-the clock care have cognitive impairment [12]. Round-the-clock care is provided most often in sheltered housing with 24-hour assistance. Sheltered housing has widely replaced institutional care provided in nursing homes and inpatient wards of health centres [13]. Health centres have an important role in care for older people, nowadays more in acute care instead of the earlier LTC role. It also serves as an important place of end-of-life care and place of death. [14,15]

**Table 1. Coverage (%) of services in 2018.**

	75+	85+
At home without formal care	75	53
Support for informal care	5	7
Regular home care	11	22
Round-the-clock care	9	18
Total	100	100

*Source:* [12]

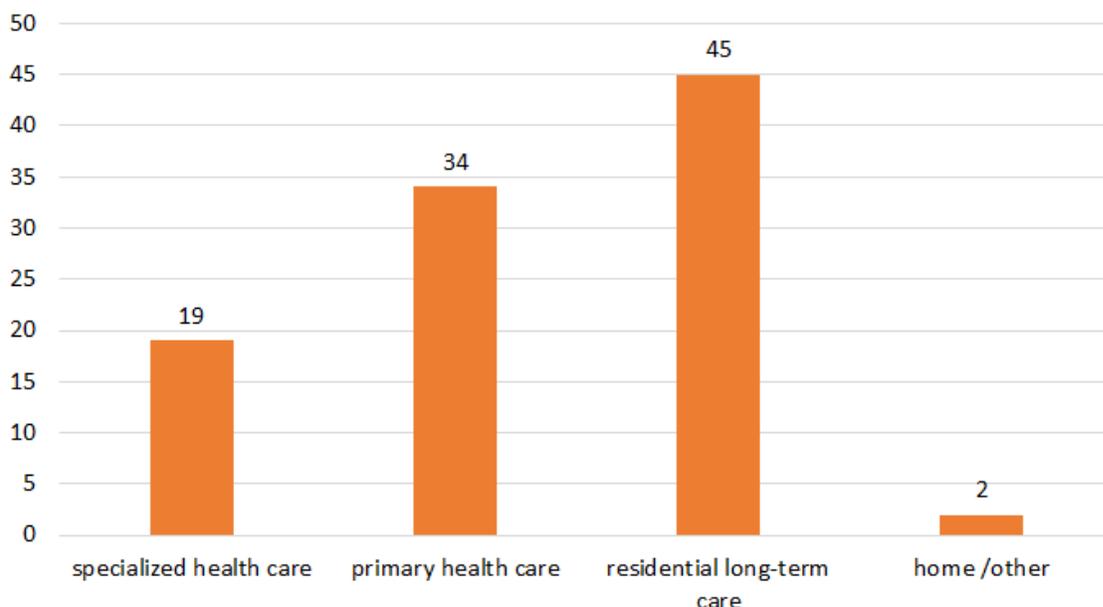
In the last decade, the role of the for-profit private sector has increased, and half of sheltered housing for older people is provided by the private sector [9,13]. Older people seldom purchase the private care themselves, and most often care is outsourced by municipalities. In 2019, several shortcomings were

revealed in care for older people, especially in private sector care homes (by care homes, we mean all round-the-clock LTC facilities). This ‘care crisis’ caused a public uproar and some care homes were closed or municipalities took the responsibility for providing care in them. Some of the shortcomings have been fixed with guidance and close monitoring, and it has been assessed that the situation in care homes was, to some extent, better when the COVID-19 pandemic arrived than earlier [16]. The Act on care services for older people is under reform and a minimum number (0.7) of nurses per clients will be required by April 2023.

## 4.2. Places of death for COVID-19-related deaths

According to the statistics by the Finnish Institute for Health and Welfare, almost half of the COVID-19 deaths have occurred in care homes. The second most common place of death was primary health care.[6]. It should be noted, though, that these figures only reveal the place of death, hence it is not yet known how many people who died in the health care unit were hospitalized from home and how many from care homes.

