



The Impact of Covid-19 on Long-term Care Facilities in South Africa with a specific focus on Dementia Care

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STRiDE South Africa

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1. Key points

- Provision of long-term care for older people in South Africa reflects the inequalities of the society in general. Most elders are cared for at home by unpaid family members, most of whom are female.
- Most public sector long-term care facilities (LTCFs) are run by non-governmental and faith-based organisations. These are generally underfunded and there are not enough to meet the demand. There are no public-sector dementia-specific facilities. Private sector facilities are expensive and not accessible to the majority of the population. Many private LTCFs provide dementia care, and some are dementia-specific facilities.
- The Covid-19 pandemic has highlighted issues in elder- and dementia care that need to be addressed. For example, older persons appear to be less of a priority for government than children, youth, women, and people with disabilities; no nationally representative data on dementia exist; and there is still no accredited training and registration system for caregivers.
- While many LTCFs went into lockdown before this was formally announced, in most provinces the response from the relevant government departments was delayed and inadequate, including for: detailed protocols and guidelines for coping with the pandemic; provision of personal protective equipment (PPE) and emergency funding; and monitoring of and reporting on infections, recoveries and deaths. Delays in obtaining test results of up to 14 days from public sector laboratories made testing unfeasible.
- Most LTCFs responded quickly and effectively to the need for infection control, developing their own policies and procedures to deal with the virus.
- While most of the focus in LTCFs has been on infection control, dealing with the emotional and mental health toll of Covid-19 and the ongoing hard lockdown needs urgent attention.
- Some LTCFs have shown great creativity and compassion in enabling safe contact with loved ones and creating as normal an environment and routine as possible under trying conditions. This has included special responses to people living with dementia, for whom physical distancing and the wearing of masks can be impractical and disturbing.
- Despite the relatively low levels of mortality from the virus, the constant focus on infections and deaths has contributed to high levels of fear and anxiety, as well as to the stigmatising of people who have tested positive for the virus. This has led to staffing issues in some LTCFs.
- The financial impact of Covid-19 on LTCFs has been extreme, due to increased costs, reduced income and community support, and inadequate emergency funding from government.
- In South Africa, the rapid response of LTCFs to the Covid-19 outbreak greatly delayed infections and deaths; however, as infections increase in the community and lockdown restrictions are gradually lifted, more infections and deaths are now being experienced.
- South Africa must turn the Covid-19 crisis into an opportunity to prioritise and strengthen elder- and dementia care.

2. Introduction

This report, prepared by STRiDE South Africa for the Itccovid.org website, briefly introduces the context of elder care in South Africa, with particular reference to long-term dementia care. It then explores the impacts of the Covid-19 pandemic on the long-term care sector.

Data on the impact of Covid-19 were initially gathered using a questionnaire (**Appendix 1**) sent to long-term care facilities (LTCFs) that accommodate people living with dementia. Due to delays in obtaining approval from the Human Research Ethics Committee at UCT, the initial survey report based on the first 31 responses (**Appendix 2**) was embargoed until the beginning of July 2020. The first draft of this report for Itccovid.org was compiled using publicly available information, including media articles, webinar discussions and group email correspondence.

The initial survey report was compiled in the early stages of the pandemic, and none of the LTCFs that responded had experienced any Covid-19 related deaths (only one home had experienced infections). The intention is to develop a second questionnaire, which will be circulated now that more homes have been experiencing infections and deaths, and which will gather data related to the next stage of the pandemic in South African LTCFs.

This report also recommends a number of actions. These have been discussed by the STRiDE Covid-19 Committee and will be circulated and discussed more widely within the long-term care sector. It is hoped that the Covid-19 crisis will prove to be a catalyst for positive developments within the elder care sector in South Africa.

2.1. Socioeconomic challenges

South Africa is one of the most unequal societies in the world, with a Gini coefficient in 2015 of 0.63 (The World Bank, 2018a). The country faces the 'triple challenge' of high poverty (76% of the population), inequality, and unemployment.

Even before the massive and as yet unquantified loss of employment triggered by the Covid-19 lockdown, the national unemployment rate at the first quarter of 2019 stood at 27.6% and the expanded unemployment rate (which includes people who have stopped looking for work) at 38% (StatsSA, 2019a).

Between 2011 and 2015, the poverty rate in South Africa increased from 36 to 40% (The World Bank, 2018a), with the economically dependent population outnumbering and relying upon a minority of employed individuals. Female-headed households, black South Africans, the less educated, the unemployed, and larger families experience higher levels of poverty in South Africa, especially those who live in rural areas (The World Bank, 2018a).

Prior to the outbreak of Covid-19, South Africa's economy had already been crippled by years of corruption, maladministration, and growing government debt, which stood at US\$67,998 million in the third quarter of 2018 (Trading Economics, 2019). It is now being dealt a further blow by the combined costs of the Covid-19 pandemic and the losses created by an extended

lockdown. With long-term elder care not being a priority of the South African government, this represents a crisis for the current functioning and longer-term sustainability of the sector.

Owing to widespread poverty and unemployment, dependency on social grants from the South African government has grown to such an extent that in 2018 grants represented the second most common source of income (45.2%) for households nationally (StatsSA, 2019b). This exposes an economic threat to the country, as it illustrates how few economically active taxpayers are contributing to the country's revenue.

With many more South Africans now out of work due to the lockdown, the government has temporarily increased social grants and is providing financial relief for certain sectors of society, including through increasing unemployment insurance fund (UIF) payments. This, however, is contributing to government debt and further compromising the ability of the state to support vulnerable groups like the elderly in the future.

2.2. Health and safety challenges

Rates of non-communicable diseases (NCDs) in South Africa are very high. In 2016, 51% of all deaths were attributed to NCDs, including cardiovascular diseases (19%), cancers (10%), diabetes (7%), and chronic respiratory diseases (4%) (WHO, 2018). This is of great concern, considering the high mortality rates of people with chronic diseases who are dying with Covid-19 as a comorbidity.

Compounding the chronic disease burden are the very high numbers of people living with communicable diseases such as HIV (an estimated 7.52 million people in 2018) (StatsSA, 2018) and tuberculosis (TB) with an estimated 301,000 active cases, and 64,000 people dying of TB in 2018 (WHO, 2019). No prevalence estimates are available for TB infection.

While the hard lockdown temporarily reduced South Africa's high mortality rate due to homicide, road injuries and accidental gunshots, deaths due to interpersonal violence (ranked as the eighth highest causes of premature death in South Africa in 2015) (Groenewald et al., 2017) continue to plague vulnerable families, especially as stress increases due to confinement, joblessness, poverty and hunger.

2.3. The healthcare sector

About 82% of South Africans (45 million) depend on public healthcare (StatsSA, 2017), this sector being governed by the National Department of Health (DoH). Provincial health departments are responsible for providing primary, secondary and tertiary care services through public clinics and hospitals (Mahlathi & Dlamini, 2015). Having to serve the vast majority of South Africans, these overburdened public healthcare services are further constrained by factors that include poor management, a shortage of professionals, weak service delivery, and the inadequate supply of products and technologies (for example, the limited availability of personal protective equipment (PPE) at this time).

Access to private medical care is largely contingent on whether South Africans have access to medical insurance, with only 12.7 million persons (17%) able to make use of these services (StatsSA, 2016, 2017a). The private sector consists of services provided by general

practitioners, medical specialists and private hospitals and tend to be located in more urban areas (Mahlathi & Dlamini, 2015). Private healthcare is extremely expensive and unaffordable to the majority of the population

2.4. Government responsibility for dementia care

The Ministries of Health, and Social Development are primarily responsible for the wellbeing of people living with dementia in South Africa. There is no representative within National Government who is responsible for dementia, nor is there a dementia-specific national policy or plan.

The relevant government programmes include:

- Department of Social Development (DSD): Older persons programme (South African Older Person's Forum)
- Department of Health (DoH): Non-communicable diseases.

According to the Older Persons Act (no.13 of 2006), the DSD is responsible for developing community-based programmes aimed at dementia prevention and promotion, as well as home-based care with regards to information, education, counselling services and care for Alzheimer's disease and dementia (amongst others) (see section 11 (2)(c) of the Older Person's Act, p.13) (Government Gazette, 2006). This Act also requires that services be provided for people living with dementia at residential facilities (see section 17 (b) and (d), p.17).

The White Paper on the Rights of Persons with Disabilities (Government Gazette, 09 March 2016, no.39792) also briefly mentions older persons with dementia (see p.71) (DSD, 2015).

Currently, no information is collected or analysed to assess the healthcare system's performance for persons living with dementia specifically.

With dementia remaining a low priority of the South African government, most support services for persons living with dementia and their families are provided by the NGO sector, for example Alzheimer's South Africa (ASA) and Dementia SA.

3. Impact of COVID-19 on long-term care users and staff so far

3.1. Number of positive cases in population and deaths

Covid-19-related statistics are updated daily on the official government website, <https://sacoronavirus.co.za/> (see also <https://datastudio.google.com/reporting/1b60bdc7-bec7-44c9-ba29-be0e043d8534/page/hrUIB>). As at 11h30 on 10 July 2020, 2,000,569 tests had been conducted and 238,339 positive cases identified. A total of 113,061 recoveries and 3,720 deaths had been reported.

The rise in infections was initially slow in South Africa, possibly helped by the early implementation of a 'hard lockdown' which started at midnight on Thursday 26 March, when only 1,170 infections had been reported. The first death was reported the following day (27 March 2020) (https://en.wikipedia.org/wiki/COVID-19_pandemic_in_South_Africa).

3.2. Rates of infection and mortality among long-term care users and staff

By the time of writing of this report, it was not possible to determine how many infections, recoveries or deaths from Covid-19 had occurred in long-term care facilities in South Africa. It was also not clear if these data were being collected and collated by government departments.

A member of the advisory group for the STRiDE Covid-19 project, who runs a care home at which there had been a suspected Covid-19 case, reported that the officials to whom she had reported the case did not record the fact that the person lived in a care home. However, in a [radio interview](#) on 28 May 2020, Mr Robert Mc Donald, Head of Social Development in the Western Cape, reported that the department was keeping a record of infections and that 140 people in 20 old age homes were known to have been infected, 65 of these being staff members.