**Figure 3. Places of death for COVID-19-related deaths. Percentages (%) in different places. (June 8, 2020) [6].**



## 4.3. Rates of infection and mortality among long-term care users

The number of coronavirus cases varies greatly across the country. However, as the total number of coronavirus cases is highest in Uusimaa and Helsinki region, the number of coronavirus cases in care homes is also high there. In Helsinki by 7<sup>th</sup> May, infections were reported in 36 care homes in total (constitutes 12% or care homes in Helsinki). The first infections in care homes in the Helsinki area were identified at the end of March 2020. Since the beginning of the epidemic, 132 care home residents have had a coronavirus infection, which is 3% of all residents of care homes in Helsinki. Eighty of the residents have died of COVID-19. Some of them have died in care homes and some have been hospitalized. Infections were reported in both the care homes of the City of Helsinki and those private LTC facilities from which Helsinki purchases the services. [17].

There are smaller areas in Finland with a relatively high number of COVID-19 cases. This is due to situations where, for example, one person has infected several other residents of a care home. One of the most infamous is the nursing home in Kiuruvesi, Northern Savonia region, where approximately a third of the residents died. In this residential home, owned by a private company Attendo, medication and medical care were not carried out properly, staff were insufficient and, for example, cleaning and hygiene were not adequately taken care of. Thus, the care home was transferred from Attendo to the responsibility of the Northern Savonia Health and Social care Municipal Association. The transfer was made because client and patient safety in the care home was assessed to be endangered. [18].

## **5. Long-term care policy and practice measures**

### **5.1. Responsibilities of the authorities in prevention and care of infectious disease**

The Ministry of Social Affairs and Health has the responsibility for the general planning, guidance and monitoring of the prevention of infectious diseases under the Finnish Government. The Ministry directs, monitors and coordinates health care and social welfare services' preparedness for incidents and emergencies together with other operators. [19]

Another important national operator is THL, which among other things, guides and supports municipalities, hospital districts and regional state administrative agencies in their work to prevent infectious diseases and gives the public guidance on how to avoid infection and prevent the spread of disease. THL is an independent national research institute operating under the Ministry of Social Affairs and Health. [19]

National directions are implemented at the local level by the municipalities that are responsible for the prevention and care of infectious diseases in their respective areas. [19] Outpatient care of infected people living at home is provided at municipal health centres. Those older people who live in care homes are supposed to receive primary health care in their residence, but there are no resources for acute or specialized medical care available in these facilities. Thus, both those living at home and in care homes who are severely ill are treated at inpatient wards at the health centres or in the central hospitals of the hospital districts.

In Finland, each municipality need to pertain in a hospital district that offers specialized health care [9]. These hospital districts are experts in the prevention of infectious diseases in their respective regions [19] and as such they have also given instructors to the municipalities [20].

### **5.2. Whole sector measures**

The measures that the Finnish Government launched on 16<sup>th</sup> March had several effects on care for older people. First, as it was issued that people aged 70 years and older must refrain from contact with other persons to the extent possible (quarantine-like conditions), also the visits of family members who take care of the older people living at home were supposed to be restricted. Secondly, visits to both long and short-term care facilities for older people, such as care homes and hospitals, were prohibited with few exceptions. [21, 4] Also related to old age care, the Government declared that the capacity of health care and social welfare services will be increased in the public and private sectors, and non-urgent activities will be reduced. The capacity of the private sector, as well-trained professionals in health care and social welfare who currently worked elsewhere, was planned to be mobilised for work in the public sector as necessary. [21]

At the end of March, national operators issued several guidelines for both the care homes and home care [incl. 22, 23]. These guidelines were supplemented a few times as the situation progressed in April and May. One key guideline was to avoid transfers between the care sites, such as between care homes and hospitals, whenever possible. Transfers were allowed only for medical reasons, and the new treatment site had to be notified on whether the person had had respiratory symptoms. [22]

The guidelines for both LTC units and home care are summarized in Table 2. Most of the guidelines at the national level were not binding on municipalities which means that municipalities have also had the opportunity to disregard them. For example, while in some municipalities the visiting bans were implemented already before the Government’s guidelines [24], in other municipalities these were still not being followed by end of April [25]. Also, as there have been regional variations in the spread of the virus, in some parts of Finland the restrictions could have been dismantled earlier [26].

**Table 2. Guidelines for round-the-clock service houses\* and home care\*\* to prevent infection and the spread of the coronavirus.**

Round-the-clock service houses	Home care
<ul style="list-style-type: none"> <li>- Make sure <b>staff do not come to work sick</b>.</li> <li>- Make sure that <b>staff turnover is kept to a minimum</b>.</li> <li>- Follow national guidelines on <b>visiting bans</b>. If visits are necessary, make sure visitor is not ill.</li> <li>- <b>Inform</b> residents and staff about the communicable disease situation.</li> <li>- <b>Avoid transfers between care sites</b>. If transit is necessary, make sure the new resident is not exposed to COVID-19 infection. If exposed, he should be quarantined in a single room, if possible. Monitor new residents entering the unit for symptoms of respiratory infections.</li> <li>- Make sure there is a <b>contact person in the unit</b> (e.g. hygiene contact person)</li> <li>- Emphasize <b>careful hand and cough hygiene</b> for staff, residents, and visitors.</li> <li>- Ensure that personnel are <b>properly protected</b>.</li> <li>- <b>In addition to the usual precautions</b> for contact with a resident with a respiratory infection, <b>follow contact and droplet precautions</b>.</li> <li>- Wear the following protective equipment: disposable gloves, surgical nasal protection and goggles or visor surgical nasal protection, protective sleeve / apron. Ensure hand hygiene before putting on protective equipment and immediately after removing it. Ensure the availability of protective equipment.</li> <li>- Provide a <b>single room</b> for symptomatic or exposed residents, if possible.</li> <li>- if the unit has symptomatic residents <b>restrict the use of common areas</b> + Test also asymptomatic staff and residents (added 9<sup>th</sup> April)</li> <li>- Ensure that <b>guards</b> are available.</li> </ul>	<ul style="list-style-type: none"> <li>- Make sure <b>staff do not come to work sick</b>.</li> <li>- <b>Inform</b> residents and staff about the communicable disease situation.</li> <li>- <b>Report possible symptoms</b> of a respiratory infection <b>when a client moves</b> from home to a hospital or LTC unit.</li> <li>- Make sure <b>staff know how to act</b> at different times of the day if a client is suspected of having a coronavirus infection.</li> <li>- Emphasize <b>careful hand and cough hygiene</b> for staff, residents, and visitors.</li> <li>- Ensure that personnel are <b>properly protected</b>. Make sure staff have access to an alcoholic hand sanitizer or the option to wash their hands with water and soap.</li> <li>- Always <b>follow standard precautions</b> when treating all customers. Inform clients/visitors about any additional precautions. Follow standard precautions and contact and droplet precautions when treating a resident with a respiratory infection.</li> <li>- <b>Ensure the availability of protective equipment</b> (disposable protective gloves, surgical mouth-nose protection, eye protection and apron)</li> <li>- <b>Provide guidance and training to staff</b> on infection prevention and control practices.</li> <li>- <b>Monitor</b> whether <b>clients or staff</b> develop symptoms of respiratory infections (collaborate with occupational health care).</li> </ul>

<ul style="list-style-type: none"> <li>- <b>Provide guidance and training to staff</b> on infection prevention and control practices. Train staff to identify symptoms of a respiratory infection and report them immediately to a doctor or nurse.</li> <li>- <b>Monitor</b> whether <b>residents or staff develop symptoms</b> of respiratory infections (collaborate with occupational health care).</li> <li>- <b>Intensify the cleaning</b> of the treatment environment.</li> <li>- <b>Check for problems with the use of personal protective equipment.</b> Also consider the use of protective equipment in the treatment of asymptomatic residents in situations where infections have been reported in unit residents.</li> </ul>	
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\*mostly dated 21<sup>st</sup> April, \*\*Mostly dated in 30<sup>th</sup> March.

Sources: THL (2020) Prevention of Corona virus infection at long-term care units. <https://thl.fi/fi/web/infektiaudit-ja-rokotukset/taudit-ja-torjunta/taudit-ja-taudinaiheuttajat-a-o/koronavirus-covid-19/koronavirustartuntojen-torjunta-pitkaaikaishoidon-ja-hoivan-toimintayksikoissa> (Referred 8<sup>th</sup> May 2020); THL (2020) Prevention of Corona virus infection at home care. <https://thl.fi/fi/web/infektiaudit-ja-rokotukset/taudit-ja-torjunta/taudit-ja-taudinaiheuttajat-a-o/koronavirus-covid-19/koronavirustartuntojen-torjunta-kotihoidon-palveluissa> (Referred 8<sup>th</sup> May 2020)

Most of the municipalities have acted vigorously to prevent the spread of the virus and followed the given instructions [27]. Many municipalities have also introduced additional measures on their own initiative. Among other things, helplines and grocery services for people aged over 70 years have been organized in municipalities on a fast schedule and various forms of outreach work have been launched [27]. In the following sections we describe what measures municipalities have implemented, and what additional means they have adopted.