These data were not freely available, however. In response to the death of a resident at [Sen-Cit Resthaven](#) Old Age Home in the Western Cape, Mr Joshua Chigome, spokesperson for the Western Cape Member of the Executive Council (MEC) for Social Development, [stated](#) that the DSD could not “disclose any confidential information on any old age home that has positive cases”.

Consequently, the only available sources of information drawn on to produce this report have been the mainstream- and social media, as well as personal communications with colleagues in the sector.

It is of concern that, knowing that Covid-19 disproportionately affects older people, and having seen the devastation the disease has wrought in the elder care sector in other countries, the DSD, the national government department responsible for the sector, does not appear to be communicating statistics on infections and deaths in elder care facilities in South Africa.

A [follow-up article](#) about infections at Sen-Cit Resthaven reported that the home had waited 11 days to receive 32 positive test results from 60 Covid-19 tests conducted after a nurse had tested positive. During that time two residents had died of the virus. The report stated that they felt that “their pleas for help have fallen on deaf ears as they grapple with a crisis.” With so many staff self-isolating, the home was dealing with a serious shortage of carers.

Considering that the elderly are most vulnerable to Covid-19, the home had expected the DSD and health authorities to act fast after they reported that a nurse, and a resident who had died in hospital, had both tested positive. The health authorities had arrived a day later than arranged, after a second resident admitted to hospital had also died.

The manager of the home stated that, “Our sadness and concern is that the government departments who are tasked to help are struggling to make a rapid and adequate response. Even the Disaster Management Team who I was told was contacted on our behalf has yet to make the promised site visit to assess how to assist us. We are a small organisation with limited resources and a huge task.”

3.3. Population level measures to contain spread of COVID-19

Government advice to the public, available on their [official website](#), includes basic advice on avoiding infection, namely to:

- Avoid touching your eyes, nose, and mouth with unwashed hands
- Avoid close contact with people who are sick
- Cover your cough or sneeze with a flexed elbow or a tissue, then throw the tissue in the bin, and
- Clean and disinfect frequently touched objects and surfaces.

In March 2020, President Cyril Ramaphosa [announced](#) the start of the hard lockdown from 11:59 pm on Thursday, 26 March 2020. All South Africans would have to stay at home, unless strictly for the purpose of performing an essential service, obtaining an essential good or service, collecting a social grant, or seeking emergency, life-saving, or chronic medical attention. On 9 April, he announced the extension of the lockdown for a further two weeks until the end of April 2020.

On 23 April, the President announced a five-level risk-adjusted strategy, details of which can be found on the same [website](#). On 1 May 2020, Lockdown moved from Level 5 to Level 4, allowing a few people to return to work and people to exercise between 6 am and 9 am within five kilometres of their homes. Wearing of cloth masks was mandatory unless at home. Since then, on 24 May 2020, he announced that on 1 June 2020 the country would move to Level 3, allowing many more people to return to work, people to exercise between 6 am and 6 pm, and limited grades to return to school.

4. Brief background to the long-term care system

South Africa provides old-age pensions to persons who are financially needy (WHO, 2017). All older persons are entitled to free primary healthcare, while access to hospital care is free only for those who do not have the means to pay for these services. This includes long-term care services such as residential care services.

Long-term care in South Africa reflects the legacy of Apartheid, with availability of and access to residential care catering primarily for the older white population, while the care of older black South Africans is primarily a family responsibility (Lloyd-Sherlock, 2019).

The quality of long-term care services in South Africa is highly variable. This is especially obvious when public and private sector facilities are compared. Private care is limited to those who can afford it. Typical of the private sector in South Africa, it is expensive and inaccessible to most South Africans.

The South African government funds public long-term care for older persons, mainly through residential facilities (WHO, 2017). Rationed by long waiting lists and a queuing system, public services cater for a small portion of the older population only and this is largely confined to urban areas (WHO, 2017).

All registered facilities can apply for subsidies for individual residents, with eligibility restricted to the frail and destitute (South African Government, 2019). Reductions in subsidy amounts

paid out by the DSD has become a barrier to care, as it has resulted in facilities failing to provide services to poor, frail persons who are eligible, while admitting wealthier persons who can afford to pay (Lloyd-Sherlock, 2019). Furthermore, the lack of training of primary healthcare nurses undermines efforts to create an integrated health- and social care system for older persons, especially in rural areas (Lloyd-Sherlock, 2019).

Currently DSD subsidies cover 51.9% of the costs of frail care, with non-profit organisations left to cover the remaining costs, which amount to around R3,800 (+/- US\$240) per person per month (TAFTA, 2019).

Historical racial discrimination and cultural preferences in admissions restrict racial transformation and the care of all population groups at facilities. An audit of residential care homes in 2010 revealed that:

- Only 4% of residents across 405 homes were black
- Ten homes had physically separated white and black residents, and these groups had clearly not received the same quality of care
- In some instances, family members had threatened to remove older persons should homes become integrated, and
- There was very little knowledge of and sensitivity toward different religions and cultural practices (e.g. language and food preferences) (Department of Social Development, 2010; Lloyd-Sherlock, 2019; WHO, 2017).

There are an estimated 1,150 residential care homes for older persons in South Africa, of which 415 are officially registered with the DSD, as mandated by the Older Person's Act (Mahomed, 2017). Residential care is largely run by Non-profit Organisations (NPOs) and Faith-based Organisations (FBOs), and only eight of these registered facilities are managed directly and fully subsidised by the State (Lloyd-Sherlock, 2019; Mahomed, 2017).

All registered facilities can apply for subsidies for individual residents, but will only qualify if the older person is frail and destitute, in need of full-time care, 60 years and older, and a South African resident (South African Government, 2019). According to Dr Leon Geffen, a doctor attached to various care homes in Cape Town, who addressed a [webinar](#) hosted by the University of East Anglia on 1 May 2020, a concern relating to the Covid-19 lockdown is that it is the resident rather than the care home who is subsidised by the DSD. In the event that a resident should die during lockdown, that subsidy will be lost, and the home will not be able to admit a new resident, thus losing that income.

There are over 1,000 private sector long-term care facilities for older persons in South Africa (Mahomed, 2017). These include residential homes, retirement villages, frail care facilities, nursing homes and step-down facilities. Private facilities offer a range of long-term care services, such as assisted living, frail care, convalescence, as well as old age care (nursing / retirement homes). Residents can buy or rent accommodation and are responsible for the full cost of their stay.

Medical aid schemes in South Africa cover medical events, but long-term care such as frail care is rarely supported (Du Preez, 2015).

Most people living with dementia in long-term care facilities are looked after by caregivers who are supervised by nursing staff. While nurses are regulated by the South African Nursing Council (SANC), to date the caregiver sector has been relatively informal and unregulated.

Recommendations to the Older Persons' Act amendment bill have called for all caregivers of older persons to be registered with the DSD (SAHRC, 2017).

The DSD has published Generic Norms and Standards for Social Welfare Services that state that:

- together with the DOH, practitioners should be trained and understand the dynamics of ageing and disability when rendering services to older people, and
- the application of this understanding should be monitored through performance management (DSD, 2011).

However, according to Dr Leon Geffen in the aforementioned [webinar](#), after ten years of trying, no training curriculum or register of caregivers exists.

The carer sector experiences high levels of attrition due to poor remuneration, challenging workplace conditions and workloads, lack of professional development, workplace insecurity, low morale, poor relationships with management, and risk to personal safety and health. The DOH reported a staff turnover rate of up to 80% in some provinces (DOH, 2011; Rawat, 2012; WHO, 2017).

5. Long-term care policy and practice measures

5.1. Whole sector measures

According to the [Western Cape Government](#), as a condition of registration, all old age homes run by NPO partners must have an infectious disease control policy and a disaster management plan in place. These are submitted to and monitored by the DSD. Having these in place helped to prepare care homes to respond to Covid-19.

The response of the South African Government to the threat of Covid-19 to long-term care facilities has been described as slow, vague and inadequate. The first reference to 'Old Age Homes and Frail Care Facilities' was a list of four directives in the Government Gazette [No. 43182](#) published on 30 March 2020, Page 7, section (d) (i)-(iv): *Directions issued in terms of Regulation 10(5) of the regulations made under Section 27(2) of the Disaster Management Act, 2002 (Act No. 57 of 2002): Measures to prevent and combat the spread of Covid-19*. These included that: no clients be released from the facilities; no visitation be allowed during the lockdown period; the family reunification and interaction programme be suspended; and no new admissions be allowed, except in the case of persons with disabilities in distress.

When consulted on 28 May 2020, the National Department of Social Development's official website was found to provide no obvious information relating to the impact of Covid-19 on the elder care sector.

One of the first responses to Covid-19 in the Western Cape was the publication, on 6 May 2020, by the provincial DoH of *Circular H 70 of 2020: Preventing and managing coronavirus infection in the workplace*. This general document provided in-depth guidelines, including:

- Background on how the virus is spread and how to prevent its spread
- Advice on what to do if someone in the workplace is infected
- Additional guidance to specific sectors re preventing infection.
- Section C13 provided brief guidance to care facilities and old age homes on prevention of infection (recommending education and training, screening, physical distancing, and the use of PPE) and management of a resident diagnosed with Covid-19.

On 7 May 2020, communication from the Western Cape DSD to long-term care facilities in response to the Level 4 Lockdown announcement, consisted of a one-page notice only. Entitled *Containment measures for Covid-19 at residential facilities (old age homes) for older persons under Lockdown – Level 4*, it stated that old age homes and similar facilities should:

- Practise good hygiene
- Identify infected people and trace contacts
- Not allow visitors, and separate new intakes until they were tested
- Manage those found positive according to the World Health Organisation (WHO) guidelines
- Implement an infection prevention and control programme
- Implement a safety programme referring to a disaster plan and dealing with clinical emergencies.

This was followed on 19 May 2020 (about two months after most care homes had gone into voluntary lockdown already a week before the rest of the country) by a two-and-a-half page *Circular H70: Protocol for funded residential facilities where there are suspected positive or confirmed positive Covid-19 cases*. Interventions required included:

- Training and advice: to implement the WHO guidance, and stating that homes would receive training materials and could get support with policies from the DoH
- Identification and testing: to practice protocols (screening, masks, sanitising hands, physical distance) and, if there were concerns, phone the Covid-19 helpline
- Random testing arranged through a local health facility: this could be escalated to the DSD
- Infection and treatment: to isolate people with symptoms, contact a health facility for testing, and identify persons who had been in contact; to inform the DSD of confirmed cases of residents or staff members infected and what steps had been taken
- Vaccination: recommending the flu vaccine
- PPE: explaining that due to high demand, it was a challenge to get hold of these and that the DSD National and donors had been asked to help.