## 5.3. Round-the-clock LTC

### 5.3.1. Prevention of coronavirus infections

To prevent infections in round-the-clock LTC units hand hygiene, both among the residents and staff, has been enhanced in municipalities. Also, physical distances are maintained where possible. For example, in-room dining has been increased or co-dining has been allowed only for a few residents at a time. [27]

Visits by relatives and others have been stopped almost entirely as a very first measure. There has been flexibility only, for example, if the resident is in a terminal phase. [27] As the situation has dragged on, municipalities have also come up with other ways to visit, such as meeting outdoors or in meeting containers [27, 20]. In mid-May these optional measures regarding visits were also added to national guidelines.

The use of face masks for staff was made mandatory on 15<sup>th</sup> May. Before this, different authorities gave contradictory guidance on the use of masks, causing confusion in the municipalities [27]. Also, due to the shortage of masks in the municipalities, there have been varied practices in the use of masks between LTC units [28]. Municipalities have also been innovative and made their own masks with the help of voluntary residents. Masks that meet surgical quality requirements were self-manufactured in order to provide care for patients and secure testing. In the early days of the corona period, it was believed that the epidemic would worsen and the need for high-quality protection would increase before domestic factory production could begin. [20]

There has been also discussion on the reliability and usability of the tests during the spring. On 15<sup>th</sup> May directive was issued stating that if a coronavirus case has been confirmed in the unit, testing of all residents and employees should be considered [29]. Before this, there was an instruction that social and health care staff and new residents should be tested if they have symptoms, but there have been reported shortcomings in testing among both [25].

### **5.3.2. Controlling spread once infection is suspected or has entered a facility**

Treatment has been provided in the care home, if there has not been need for intensive care. The residents are cared for in their own rooms and the staff use stronger protection, such as surgical mouth-nose protection and eye protection, protective gloves and a protective jacket or sleeveless apron to protect their work clothes. [27]

Some care units, however, have not been able to avoid the spread of the infection, resulting in the death of several residents [30]. The reason for the failure in controlling the spread was probably that the necessary isolation measures had not been taken early enough, same staff had worked both among healthy and infected residents, the units did not have sufficient protective equipment for staff, or there had been a lack of nursing staff [30, 28]. However, these cases have been rare because, by the beginning of June 2020, there are many municipalities with only a few or no coronavirus cases.

### **5.3.3. Managing staff availability and wellbeing**

Care managers at the municipalities have been on call even on weekends and evenings. As the other services of the municipalities have been closed or reduced (e.g. day care centres, early childhood education, libraries) the staff from these have been relocated to care for older people. Also retired care staff, who didn't belong to the risk group themselves, and students have been recruited as necessary. [27, 20.]

Despite special arrangements made in the municipalities, in some places the shortage of staff has escalated. Deputies may have had to be recycled from one unit to another, contrary to the instructions. There have been situations where almost all permanent staff in a unit have had to be temporarily replaced by deputies because of quarantine. [28]

As restrictions have not been followed in some units, there have been concerns about the well-being of staff. Especially the trade unions have called for better protection of carers. [25.] Care staff themselves have signalled that they are on the brink of coping. They feel that their work has not been valued and that they have been blamed for the failures of their superiors. [30] On the other hand, the media has also published hero stories about the flexibility of staff and praised their perseverance.

## **5.4. Home care**

### **5.4.1. Measures to prevent spread of coronavirus infection**

The guidance for home care has not been as detailed as for round-the-clock LTC, possibly due to the diversity of home care services and the clients [31, Table 2]. For example, the guidelines for the use of masks have been even more vague at home care than in round-the-clock LTC.

It seems that home care visits have decreased, even though they were first expected to increase if relatives' visits to older people would decrease [31].

Home care has been reorganized in the municipalities. In practice, for example, the areas allocated to home care teams have been reduced in size, meaning that the same staff are treating the same home care clients as much as possible [27, 20; Rissanen et al. 2020]. The sick and the symptomatic are treated

by different staff than healthy clients, whenever possible. Municipalities have also introduced remote home care visits and organized testing at home [31].

Day care services were closed in mid-March, and they were planned to be opened again on 1<sup>st</sup> June [27, 4]. Efforts have been made to maintain the well-being of day care and home care clients by giving instructions for physical exercises in the yard, on the balconies or via the internet. Instructions for exercises have also been provided with shopping bags, and check-up calls have been made for clients. [27]

#### **5.4.2. Controlling the spread of infection if suspected or occurred among home care client**

The spread of the infection has been controlled by stronger protection of staff and providing treatment at home if there is no need for hospitalization. Home hospital services and remote consultations with health care services have been used to support home care as necessary. The turnover of care staff is also minimized. [27] Municipalities have also done extensive work to identify potential exposed people in order to halt the spread of the virus through home care staff [20].

#### **5.4.3. Managing staff availability and wellbeing**

Means to manage the availability of home care staff are mainly the same as in care homes (see in section 5.3.3.) [27]. The staffing for home care has been increased [20]. This has been done by, e.g., relocating staff from day care services to home care and people who have health care education and experience from the city division of education and culture [20, 24]. Day care staff have also helped to detect, and contact people suspected for the infection in home care [20].

### **5.5. Impact on unpaid carers and measures to support them**

Carers Finland and the member associations have compiled information on the effects of the coronavirus period on families with family caregivers. The information gathered in the following section has been compiled from direct contacts with family caregivers and the associations' helplines and chat services during the COVID-19 epidemic.

*Loneliness and insecurity.* The coronavirus situation emphasizes the loneliness of older family caregivers by taking away the social contacts that occur in normal life. Those caregivers who have had a lot of social relationships and networks before the coronavirus epidemic seem to be able to cope better, as they have more contacts outside the household, for example by phone, even in these exceptional circumstances.

In normal circumstances, effective support services increase the feelings of security among family caregivers. Yet in the absence of these services, caregivers fear being left alone with care responsibilities. The feeling of insecurity experienced by caregivers is related to both the condition of the person being treated and the caregiver's own fear of contracting the virus or some serious illness other than COVID-19 that prevents care responsibilities from being met. The concerns about one's own coping and the perceived obligation to take care of another person – in a situation where normal support services are not available – are both burdensome. The experience of insecurity increases uncertainty about the future.

Yet the situation does not always appear only as negative. In some cases, life has already been very limited before COVID-19 due to the family care situation, but now more active communication between older people and/or caregivers and their children is described as a positive phenomenon.

*Physical and mental functioning.* Older family caregivers and the persons who are cared for, cannot leave the home due to restrictive measures which affects the physical and mental functioning of both parties. With a decrease in normal physical activity and the absence of outdoor activities, physical condition and ability to function deteriorate.

During the epidemic, older caregivers have reported mental symptoms such as anxiety, stress, and fear. Normally, caregivers have some opportunities for leave or respite from care. Family caregivers are entitled to a respite of 2 or 3 days in a month [9]. However, during the epidemic, this is not possible. Thus, caregivers do not have a break from their caring responsibilities which in turn affects their own coping and thoughts about the future. In these situations, even self-destructive speech by caregivers has emerged. Family care situations have also been dismantled where the caregiver's resources for care have been exhausted.

*Need, use and access to services.* The closure of some of the care services and the reduction of home support increased the need for care provided by family caregivers. In addition, the use of services is reduced by the fact that some caregivers do not dare to use them for fear of contracting the virus. There have also been challenges in accessing information: There is no definite information on what services are available despite the coronavirus situation and how quarantine practices affect, for example, the implementation of respite care. Even if respite care was available, caregivers would not always want to use this opportunity because they would not be able to visit their loved one during respite care in the care home.

The interruption of some of the rehabilitation services normally provided at home is a challenge to the older person's ability to function. For example, it may be challenging for a family caregiver to motivate the person being cared for to do home gymnastics which has previously been the responsibility of a physiotherapist.