The document also stated that the DSD would continue to monitor containment of Covid-19 and give advice.

The Western Cape DoH published *Circular H77 of 2020: Guidelines for the prevention and management of coronavirus infection in healthcare facilities*, which was officially distributed on 13 May 2020. Although not specifically aimed at long-term care facilities, this proved helpful to the sector.

Thereafter, collaboration between the DSD and DoH finally resulted in the publication of [a guideline document](#) specifically for long-term care facilities, which was released on 21 May 2020, entitled *Practical guidelines for the prevention and management of coronavirus infection in long term care facilities (LTCF)*.

5.2. Care coordination issues

5.2.1. Hospital discharges to the community

This report focuses on long-term care facilities and not community-based care. However, the Disaster Management regulations state that care home residents may not be released to their communities during lockdown, so it would not be possible for a care home resident to be discharged from hospital into the care of their families rather than back to the LTCF.

5.2.2. Hospital discharges to residential and nursing homes

According to guidelines, upon return to a LTCF, a patient should be placed in isolation and monitored for 14 days.

5.3. Care homes

5.3.1. Prevention of COVID-19 infections

For about the first two months after concerns about the impact of Covid-19 on long-term care facilities started mounting, the DSD referred care home managers to the WHO guidelines on preventing infections. As described above, at least in the Western Cape, detailed guidelines have since been developed for long-term care facilities by the DoH and DSD in the province.

Basic infection prevention and control include:

- Identifying a responsible officer, washing and sanitising of hands, respiratory etiquette, environmental cleaning and disinfection, ventilation, laundry, catering, receiving of goods and supplies, waste management and travelling to work.
- Physical distancing in the facility, including visitors, offices, residential areas, communal areas.
- Risk identification: daily screening, staff member risk assessments and work procedure plans, and workplace health risk assessments.

In addition to these measures, care homes have reported that they have also:

- Placed non-essential staff members on 'temporary lay-off' to reduce the number of people entering the premises; required essential staff to isolate themselves in the facility in which they were employed; accommodated essential staff members within the facility ([Nazareth House](#))
- Introduced lockdown nine days before the official lockdown; trained staff to use PPE; issued face masks in mid-April for travelling and for use in the facility; no longer served food in communal rooms; quarantined all residents who needed hospitalisation, had

medical appointments or had to leave the facility for urgent matters, for two weeks ([Highlands House](#)).

Despite over two months having elapsed since the official start of lockdown, it appears that relatively few infections or deaths from Covid-19 have been recorded in long-term care facilities in South Africa. For example, during a [radio interview](#) on 28 May 2020, a spokesperson for the NPO BADISA, which runs 47 old age homes accommodating 3,800 residents, reported that only three residents had tested positive, two of whom had later tested negative, and one of whom was in hospital.

This is, however, likely to change as the lockdown progresses into its third month, and as the country moves to Level 3 lockdown on 1 June 2020.

On the same radio programme, a retirement home called Panorama Palms, despite having put extensive protocols in place, reported that 41 residents and 35 staff had tested positive since the first case had been detected on 15 May. The home partnered with a private lab and tested all staff, frail residents, and contacts of the first resident, discovering that even asymptomatic people tested positive. Now, as the manager reported, the greatest challenge is “having to do so much with so few” – dealing with the increased demands of accommodating, monitoring, and communicating with families about, those infected, while a large proportion of the staff are in quarantine.

Available media reports all confirm that, where infections and deaths have occurred, this has been in spite of close adherence to the guidelines.

Sources include:

[31 March 2020](#): Three more test positive for Covid-19 at Durban old age home

[31 March 2020](#): Covid-19 spreads tentacles into townships, old age homes

[6 April 2020](#): How Cape Town old age home [Kensington Home for the Aged] is ensuring safety for its elderly

[12 May 2020](#): Resident at Sen-Cit Old Age dies while tested positive for Covid-19, nurse also tested positive

[13 May 2020](#): Covid-19: As infections surge, how well are older persons in SA protected?

[13 May 2020](#): Covid-19: Nazareth House care home in Cape Town confirms death of third resident

[14 May 2020](#): How we are dealing with Covid-19 in care homes

[14 May 2020](#): Fears for elderly as more Covid-19 deaths reported at old age homes

[20 May 2020](#): 16 by Othello-aftreeoord met virus besmet [16 at Othello retirement home infected with the virus]

[26 May 2020](#): Old-age home's desperate pleas 'ignored' after two deaths, 32 positive cases

According to the article *How we are dealing with Covid-19 in care homes*, the response from the DSD (the department responsible for lower socio-economic elder care facilities) to the early outbreaks of Covid-19 in Western Cape care homes was poor. When criticised about its response to the outbreak at Sen-Cit Resthaven, which received funding from the DSD, the department's response was that it did not "operate or own any residential facilities for older persons," but that these were "independent from government and managed by a Board."

The detailed guidelines that the DSD spokesperson stated had been circulated to care homes had not been released until nearly ten days after the outbreak at Resthaven. By then most care homes had developed their own policies and protocols. While there was a referral protocol in place, the home had clearly experienced delays in both testing and in the results being provided (see *Old-age home's desperate pleas 'ignored' after two deaths, 32 positive cases*).

In a [radio interview](#), Robert Mc Donald, Head of the DSD in the Western Cape, acknowledged that the smaller independent homes in particular were battling to implement the measures outlined. Homes that were part of a larger organisation were coping better because their head offices had helped them to put these measures in place. He mentioned that BADISA had also assisted an independent home with staff when all their nurses had fallen ill.

A concern expressed by Dr Leon Geffen in a [webinar](#) is that, in sub-economic homes, residents may be accommodated in wards rather than in private or twin rooms, making physical distancing unlikely.

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

According to the DSD, persons with symptoms or confirmed Covid-19 cases must be isolated, and the local health facility must be contacted to assist with testing. Ideally, persons who have been in contact with the confirmed case should be identified for testing. Strict hygiene protocols apply. Staff who test positive should immediately be relieved of their duties and placed on sick leave.

Managers need to inform the DSD as soon as there is a confirmed case at the facility and indicate what steps have been taken to manage the situation. A decision-support guide is available to support decision making. Counselling should be offered.

One of the first care homes to be affected by Covid-19 was [Bill Buchanon](#) Home in Durban, KwaZulu-Natal. The manager described how they handled the situation: Four patients were isolated in a separate building, and one was in hospital. The nurses who treated only the four sick patients wore disposable hazmat suits. After each visit, the suit was disposed of in a box at the door.

Problems experienced included the financial impact of purchasing PPE, including the hazmat suits (this home had spent R350,000 [+/- US\$21 800] buying supplies). Masks and hand sanitizer were in short supply and extremely difficult to find, and some companies ruthlessly exploited the situation by vastly inflating prices. At the time, the manager warned other care homes to stockpile masks and protective gear so that if the disease hit, they could protect their staff.

As an indication of the spread of Covid-19 panic, the manager of Bill Buchanon Home was approached by local banks, asking that healthy residents not visit the branches to collect their pensions.

At [Highlands House](#) in Cape Town, the day a resident became ill, a Covid-19 test was done. The resident died within 48 hours. Within 24 hours of getting the positive result, plans were put in place to test all residents who had been in contact, and all staff, totalling 30 tests. Fourteen staff were advised to quarantine at home. The next day management decided to test all staff and residents.

What followed may have been unprecedented in any care facility worldwide: more than 460 tests were conducted by private labs over 48 hours. Results were received within 48 hours and 12 residents and 26 staff tested positive. About 185 residents were quarantined in their rooms (which was very difficult for them) and 40 of 280 staff were quarantined or in isolation at home. All positive residents were seen daily by a doctor who monitored their symptoms. Those who tested negative but presented with symptoms were retested. This was only possible because the facility is well-resourced.

At [Nazareth House](#) in Cape Town, after the first resident died, the movement of residents and staff was further restricted and a deep clean took place. An investigation was carried out to trace contacts, who were tested and placed in quarantine. The remaining residents were tested and three more were found to be infected. They were placed in isolation.

5.3.3. Managing staff availability and wellbeing

In a [radio interview](#), Robert Mc Donald, Head of the DSD in the Western Cape, noted that care homes were recognised as an essential service, and therefore staff were required to continue working. However, it was the movement of care home staff between their communities and the facility that presented the greatest risk of infection.

In the same interview, it was mentioned that the Cape Peninsula Organisation for the Aged (CPOA), with homes accommodating 2,300 residents, had offered to have their staff members sleep in, or to transport them to and from home in private vehicles in order to reduce the risk of infection through traveling on public transport. They had also provided all staff with PPE.

Sadly, at [Kensington](#) Home for the Aged, the home decided to ask some of the carers who live in township areas to stay at home because their lives were being threatened by some in the community who feared that they were bringing the virus to their communities from the care homes.

[Dr Leon Geffen](#) expressed concern that the DSD had not prepared many of the long-term care facilities to deal with this situation. Staff members who had received minimal training and support from the DSD were fearful. Family members were also anxious and tended to lash out and blame the staff when family members became sick or died. This was profoundly unhelpful and disrespectful to people who were doing their best under extreme stress. Staff members often put their own health in jeopardy in their efforts to provide care. They needed to be supported rather than criticised.

5.3.4. Provision of health care and palliative care in care homes during Covid-19

To date, no official guidelines have been found dealing with this. Initially, care homes were dissuaded from sending all but emergency cases for medical attention.

5.4. Impact on people living with dementia and measures to support them

Residents in long-term care facilities, whether living with dementia or not, have been struggling to come to terms with being confined to the homes, and in some cases for extended periods to their rooms, without any physical contact with their loved ones. In a [radio interview](#), Waldi Terblanche, BADISA's Coordinator for Disability and Elder Care programmes, stated that residents had been experiencing acute loneliness and an ongoing need for human contact. They were very concerned about the effect of social isolation on residents and had developed daily programmes to keep them busy and encouraged electronic contact with loved ones. They hoped that it would soon be possible to allow contact with loved ones, but according to the regulations this might only be possible once Level 2 of lockdown was reached.