*Measures of support.* During the epidemic, the member associations of the Carers Finland employed telephone services to contact the families. The telephone contacts were found important as they gave families the experience of not being alone. The support measures were reformed so that peer and / or individual support is provided online. However, this approach excludes some caregivers, especially older caregivers, who have not previously had an interest, ability or opportunity to use online services. They do not have the adequate technical equipment or do not know how to use it, and such help is not readily available during the epidemic.

Online meetings can be beneficial, but there are also challenges associated with these meetings. For example, issues of confidentiality arise when compared to physical meetings. In online meetings, one may not dare to talk about difficult and personal things in the same way because there is no certainty about who else is present at other group members' devices. Also, the fact that the spouse being cared for may be present when the caregiver participates in the group prevents the caregiver from openly sharing their own feelings and experiences.

[32]. *The information in Finnish has been compiled by Kaisa Parviainen, Development Manager (Carers Finland), Marjo Ring, mental well-being expert (Carers Finland) and Sari Tervonen, Executive Director (Carers Finland).*

## 5.6 Impact on people living with dementia and measures to support them

The Alzheimer Society of Finland and the regional member associations have compiled information on the effects of the coronavirus period on people with dementia and their families. The information gathered in the following chapter has been compiled by the regional member associations.

When the coronavirus epidemic started, people with dementia and / or their family members were contacted by phone and sent letters with information about the coronavirus. In addition, at least one member association sent some mood-refreshing and stimulating material. The Alzheimer Society of Finland and the regional member associations opened helplines that family members, family caregivers and those with dementia can call. Digital services were also promoted, among other things the use of WhatsApp, email, Teams and other video call services. Of these, the first two were more familiar to people and thus used more actively, but video calls were new to many individuals. The regional member associations reported that the use of digital services was not possible for everyone and many were left out. Alternative communication methods were requested by the families because the current ones were too cumbersome to use for many older people.

When the restrictions came into effect, people took the situation quite calmly. It was not the first time in their lives when they had had to face difficult situations. For many older people with memory disorders, everyday life concentrates tightly around the home, so no significant changes were experienced. It also seems to be a question of honor for many older people to cope with the situation. In addition, it is rather difficult for some of them to express concerns. Those families with early stage dementia reported minor impacts on their everyday lives.

Yet, as the restrictive measures continued indefinitely, for many, the situation kept getting worse. In the absence of stimuli, memory disorders progress faster and the burden on the relative(s) increases. The functional capacity of people with memory disorders had begun to deteriorate, e.g., in terms of balance and mobility. Some experienced speech impairment due to a lack of social interaction. Changes in the patient's circadian rhythm affect the family caregiver's ability to sleep and rest, and his/her resources are depleted. The family caregiver's well-being is then reflected in the person with a memory disorder, and the problems begin to pile up. Some family caregivers have even reported self-destructive feelings. The situation is complicated by the fact that, in many municipalities, short-term care, not to mention day activities, are not available and it is not possible to arrange family care leave. In addition, memory tests and appointments have been delayed and home visits by memory coordinators are suspended for the time being. However, one regional member association reported on visiting family care nurses (one form of service in Finland, although not very common) who were able to offer help to families with memory disorder. Some families reported strengthening relationships with children or other relatives as they offered their help more than before.

For those living alone with dementia, the situation is extremely challenging. In principle, relatives should not visit them because they belong to the high-risk group. Hence the concern of non-cohabiting family members is great. Already in the early stages of the memory disorder, the deterioration of some memory functions makes it difficult to protect oneself against the coronavirus and follow the instructions. For people living alone with dementia, coping with everyday life is extremely difficult, but even more so in these exceptional circumstances.

The arrival of the epidemic in care homes caused fear among people whose family members are care home residents, and among those who were considering a move to a care home. People do not currently dare to apply for a care home placement, even if they can no longer manage at home. The situation is very painful for family members who have had to give up on care responsibilities and, due to restrictions, are unable to visit their loved ones in a care home. Giving up care responsibilities is a

painful and difficult decision for many relatives, even under normal circumstances, and the ban on visits exacerbates the situation.

[33]. The information in Finnish has been compiled by Teija Siipola, Executive Director, Pirkanmaa Memory Association, The Alzheimer Society of Finland; Katariina Suomu, Executive Director, The Alzheimer Society of Finland, and the regional member associations.