[Dr Leon Geffen](#) agreed that restricted access was psychologically difficult for both residents and their regular visitors. He observed that Covid-19 had immeasurably changed the lives of residents in care facilities because they were no longer able to socialise with friends. Residents living with dementia needed close contact with staff and were difficult to isolate in their rooms. They were frightened by staff wearing masks, which caused behavioural disturbances.

Lockdown is distressing for residents of long-term care facilities, as two elders living in a [Neighbourhood Old Age Home](#) (NOAH) in Cape Town explained:

I'm a person who doesn't sit indoors much ... you miss the interacting with other people ... it is good to be amongst people. - Maureen Phillips

That personal contact though is what you need. That's really getting to everybody. Especially people my age, who have children and are always with them. [Doreen had to celebrate her birthday under lockdown without family.] I was all alone, which was very, very sad. I'm starting to feel very, very frustrated because I can't go anywhere. I am feeling very dispirited. It's a very scary situation to be in. - Doreen Stoltenkant

The Manager of the [Kensington](#) Old Age Home agreed that it was very difficult for the residents, even though they tried to keep them occupied with music and activities. He drew attention to the impact of one of the uniquely South African lockdown regulations – the ban on the sale of tobacco products – which was having a negative impact on residents who had been smoking for decades.

6. Lessons learnt so far

The lessons in this section are drawn from the following sources:

1. Comments by Dr Leon Geffen, a medical doctor and the Executive Director of SIFAR (Samson Institute for Ageing Research), in two articles:
 - <https://www.spotlightnsp.co.za/2020/05/13/covid-19-as-infections-surge-how-well-are-older-persons-in-sa-protected/>
 - <https://www.groundup.org.za/article/how-we-are-dealing-covid-19-care-homes/>
2. An email from Mr Wayne Devy, CEO of Nazareth Care, on 16 May 2020 to colleagues in the aged care sector, sharing insights from having experienced Covid-19 infections and deaths at Nazareth House and The Villa.
3. An email from Mr Rob Jones, MD of Shire Retirement Properties, on 11 May 2020 to Vrye Weekblad and colleagues in the aged care sector, sharing insights from their experiences
4. An email from Mr Syd Eckley, TruCare Consult Age, a Member of the Section 11 Committee on older persons of the SA Human Rights Commission, on 1 May 2020 to Vrye Weekblad and colleagues in the aged care sector, sharing background about the retirement and elder care sector in relation to Covid-19.

A key dilemma of the Covid-19 lockdown – balancing safety and individual rights – was expressed by [Dr Leon Geffen](#), who referred to the severe limitations on the movement of older people in long-term care facilities: *We'd like to protect people. However, that means that we are limiting their rights and ability to go out and participate in their normal daily activities.*

5.1 Regulation and management of the elder care sector

- Very few elder care facilities in South Africa are owned and managed by the DSD. The care industry in South Africa is 98% voluntarily owned and managed, and therefore responsible for regulating themselves. The DSD is responsible to inspect and evaluate that the standards and norms set in *The Older Persons Act, No. 13 of 2006* are correctly applied. Unfortunately, this function does not always happen, meaning that some facilities may have been relatively unprepared for Covid-19.
- The DSD is responsible for registering and monitoring long-term care facilities in South Africa; however, an estimated 25-28% of care facilities are not registered, including an increasing number of small care homes, usually situated in ordinary houses. This represents a risk to residents and staff, and the impact of Covid-19 in these homes is unknown and may not be accounted for.

5.2 A lack of government support

- In South Africa, the priority of government lies mainly with children, youth and HIV-infected persons, and less so with older persons. This is reflected in the inadequate response of the government to the threat of Covid-19 to elder care sector, despite older people being recognised globally as the most vulnerable age group.

- Other than four points in the Government Gazette No. 43182 (30 March 2020), no directives or guidelines pertaining to older persons were issued by the authorities nationally. Organisations therefore had to produce their own guidelines and many facilities struggled to do so on their own, especially the smaller independent homes that lacked the support of a head office infrastructure.
- The DSD has provided little to no assistance to care homes, with facilities where residents receive government subsidies receiving some masks and hand sanitizer only. One care home where residents had died reported that there had been no response to a request for psychosocial support or counselling for staff and residents. The DSD needs to provide support to facilities that lack resources and staff, and cannot afford the costs of infection prevention and control.
- The DoH has been unable to provide much assistance, as they have minimal swabs, and many staff have been in quarantine due to infection. Homes therefore have had to fend for themselves and arrange their own swabs and testing. Care homes are therefore advised to train staff to do the swabs and manage the paperwork, and to identify local doctors to assist.
- Because the DoH will only swab those who screened positive and are symptomatic, infected but asymptomatic staff may continue to work, resulting in the infection of residents and staff previously confirmed negative.
- The turnaround time for tests can be 4-5 days in the private sector and 8-11 days in the public sector, due to a huge backlog of tests at the state-run National Health Laboratory Service. This makes testing everyone both expensive and pointless, as by the time the results are available, someone who tested negative may well have been infected.

5.3 Long-term care facilities' responses to Covid-19

- Having witnessed devastating scenes unfolding in other countries, care homes and care centres within retirement villages did not wait for government permission or guidance but responded rapidly to the threat of Covid-19.
- The response was firm and unapologetic, erring on the side of caution. Actions taken included:
 - Going into voluntary lockdown before the official announcement
 - Introducing a Covid-19 infection control officer to co-ordinate the implementation of protocols
 - Increasing monitoring to ensure compliance
 - Encouraging staff to stay on site, and ensuring that these staff were accommodated according to the zones in the facility where they worked
 - Allocating one person to do the shopping, and sanitising items entering the home
 - Reducing the use of public transport by transporting staff privately
 - Having a color-coded system to identify isolation zones within the home and the staff allocated to these zones (colour-coded badges)

- Cleaning more thoroughly.
- Even with the most stringent controls, infections can occur. As [Dr Geffen](#) stated: *It's important to temper expectations and accept the grim truth. No matter what we do, there will be Covid-19 outbreaks in care homes and people will die. Once infections get into a care home, it's likely that within a few weeks, most of the residents will be infected.*
- At the same time, though, it needs to be remembered that Covid-19 is not the only cause of death in long-term care facilities at this time. Many residents are also terminally ill, with existing medical conditions and comorbidities.
- Older persons who need ordinary health and medical care and possible operations have been forced to go without these services. Hospitals have been found to be a source of infection for some care homes, with returning residents being infected with Covid-19.
- Some residents who have died have shown no symptoms. Only once positive test results have been received have people realised that the virus had been present in the facility for at least two weeks.
- The possibility of managers and administrators getting infected should not be underestimated. Facilities should ensure access to information by more than one person. Consider the contingency of the general manager, nursing services manager or registered nurse being infected. The shortage of staff becomes a real threat to the care of residents.
- Contract service providers (e.g. catering, cleaning and laundry staff) who have been infected have been quickly isolated, tested and replaced. Finding replacement staff is proving difficult as increasing numbers become infected.
- Tests have been carried out in some homes based on contact with known positive cases rather than on detection of symptoms.
- Many residents in care homes are highly dependent on close contact with staff who wash, dress, and feed them, brush their teeth and hair, and assist them with the toilet and walking. It is not possible to practise physical distancing in these situations.
- The willingness to share policy and opinion between facilities has been a great help.
- Family members and communities have in many cases been helpful and supportive.

5.4 Financial and resource issues

- The response to the virus reflects South Africa's highly unequal society, with wealthy homes being able to afford to test all their staff and residents privately, but others having limited testing and having to wait more than ten days for results from overburdened public laboratories.

- The cost of testing and PPE is far too high. A private lab test costs about R850 (+/- US\$53), the price of hand sanitisers has increased nearly four-fold, and one disposable mask costs R15 (+/- US\$1).
- In addition to the vastly increased expenses caused by Covid-19, many retirement villages and care homes are unable to earn an income from the resale of units during the lockdown. The long-term financial implications of Covid-19 and the lockdown on this sector are likely to be dire.

5.5 Emotional concerns

- Staff at long-term care facilities are concerned for themselves and their families, and rightfully so.
- The media have contributed to panic amongst the staff, who tend to equate a positive test result with a death sentence.
- There have been numerous training programmes on managing the virus at work and at home, but these have tended to focus on clinical aspects and prevention. It is imperative for staff to be educated about the actual percentages of people at risk, infected, and deceased, in order to reduce fear of the virus.
- As panic spreads through facilities, staff have been absconding and/or self-isolating, even if they work in a different unit at the facility.
- Many staff expect to be tested and do not understand that they have to be symptomatic before they will be tested by the DoH.
- Support, in the form of counselling, therapy and debriefings, needs to be made available. As residents test positive and die, staff members feel the pain and responsibility. Those living in and not seeing their families also need assistance.
- Some homes that have experienced deaths from Covid-19 have experienced harassment from reporters and the sensationalising of the situation in the media. This is extremely stressful for organisations and individuals trying their best to protect residents and staff. A home that experienced this recommends that residents, staff and families be asked to forward all requests for information to a designated spokesperson. They warned that reporters had made up stories in order to get a response from staff members.
- The emotional pressure on older persons living in isolation is disturbing for residents, family members and staff. There have been reports that some very frail persons have just given up and died because they were not able to bear the stress and loneliness.

- Lockdown has had the most adverse effects on residents in the early stages of dementia, who struggle to understand the changes to routine and the lack of visits.
- Due to concerns for the mental wellbeing of residents, some homes have been allowing visits from family members, especially during end-of-life periods. This isolation cannot continue without taking measures to ease their distress and loneliness.
- We do not know what lasting effect the Covid-19 lockdown will have on older persons in long-term care facilities, especially those living with dementia. It is highly likely that trauma- and grief counselling services will be needed to assist staff, residents and family members to come to terms with the long-term effects of the Covid-19 lockdown.

7. Calls to Action

These calls to action are based *upon ten policy objectives and key actions* to address the impact of Covid-19 in Long-Term Care systems, presented in the draft LTC Covid programme's report *Mitigating the impact of COVID 19 across long-term care services* (in prep.).

1. Ensure inclusion of Long-term Care (LTC) in pandemic planning throughout the phases from prevention, preparedness, response and recovery and ongoing effective governance of LTC services

THE ISSUES

- Despite knowing that the LTC sector was most vulnerable to Covid-19, it has received inadequate attention, guidance, support and funding from the relevant government departments, namely the DoH, DSD and Disaster Management.
- Many working in LTC Facilities (LTCFs), who had anticipated that this support would be forthcoming, were disappointed to find that the sector had not been prioritised.
- It should be noted that the response from different provinces varied greatly. In some, the response of and coordination within and between departments was poor, while in others it was more proactive and effective.

ACTIONS

- The official body/bodies coordinating the response to Covid-19 (e.g. the National Command Council, Ministerial Advisory Committee, provincial and local coordinating bodies, e.g. Disaster Management) must include representatives of the elder care / LTC sector.

- The DSD, being the department overseeing the LTC sector, requires greater capacity to respond to the needs of this sector.
- Effective coordination is needed both within the LTC sector (including NGOs, NPOs and businesses; care homes and home-based care), and between the LTC sector and government departments. Coordination must be strengthened at national, provincial and local levels.
- Mutual respect, support and cooperation are needed between the LTC sector and government, especially during this time of crisis.
- The LTC sector has a wealth of expertise and information that can be shared with government departments to strengthen their capacity and ability to respond during a crisis. Collaboration is needed to enable the free flow of information and the availability of necessary funding and resources.

2. Mobilize funding for LTC to respond to the COVID-19 pandemic

THE ISSUE

- Many LTCFs have complained about a lack of funding support at a time when they are facing increased Covid-19-related expenses and a reduction in income due to being unable to advertise available accommodation. This issue is related to the previous point: the apparent lack of prioritisation of elder care during Covid-19.

ACTION

- Due to the severe impact of Covid-19 on the elder care sector, emergency funding needs to be prioritised to support organisations and families in need. One possible source is the Solidarity Fund (a fund set up by the South African National Government to support efforts to manage the pandemic).
- Accommodation units that become available during lockdown must be allowed to be filled.

3. Ensure adequate functional and integrated information systems in LTC to inform planning and monitor impact

THE ISSUES

- There is a lack of clarity as to who is monitoring Covid-19 in LTCFs locally, provincially and nationally, and how Covid-19-related information (e.g. infections, recoveries, deaths) can be accessed.

- It is unclear if these data are enabling realistic budgeting and resourcing of the sector, more effective planning, or a more targeted response.

ACTIONS

- Efficient reporting and governance are needed to enable the rapid deployment of resources and support, and to inform realistic planning and effective management of the developing Covid-19 situation in the LTC sector.
- Data collection should go beyond the reporting of infections, recoveries and deaths. Reporting should also enable facilities and individuals to share their needs and concerns, as well as key observations and innovations that may benefit the sector.
- Mechanisms are needed to facilitate the sharing of information within the LTC sector in order to improve the response to the unfolding crisis.

4. Ensure infection prevention and control standards are implemented in LTC services to prevent and safely manage Covid-19 cases

THE ISSUES

- Infection prevention has been the primary focus of action to date. The sector has done well, with very few homes reporting infections or deaths during the first two months of lockdown.
- LTCFs have instituted a wide range of protocols, despite:
 - many homes being poorly funded
 - difficulties obtaining the necessary resources (e.g. PPE, cleaning materials)
 - long delays in the publication of LTCF guidelines by government.
- At the time of writing (late June 2020), South Africa is moving into the next phase of the Covid-19 crisis. After three months of strict lockdown, many people are returning to work at the same time as LTCFs are experiencing more infections and deaths. There are concerns about how the LTC sector will cope:
 - Staff and residents are tired and frustrated after months of lockdown
 - People are feeling afraid as LTCFs start experiencing infections and deaths
 - There is greater movement between communities and LTCFs, and as lockdown regulations are relaxed, residents are desiring greater freedom
 - As staff get sick, and agency staff are unwilling to relieve them, it becomes harder to maintain strict hygiene protocols
 - When infections and deaths occur, there is a chance that staff / families / departments may blame LTCFs for negligence and even institute legal proceedings against them.

ACTIONS

- LTCFs need to continue providing clear and detailed guidance on infection control and management.
- Management and government need to ensure that the necessary resources and materials are made available to staff and residents.
- Both because it is good practice, and because of the risk of litigation, LTC providers need to be able to prove that they have adhered to the relevant guidelines and regulations of DoH and DSD. Record-keeping (forms, diaries, photographs) is essential at all stages to make sure that it will not be possible to prove negligence.
- Open communication is needed to ensure that all involved are appraised of risks and protocols, and to facilitate feedback regarding obstacles to implementing health and safety measures.
- In addition to supporting physical health, the emotional and mental health needs of staff and residents need to be monitored and the necessary support provided.
- Examples of effective strategies and best practice in relation to mental and emotional health during the Covid-19 lockdown need to be shared within the sector, including how to support the families of live-in staff members.
- Participatory decision-making with staff- and family members is needed to ensure, in advance, that there is agreement in relation to protocols and approaches that foster soul-centred care.

5. Prioritize testing, tracing and monitoring the spread of COVID-19 among people receiving and providing LTC services

THE ISSUES

- Asymptomatic carriers, unreliable tests, the high cost of private testing, and having to wait for up to two weeks for results from some public-sector laboratories, have made it hardly worthwhile testing people for Covid-19 in some areas. People have started relying on other approaches, such as close observations to detect symptoms (which are often atypical in older people), and the tracing of contacts.
- The uncertainty around testing has made people scared and suspicious, which in some cases has strained relationships between staff members, management, residents and families
- LTCFs have reported limited inspections and follow-up from the DOH and DSD after infections have occurred.

ACTIONS

- Testing should not be relied upon as the only strategy for infection control; in addition:

- Continue to monitor staff and residents for a variety of symptoms
- Keep records of contacts in order to support others who may have infected or been infected by positive cases.
- There is still much we do not understand about Covid-19. Remain vigilant, open and critical, and trust your observations.

6. Identify and mobilize surge capacity to secure staff and resources for delivery of appropriate LTC services, ensure this includes adequate health workforce and products

THE ISSUES

- There has been a great deal of education around *infection control* but relatively little on the *nature of the virus*, or the *morbidity and mortality rates* of Covid-19. It appears that some people may be confusing the coronavirus with the HI-virus, and fear that a ‘positive’ test means that they are not going to recover. As in the case of HIV/AIDS, some people testing positive for Covid-19 are being stigmatised in their communities. As a result, some LTCFs are finding that staff members panic as soon as someone tests positive in the home. Some refuse to come to work, exacerbating staff shortages.
- As staff members become infected / sick, it becomes challenging to find emergency replacement staff. Many agency staff are unwilling to work in LTCFs where there has been an outbreak. Also, the Western Cape DoH has been told that they can employ another 5,000 nurses and doctors. Because they are paying more than LTCFs, many nursing sisters are choosing to work for the State rather than the LTC sector.
- Despite efforts by the LTC sector to get carers appropriately trained and registered, there is not yet a register of trained carers who can be drawn on in an emergency.
- The financial issues relating to the sustainability of LTCFs in general are addressed above. The need to enable *surge capacity* is one of many additional expenses that LTCFs need help with.

ACTIONS

- Education is needed to help address the fear and panic related to Covid-19. In the case of HIV, about which there has been considerable public education in South Africa, people who test positive require lifelong anti-retroviral treatment in order to survive. However, most people who test positive for SARS-CoV-2 appear to be asymptomatic, and most people who develop symptoms recover. South Africa has had a maximum case fatality rate of about [two percent](#), with most deaths occurring in people with co-morbidities. Once a person has recovered from Covid-19 they will continue to test positive but are then likely to have *natural immunity* to the virus.

- Initiatives are needed to retain existing staff and attract temporary staff, e.g. through financial and other incentives, including physical and mental health support.
- Persevere with existing initiatives to train and register carers, so that they can be more easily mobilised during an emergency.
- Ensure that financial resources are made available (e.g. through the Solidarity Fund) to support LTCFs with Covid-19-related needs.

7. Scale-up support for family caregivers

THE ISSUES

- While this report focuses on LTCFs rather than on community-based caregivers, day care and respite care facilities have been unable to function in most cases, leaving home-based caregivers of people with dementia with little support.
- Staff members who are living in LTCFs in an effort to reduce infection risk are also caregivers of their own families. Being absent from their homes for up to a week presents problems.

ACTIONS

- Provide home-based caregivers training and support on managing infections and reducing the stress of caregiving without the option of day care centres or respite care.
- LTCFs must consult staff before they are required to live in and provide support that ensures that their families are safe and well cared for.

8. Ensure the continuum and continuity of essential services for people receiving LTC

THE ISSUES

- The State of Disaster regulations have prevented families from taking their loved ones in LTCFs home during Covid-19. Many LTCFs have reported that they lack space to keep residents physically distanced. Being separated for months on end has caused many residents and families emotional distress. Carefully facilitating home transfers might alleviate some of these challenges.
- To reduce infection risks, people have not been allowed to go to hospital or consult their doctors except in emergencies. In some cases, this has resulted in existing conditions not being treated and medications not being dispensed.

ACTIONS

- Investigate safe ways of enabling residents of LTCFs to stay with family members during the Covid-19 crisis and develop strict protocols to enable this.
- Put procedures in place to ensure continuity of care for residents who are prevented from visiting hospitals, clinics and practitioners' offices for check-ups and medications.