## 6. Lessons learnt so far

Guidance for restricting the spread of the virus in care for old people has been, to some extent, ambiguous and contradictory. Many different sources have given guidelines, and those providing the care have interpreted the guidance and carried it out, taking into account their limited resources. One example has been availability of protective equipment: there has been a guideline to use them, but they have not been sufficiently available. Care homes have been obligated to store protective equipment for special circumstances, but earlier preparing has not included using masks in daily care. The Association of Finnish Municipalities stated that using masks cannot be demanded, if they are not available [34].

In future, special attention should be paid to the clarity, as well as the feasibility of the guidelines. The guidelines and regulations should be such that care providers have the ability to implement them in their facilities. Now the unclear instructions may have led to unnecessary deaths, among other things. Police started an investigation of deaths related with COVID-19 in one care home [35]. Insufficient safety practices and possible malpractices need to be revealed and investigated so that we are better prepared for similar exceptional situations in the future. In all, police intervention emphasizes, to service providers as well as to local authorities, the seriousness of the situation.

The instructions have been more detailed for care homes than home care. Also, public discussion has mostly focused on restrictions and consequences of care home clients. For example, there is no estimation on the number of coronavirus-related deaths among home care clients. However, the care at home has altered too, as home care visits may be shorter and decreased, and as family members have reduced their visits to their older relatives. It has been argued that these measures may have reduced coronavirus cases among those living at home, but they may also have contributed to subsequent problems, such as increased depression. With this experience, it will be possible in the future to take more into account the indirect problems that restrictions on the lives of older people may cause.

Family caregivers provide a large share of long-term care at home. In most cases, older people receive care from both formal home care and family care. Yet in many cases, informal care provided by a family member is the only long-term care people receive. Family caregivers and their disabled family members co-habiting in a private home face more mental, physical and social problems the longer the isolation continues. In such situations phone support has been provided by NGOs. In addition, many older people live alone in their homes and need help and care from their loved ones living outside their household. In these cases, restrictions have not been followed entirely, as the need for help is high and the relatives have had no other option except to visit the people belonging to the risk group. In addition to phone support, if a similar situation recurred in future, visit from support services – a volunteer or professional who has not the risk of infecting others – would be needed as different problems escalate at home.

The coronavirus epidemic has long-term effects on health and social care policy. It has been recognised that the need for services among older people has changed due to the epidemic for five reasons: 1) concern about safety of older people and their caregivers, 2) the situation of people aged 70 years and over who have diseases but do not receive services, 3) the lack of personal protective equipment, 4) psychological symptoms among older people without social contact and 5) fear of family caregivers getting exhausted. [31]

If the epidemic situation is prolonged and the vaccine against the virus is not available, e.g., in a year, many restrictions need to be assessed again. How could the restriction on visits to care homes be lightened, day care started again safely and the use of needed non-urgent health care ensured?

There has not been much public discussion on staff in care for older people. So far, we do not have information on the number of health care staff exposed and how many have been infected at work. Instead, we know that in some care homes, almost all or all care staff may have been replaced with new employees due to quarantine. At least some of these cases have led to situations where the care of the residents has been jeopardized. As care staffing has been insufficient in many places already before the epidemic, family members used to have a substantive role in taking care of daily tasks in care homes. Thus, the reduced visits of family members may have impaired the every-day care of care home residents. This highlights the importance of competent and sufficient staff, as well as the familiarization of substitutes.

Even though registers for health and social care in Finland are of a high quality and coverage, in this situation, up-to-date data on, e.g., deaths in care homes and among home care clients has not been available. Information for many registers is completed much later, which is understandable in terms of ensuring the reliability and accuracy of the data. Statistics Finland has started to publish preliminary statistics on deaths (also used in this report, Figure 2) but they point out that there may be inaccuracies in the preliminary data. It takes even more time to ascertain the causes of death.

In all, care homes are not designed for a situation where some people – or all – need to be isolated from other residents and family members and other loved ones. Care homes are important providers of end-of-life care. Staff with palliative care skills, medicines and equipment need to be available in care homes to make the quality of last days of life and death good. Allowing visits of loved ones in the end of life, even in times of high restrictions, would be humane. Solutions made in hurry may not be sustainable in the long run, such as locking people into their rooms [36]. For the future, more extensive and detailed emergency plans and preparations should be made for situations such as the spread of an unknown virus.

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