9. Prioritize the emotional well-being of people receiving and providing LTC services during the pandemic

THE ISSUES

- With most LTCFs having gone into early lockdown, and with the peak of infections only starting to be reached about three months later, people within the sector are having to face the greatest challenges at a time when many are exhausted, and when the lockdown levels are being relaxed, resulting in increasing risks of infection.
- The focus on infection control in LTCFs has been necessary but has often eclipsed the emotional needs of staff, family members and residents. Being unable to see family members, being constantly reminded of the danger of the virus, living in fear, being confined to your room for extended periods, lacking access to the outdoors, avoiding contact even with other residents, lacking physical touch, being unable to leave your residence for months on end, wearing a mask that hampers communication and frightens people with dementia – all these measures have unfortunately had a negative impact on some people's mental and emotional health.
- Many staff, residents and family members have been experiencing considerable emotional distress due to fear, frustration, loneliness and desperation associated with Covid-19 and the prolonged lockdown. There have been reports of suicides and of elders simply 'giving up on life', as separation becomes too much to bear and there is no end in sight.
- The additional workload and fear of infection caused by Covid-19 has resulted in less time or inclination to provide basic care and nurturance practices (e.g. hair and nail care) for residents.
- It is not known if there are any free counselling services available that specifically support LTC providers, residents and families.

ACTIONS

- Both the virus *and* the infection control measures instituted to control its spread constitute risks to human wellbeing and survival. Discussions are needed within the sector that explore creative ways of providing care during Covid-19 that makes life worth living.

- In seeking to balance infection control and emotional wellbeing, the wishes of residents need to be determined, with all involved taking responsibility for their choices. For example, are masks always necessary, what social and physical contact is acceptable, what safe arrangements can be made for loved ones to visit, are people encouraged to spend time outdoors, what personal care is provided?
- Look for opportunities to turn hygiene interventions (e.g. handwashing) into opportunities for loving care, when the person can be held, touched and caressed.
- Some LTCFs are not enforcing the wearing of masks, e.g. if a person has dementia, as they may find it disturbing, or simply because residents in a particular section of a LTCF are considered to be a 'family unit' and should not have to wear a mask at home.
- To alleviate fear and ignite hope, it is important to focus not only on infections and deaths, but also on *recoveries* from Covid-19 and the development of natural immunity.
- Staff, residents and family members need to be supported emotionally with encouragement, deep listening, validation, counselling and debriefing.

10. Ensure a smooth transition to the recovery phase and implications for system transformation

THE ISSUES

- Every phase of the pandemic (preparation, crisis, recovery) is an unknown, requiring ongoing alertness, responsiveness and adaptation.
- This crisis has highlighted a number of existing weaknesses that must be addressed.

ACTIONS

- Lessons must be drawn from the pandemic that can inform improvements in the LTC sector in general and dementia care in particular in South Africa, e.g. improved protocols; factors that contributed to positive or negative experiences in LTCFs; strategies that allowed residents to flourish.
- Norms and standards for proper LTC in South Africa need to be developed, which include a pandemic response.
- Stories of good practice and innovation should be collected and shared with LTCFs.
- The intensity of the Covid-19 lockdown experience in the LTC sector is making debriefing opportunities essential to enable people to share experiences, insights and good practice; find support; develop collective responses; and identify lessons learnt from this experience.
- The NGO sector (e.g. Alzheimer's SA) can play a role in supporting the LTC sector through counselling, information sharing, and advocacy.

- A more collegial relationship between the LTC sector and government departments (DSD and DoH) is needed. Greater inter-sectoral collaboration and sharing of expertise are needed to strengthen elder care in South Africa.
- Networking within the LTC sector needs to be strengthened in order to engage government with greater coherence and confidence. This may take the form of a forum or committee representative of the entire aged care sector and including LTC.
- Elder care must be given a higher priority by the South African Government.
- Those who work in the LTC sector must be formally acknowledged for their exceptional commitment and contribution.

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Appendix 1

Questionnaire sent to Long-term Care Facilities

STRiDE – Strengthening Responses to Dementia in Developing Countries

The Impact of Covid19 on Long-term Dementia Care Facilities

PLEASE RETURN YOUR COMPLETED QUESTIONNAIRE TO

Alice Ashwell – alice@heartofnature.co.za

BY MONDAY 25 MAY 2020

Please TYPE your responses and return your completed questionnaire as a WORD DOCUMENT.

If you would like to respond verbally, please contact Alice on 082 720 7444.

We respect your right to privacy.

No individuals, long-term care homes or organisations will be named in the report.

Today's date					
Name of care home					
Organisation					
Name of respondent	<i>Dr/Mr/Mrs/Ms</i>	<i>First Name</i>	<i>Last Name</i>		
Role in your facility					
Landline number		Mobile number			
Email address					
Street address				Province	
No. of residents	Total		With dementia		
No. of staff	Office-based		Health/Care		Support/Other

1. What **general challenges and frustrations** is your facility dealing with in relation to Covid19?
2. What **general measures** has your facility put in place to cope with Covid19 and related challenges?
(e.g. policies, protocols and adaptations relating to staff, residents, loved ones, the physical environment, communication, learning, wellbeing, access to health care and resources, etc.)
3. What **dementia-specific issues** are you dealing with, and how have you been **responding**?

4. What and who have **helped you cope** during this time?
(e.g. guidelines, support, resources, information, funding, relief, networks, beliefs, etc.)
5. Which of your facility's **needs** have not been met during this time?
6. What are the most **important lessons** your facility has been learning from the Covid 19 pandemic?
7. If you are willing to disclose Covid19-related statistics (which WILL be kept confidential), please report any infections, recoveries or deaths since the pandemic broke out on 1 March 2020.

Case #	A resident or staff member?	Gender	Age	Currently sick	Recovered	Deceased (date)
1						
2						

Add rows if required

8. Would you like to have a **follow-up conversation** with STRiDE to discuss any of the above?
YES / NO

Appendix 2

Results of a Survey to determine the response of Long-term Dementia Care Facilities to the Covid-19 pandemic (14 May – 5 June 2020)

Introduction

South Africa's National Advisory Group (NAG) of STRiDE decided to undertake a survey to ascertain how long-term care facilities (LTCFs) that accommodate people living with dementia were responding to the Covid-19 pandemic. A short questionnaire (**Appendix 2**) was developed and circulated by members of the NAG to their mailing lists in May 2020.

Ethics approval was obtained from the University of Cape Town's Human Research Ethics Committee (HREC021/2019) for the dissemination of the questionnaire. The approval was submitted as an amendment to the broader STRiDE project.

Responses received

31 responses were received between 14 May and 5 June 2020, one from an Alzheimer's SA regional office and 30 from LTCFs.

Responses were provided by a CEO, Acting Director, General-, Nursing- and Health Care Managers, an Occupational Therapist, a Social Worker and a Senior Professional Nurse.

The 30 care homes included 20 NPOs, 6 not-for profit Section 21 companies, and 4 for-profit businesses (in some cases this is surmised, as the question was not specifically asked). Only two care homes served obviously underprivileged communities.

The 30 care home responses came from eight of the nine provinces, namely Gauteng (9), Western Cape (6), KwaZulu-Natal (3), Free State (3), Northern Cape (3), Mpumalanga (3), North-West (2), Eastern Cape (1). There were none from the Northern Province.

Thirteen of the respondents would like to keep in touch.

From the time of lockdown until the date of submission of their questionnaires, only one home had recorded Covid-19 infections (one resident plus four staff members, all of whom had recovered after 18 days).

Of the 26 homes that provided numbers, ten had fewer than 25% of the residents living with dementia; eight had between 25 and 50%, and eight had over 50% of residents living with dementia.

The responses received are summarised below according to the questions.

Questionnaire responses

1. What general challenges and frustrations is your facility dealing with in relation to Covid-19?

Policy issues

Three respondents mentioned policy-related challenges, including the constant need to review and update policies and procedures, and the frustration people were feeling about having to observe the necessary protocols and precautions. In one case, due to the lockdown, a service level agreement for the current year had not been signed.

Lack of government support

There were concerns from six respondents about a lack of support from the Department of Health (DoH) and Department of Social Development (DSD). Guidelines had, for most of the lockdown period, been inadequate, “last minute”, and described by one respondent as “very vague and broad-based one-page memos”. This had left care homes with the responsibility of doing their own research and developing their own policies based on, as another respondent put it, “gut instinct and whatever info I can find.” These concerns were exacerbated by mixed messages in the media about aspects such as the wearing of masks.

In addition to a lack of clear policy guidelines, there were also concerns that:

- *“all resources for fighting the virus were poor”*
- the government had not prioritised the elder care sector when providing personal protective equipment (PPE), so this was not available in many cases
- in at least one case, government subsidies had not been received
- the primary medical services were in disarray, with clinics overwhelmed and out of stock and hospitals not accepting non-emergencies
- no doctor was visiting one of the facilities, and
- it sometimes took over a week to obtain results of SARS CoV2 tests.

Financial and resource issues

Coronavirus disease (Covid-19) has further added to the financial burden that most care homes usually experience, both those run by NGOs or NPOs, and non-profit Section 21 companies. Expenses have increased markedly due to Covid-19. Additional unbudgeted costs have included accommodating, feeding and caring for live-in staff; and paying for PPEs, sanitation and other measures to reduce infection (at often inflated prices). Furthermore, the shortage of PPE has caused frustration. As one respondent stated, *“We had to self-fund everything.”*

At the same time, most LTCFs are on strict budgets and no relief funding has been made available by the government or from insurance companies. Income has been reduced in many cases due to:

- a lack of new admissions meaning that residential units are standing empty
- family members losing their jobs and being unable to pay monthly levies or purchase toiletries and incontinence wear for their loved ones

- companies that make regular donations closing down.

One small private home mentioned that in March 2020 their investment value had suffered a “massive loss.”

One respondent mentioned that during the initial lockdown, the home was unable to carry out maintenance because it was deemed non-essential.

Infection control

Respondents saw one of their greatest challenges to be “*keeping the virus out of the home.*” To this end, they found it challenging to get staff and residents alike to “*understand the seriousness and importance of hand hygiene and the correct handling of PPE*” as well as the need for everyone to keep a distance from one another. This required a considerable amount of ongoing education of staff members and residents alike.

One respondent stated that:

“It is challenging to train a staff that are used to a certain way of doing things to change, to be more vigilant with hand hygiene and a certain social distancing, and the importance thereof, without scaring them and yet preparing them for when the virus does come to the care centre.”

There was concern about staff “*contaminating*” not just themselves and the care home, but also their own loved ones and homes due to movement between these locations. One respondent stated the dilemma thus:

“We have put two populations together ... a staff body of relatively young women, who go back and forth from their communities with public transport, and may have a mild infection or are asymptomatic, in close proximity to frail elderly residents who do not have typical symptoms.”

One specific concern was that the public areas for residents were too small to enable physical distancing. In another case, the whole Alzheimer’s unit and social work wing might have to be evacuated in order to set up an isolation facility, with obvious disruption for residents living with dementia.

Implementing all these strict infection-control measures, plus the additional administration with regard to risk assessment and adherence to new protocols, had greatly increased the workload of staff members.

Staff accommodation and transport

While having staff sleeping in had helped to reduce infection rates, it had also presented challenges. Most homes had limited facilities and finances to enable this, and it was a challenge for staff and their families to be separated for up to a week at a time.

Minibus taxi transport, upon which most staff depended, was a potential source of infection, and their hours of operation had become restricted and irregular, influencing duty hours.

Emotional issues

As has been the case in society in general, the Covid-19 pandemic has been causing emotional challenges for staff and residents in long-term care facilities. Respondents were concerned about the mental and emotional wellness of residents and staff members.

Issues included the following:

- Covid-19 related fear and anxiety among staff, exacerbated by a shortage of PPE
- A sense of uncertainty about the disease and not knowing what the future holds
- Coping with the emotional stress of residents who were longing for their family members, and for whom the lockdown was exacerbating what has been described as ‘the plagues of nursing homes: loneliness, helplessness and boredom’
- Verbal and physical abuse from residents who were not able to access cigarettes and snuff due to a government ban on the sale of tobacco products
- Fear of infection resulting in *“expectations from staff to earn danger pay ...”* and additional incentives,
- Personnel being burned out, and
- Emotional impact on a home that had experienced infections (all since recovered) because of *“gossip amongst family and outsiders and negative media reports”* due to fears for the safety of residents. This unsupportive behaviour and blame were exacerbated by the media who were misinformed. A statement was issued to residents, staff and customers.

Staff expressed a desire to provide emotional support, bolster morale, and to help people to stay motivated. But one noted that, having *“no in-house social worker available [I as] manager also [have to] to assist with residents’ social issues”*, presumably in addition to a number of other new Covid-19-related responsibilities.

Resident- and family-related issues

The most common concern relating to residents and their families was the prevention of family visits. One manager described this as *“real tough love”*. It was a challenge to explain this to residents, especially those living with dementia, who were confused and did not understand why they could not see their families. Being cut off from their loved ones resulted in some feeling stressed, irritated and frustrated.

In one case, family members of residents who had died during lockdown (not related to Covid-19), had as yet been unable to empty their loved ones’ rooms.

It was also a challenge to keep residents occupied under conditions of physical distancing. Residents couldn’t understand why there were no longer any group activities, why they couldn’t visit the in-house hairdresser, or why they had to spend much more time in their

rooms. As one respondent summarised it: *“Frustrations: No church, strict socialising, no activities, no visitors, no going nowhere!”*

Both because of an inability to understand the concept of, or reasons for, lockdown (in the case of residents with dementia), and because of resentment towards the curtailing of their rights, including not being allowed to smoke, staff were finding it difficult to ensure physical distancing and sanitary practices.

Wearing masks was a problem (and in fact dangerous) for residents with conditions like asthma, and very difficult for people living with dementia. Having to continually raise awareness of the disease and its transmission was *“frustrating and challenging to us and to our residents”*.

One respondent stated that her challenge was that some people believed that Covid-19 was a conspiracy.

2. What general measures has your facility put in place to cope with Covid-19 and related challenges?

e.g. policies, protocols and adaptations relating to staff, residents, loved ones, the physical environment, communication, learning, wellbeing, access to health care and resources

Policies / Procedures

Most homes (16) reported that they either had policies in place (e.g. relating to communicable diseases, infection control, isolation rooms, occupational issues and health), or had updated or developed new policies, protocols and workplace plans in response to Covid-19. New or revised policies included those governing admissions, health and safety protocols, and a risk management register.

Managers of care homes that were part of larger organisations appreciated the role that their head offices had played in developing these guidelines.

Some respondents mentioned that they had followed guidelines provided by government, e.g. in the *Government Gazette*, from the DoH, DSD, and the South Africa Council for Social Service Professionals (SACSSP).

Additional procedures included having to register as an essential service, undertake a hazard identification and risk assessment, put a Covid-19 workplace plan in place, and obtain permits for staff to travel.

Infection Control

All respondents but one listed a number of infection control measures they had implemented in their facilities. These included:

- Implementing lock-down in mid-March 2020, before it was officially proclaimed
- Establishing a core group responsible for Covid-19 infection control

- Making policies available for all staff members to read
- Providing staff with PPE (gloves, face masks, face shields, aprons) and requiring that these be worn
- Teaching staff and residents to cough and sneeze into an elbow or tissue
- Hand washing and sanitising, and making hand sanitiser available throughout the facility
- Having a checklist and strictly adhering to cleaning schedules (e.g. 3 times per day)
- Getting the fire brigade to sanitise the exterior of the home once a week
- Closing all but one entrance to the facility
- Urging residents to remain in the facility other than for medical and emergency reasons, or (in some cases) essential purchases
- Preventing members of the public visiting the facility
- Limiting family visits to end of life care
- Reducing visits by essential services to a minimum (e.g. non-essential contact with doctors or dentists)
- Keeping a log of the all people (residents, visitors) entering and leaving the facility
- Physical distancing and reducing contact with and between residents
- Moving residents to other areas in order to reduce numbers in a ward
- Limiting access to the frail care to nursing, cleaning and kitchen staff only
- Closing the dining room and providing take-away meals in residents' units
- Instituting two sittings per meal, or creating an additional dining area on a veranda
- Suspending group activities in the sitting room, to allow for physical distancing
- Getting staff members to sleep at the facility for the duration of their shift (4-6 nights)
- Providing staff with immune-boosting medications
- Establishing washing zones, sanitising reminders and checks
- Requiring staff to scrub down, and sanitise their shoes before coming on duty
- Washing uniforms on site
- Assigning specific staff members to particular tasks (e.g. shopping, visiting residents in their units)
- Using delivery services instead of having staff members shopping
- Adhering to a protocol regarding parcels, e.g. parcels from family members or pharmacy deliveries left at security and sanitised before being delivered
- Regularly screening staff and residents for symptoms of infection, including checking and recording temperatures/fever (e.g. twice a day, on entering and leaving); one respondent mentioned a 13-point screening protocol for all staff entering and leaving the facility
- Nursing staff completing a screening questionnaire daily
- Providing isolation facilities
- Isolating residents after home- or hospital stays
- Requiring new admissions to be tested for Covid-19 at the local clinic prior to admission and to be isolated for 14 days after admission
- Deep cleaning isolation facilities after use
- In one case, all staff and residents had been tested by the DoH.

The following story illustrates the added anxiety associated with injuries from falls in a LTCF at this time:

“A resident had a fall and fractured his femur. When he returned from hospital with a negative Covid result he was cared for in isolation with all the necessary PPE. On day 7 he developed flu-like symptoms and a temperature. We did a Covid test which came back negative. The time waiting for the results was extremely stressful for all the staff as we had to then be extra careful.”

Communication

Most respondents referred to good communication as one of the most important measures enabling them to cope with Covid-19. It was clear that lockdown had resulted in care homes adapting to using a wide range of communications technologies, especially various video call platforms.

Approaches included the following:

- Managers communicating regularly with their governing bodies (e.g. Boards of Trustees; Head Offices of organisations managing multiple facilities)
- One respondent referred to telephonic and email communication between the organisation and the DoH and DSD
- Bi-weekly Zoom meetings of Head Office staff and all centre managers in one of the organisations managing a number of care homes
- Within facilities, regular staff discussions, interdepartmental communication and brainstorming sessions, and feedback sessions to staff regarding Covid-19
- Daily Covid-19 meetings for core staff to discuss any changes with staff and elders, and any new developments in Covid-19 care in South Africa
- Regular WhatsApp messages from facility management to residents
- Regular (e.g. weekly) updates, photos and videos from management to family members via e-mail, telephone, SMS, WhatsApp groups, and/or Facebook posts, to update them on the wellbeing of their loved ones
- Encouraging and helping residents to keep in touch with family members through regular telephone, Skype, Zoom and/or video calls
- An open line for family members to contact the nursing manager
- All relevant documentation emailed to the next of kin.

Education / Training

Most of the care homes mentioned the importance of ongoing Covid-19 education and training sessions to keep both staff and residents informed. One noted that staff in-service training was done weekly as shifts changed. In addition to practical aspects such as donning PPE, some homes also focused on general health education, and addressing fears related to Covid-19. Due to the evolving nature of the situation, training was ongoing in most cases. One respondent mentioned that they included education about ‘fake news’. Another specifically mentioned that the DoH and DSD in Gauteng had run workshops on Covid-19 and how to respond.

Flexibility / Adaptation

The Covid-19 pandemic has demanded flexibility and a willingness to adapt to an unprecedented situation. Some LTCFs, having observed what had happened in care homes in other countries, locked down a week before the general lockdown imposed by government.

Some LTCFs have created living space for both core and out-sourced staff to live in for the duration of their shifts (between 5 and 7 days reported), so that they can reduce the use of public transport and therefore the risk of infection within the home. This has required considerable adaptation of facilities. One home reported: *“We have converted our large activity rooms and our sensory room for [staff members] and provide meals, laundry and lots of treats. Full ablution facilities are available.”*

In addition, due to public transport difficulties, two homes reported that they had become more flexible in terms of staff hours.

In order to reduce the need for residents to leave the home, two reported having regular visits from designated medical practitioners (general practitioners and a physiotherapist), who observed all prescribed Covid-19 protocols when visiting. One respondent specifically mentioned that special arrangements had been made to obtain treatments for residents with chronic conditions.

Concerns for the emotional health of residents have resulted in some flexibility with regard to visits by family members. One home reported that they allowed family members to visit residents at the main entrance gate supervised by a security officer. Others reported moving elders who were approaching death to a single room and allowing family members to spend time with them to say goodbye.

Emotional support

A few of the respondents reported actions they had taken to provide emotional support, including providing counselling, having regular sessions with staff to ensure their wellbeing, and sending inspiring messages to all residents on the care home’s WhatsApp group.

Stimulation of residents

Despite lockdown, a few of the respondents reported on ways in which they were continuing to ensure that residents were kept active and involved. One referred to a schedule of activities to keep the residents busy every day. Another referred to small group activities and prayer meetings. Four encouraged residents to spend time working or walking in the garden and enjoying fresh air and sunshine. In another case, a social worker did exercises and ‘brain gym’ sessions with staff and residents. Some of the nurses played games with residents, and others got residents to accompany them on their rounds to keep them engaged.

One home decided to *“make Mother’s Day special”* by asking families to contribute presents for their relatives, getting sponsors for those without relatives, making special meals that day, and

getting families to send videos, which were played for the residents. Photos from the day were shared on Facebook with the families. Similarly, another manager reported that: *“The staff members have all put in extra effort to help the residents adapt to this current situation and we even had a little concert for the residents just to help take their mind off things.”*

In another case, two registered volunteers had delivered colouring books, pencils and treats neatly made up in packets, labelled with the residents’ names, to keep them stimulated.

3. What dementia-specific issues are you dealing with, and how have you been responding?

A few respondents observed that residents living with dementia were coping relatively well – in fact, better than their family members were. They stated that they had not noticed any changes in their behaviour due to lockdown.

However, the lockdown and Covid-19-related changes were confusing to many residents with dementia. As one respondent stated: *“Isolation and change of routine has affected everyone adversely, but especially the residents with dementia and depression have really struggled.”*

- Most respondents reported that residents were longing for their families and did not understand why they were not visiting them. This resulted in some becoming angry and emotional.
- In the absence of visits, the homes encouraged video communication between residents and their loved ones.
- One referred to residents being unable to cope with the fact that they were not allowed outside for their daily walks anymore; they had created a new route inside the frail care unit so that they could stay active.
- Some provided additional activities and entertainment to make up for the lack of visits.
- There was a great need for physical contact with loved ones; online communication was not enough.
- Some residents were unable to understand the need for, or how to implement, infection control, e.g. coughing and sneezing into an elbow, washing hands frequently, wearing masks, and practising physical distancing. They needed to be shown every day.
- Understandably, residents were battling to understand why they had to stay in their rooms.
- Some were unable to respond to new approaches, e.g. using the telephones installed in their rooms.
- In an attempt to explain to residents with dementia why their family members weren’t visiting, one respondent said that they were *“continuously showing them the daily news and keeping them informed about Covid-19.”* It is not known how residents responded to this.

Some managers used their discretion in relation to infection control measures, recognising that implementing some of these would be difficult or even disturbing for residents:

- Some LTCFs realised that wearing masks made residents feel frightened and more confused. One respondent reported that residents with dementia sometimes tried to pull masks off the carers. In one case, the decision was made not to wear masks in the presence of these residents.
- Similarly, while some homes tried to enforce physical distancing, others decided not to do so, recognising how important physical touch was for residents and that they would not be able to adhere to these rules anyway, partly because of the lack of space. One manager stated: *“Residents living with dementia need lots of hugs and touching and it would be cruel to isolate them for such a long time if not necessary. We know that it is a risk but are taking as many precautions as we can to ensure a safe environment for our residents.”* These precautions included regular sanitising of surfaces and washing of hands. Another agreed, stating: *“Not to touch and/or hold our patients is one of the most difficult issues. We do not have a responding mechanism for that!!!”*
- One mentioned that they had reinstated a communal lunch in an outside dining area every second day, ensuring that all hygiene protocols were observed.
- One respondent mentioned that they had increased nursing care for the residents with dementia.
- In a few cases the homes allowed family members to meet their loved ones at the entrance or through the fence, while one allowed one family member at a time to visit in a common area outside in the garden, while observing physical distancing.
- As previously mentioned, some LTCFs provided for compassionate visits at end of life, with one respondent emphasising that these took place *“under supervision and within strict protocols.”*
- Residents were able to adapt to frequent hand cleaning when helped by staff members. The act of washing a resident’s hands fulfilled both the need for infection control and their need for touch, and residents enjoyed this.
- One home for underprivileged elders did not have enough staff to be able to assist with hand-washing on a one-to-one basis.

From a medical point of view, respondents stated that nursing care continued as normal, with residents being well monitored and medication being dispensed promptly. In one LTCF, a doctor and registered nurse were appointed to supervise residents in the dementia unit.

Some LTCFs continued to involve residents in activities to keep them busy, happy and content. One reported that *“Elders are taken onto the veranda to enjoy the sunshine daily. They enjoy singing.”*

One manager expressed concern that two residents living with dementia had passed away during lockdown (unrelated to COVID-19) without their family members having been able to visit.

4. What and who have helped you cope during this time?

e.g. guidelines, support, resources, information, funding, relief, networks, beliefs, etc.

Some respondents acknowledged that they had battled to cope with Covid-19 and the lockdown initially, and that for some time support from government had been inadequate. However, a number of sources of support had been identified.

Sources of information

Where official sources of information were lacking, care facilities did their own research and put procedures in place, as this respondent reported:

“Initially help was not very forthcoming and we depended on research information through the internet and by the use of common sense and expertise of our experienced nurses. Subsequently guidelines were available from the Department ... [these] reassured us that measures we have in place meet and exceed set guidelines.”

Respondents referred to a wide range of information sources, including:

- The mainstream media, e.g. television and radio programmes
- Internet and social media
- Professional networks and colleagues
- Occupational health and safety organisations
- Documents such as the WHO guidelines; government gazettes; a (rather inadequate) one-page document from the DSD in the Western Cape; a directive from the CSOS Ombudsman (helpful with regard to the independent living apartments); a brief from the Healthcare Employers Organisation of South Africa (HEOSA) of 8 May 2020; and guidelines from the Western Cape DoH: Circulars 70 and H77
- Government departments in some provinces (e.g. Gauteng Province and City of Johannesburg) proved to be of greater help than some others. They provided helpful information, workshops on Covid-19, and practical assistance with the sanitizing of facilities and testing of residents. Others failed to provide adequate guidelines until nearly two months into lockdown.
- One respondent reported that the DSD in KZN required daily statistics from each elder care facility in terms of discharges, deaths, admissions, hospital admissions, and residents possibly ill with Covid-19.

At a time of great uncertainty, it was very important to receive clear guidelines: *“Guidelines were helpful because they gave directions and relived anxiety.”*

Head office support

Those care homes that were part of a larger organisation appeared to be at an advantage due to their head offices:

- providing clear policies and procedures

- organising regular online meetings at which care home managers could be updated about and discuss developments relating to Covid-19
- providing training sessions
- providing PPE
- providing travel permits and personalised letters enabling staff to travel, and
- monitoring the implementation of policies.

On the other hand, managers of independent homes received relatively little support and had to fulfil both the functions of a 'head office' as well as day-to-day operational management.

Staff: teamwork, planning & support

About half the respondents spoke highly of the dedicated staff members at their facilities, who were united and working as a team. Daily Covid-19 briefings, meetings and networking provided opportunities for mutual support. One respondent mentioned that they had an internal support group of Care Managers and staff. One manager stated that she talked regularly with staff to keep them informed and positive, and to relieve anxiety. Another stated that the staff made sure that they laughed regularly!

One manager mentioned that pre-empting what would be needed during lockdown had allowed them a smooth transition. They had ordered large quantities of PPE, sanitiser, paper towels, toilet rolls, gloves, incontinence products and medication.

One facility stood out in the way they valued and supported their staff members during this challenging time:

"All staff received their annual salary increases as of April 2020. Our head office purchased ... gift vouchers for R650.00 for each nursing staff member, which was very well received. We make sure that the staff staying on the premises are well fed and taken care of and that there are nice snacks for them to enjoy."

Faith

At some of the care homes run by Christian organisations, respondents were clear that, at this challenging time, their faith and trust in God were a great source of strength and comfort. One respondent stated that they knew they were not alone in this, another stated that the nurses prayed and sang together every morning, and another shared that *"faith and prayer has become a more prominent inclusion at our daily gatherings."*

Community support

Respondents valued the support of family members, friends and the broader community, which included residents' families, colleagues at other facilities and hospitals, and community and church leaders. One mentioned that they felt supported on social media like Facebook and WhatsApp. Another referred to a voluntary group of 'care buddies' that supported them.

Three managers appreciated belonging to a network of elder care facilities in her city which shared information. Others valued learning from the experiences of other homes that had already experienced deaths from Covid-19.

Homes reported numerous donations received from family- and committee members, local businesses, churches, NGOs and a local hospital. Donations included food, toiletries, treats for the staff, face masks and hand sanitiser, flu injections, and supplements. One respondent shared that *“we were blessed by one registered volunteer, who made us 10 theatre gowns.”*

5. Which of your facility’s needs have not been met during this time?

Five respondents felt that they were coping well. One of these had received support from their provincial DoH and NGOs.

However, nearly half the respondents complained that support from government had been inadequate, with one stating that no communication regarding Covid-19 had been received from either the DSD or DoH by 20 May 2020, and another complaining that they had had no assistance from the provincial government with policies, screening or any kind of support. That person stated that she had depended on social media for information.

Another complained that:

“When lockdown was announced I requested guidelines from DoH who told me they don’t have anything old-age specific and sent a 70-page document meant for frontline hospitals and laboratories ... The last thing DSD did was to send me a list of their requirements; including monthly updates on progress made – in the middle of a pandemic. Not one single person has picked up a phone to find out whether we’re okay or need anything.”

A common concern was the dire need for PPE (face masks and shields, disposable gloves, sanitizer, and infrared thermometers), of which there was a national shortage, and which one respondent said they had not yet received funding to purchase.

Some respondents also reported that government was not supporting the screening or testing of staff or residents. There was no access to affordable testing offering quick results.

The manager of a home for underprivileged elders reported that they could not access health care for their residents during lockdown as doctors were not visiting and hospitals were only accepting emergencies.

People felt that more attention needed to be paid to the emotional support of staff and residents. The fact that residents were unable to see or touch their loved ones was harming them emotionally.

Financial support was also not forthcoming, either from government or from insurance companies. As new residents could not be admitted or even shown around the facilities, this reduced resident numbers and therefore income to the homes. The cost of complying with Covid-19 regulations had left some homes not knowing how they would be able to pay salaries in the coming months. As one person stated:

"[We] waited more than a month for our Department subsidy, which put a lot of stress on the payment of other accounts such as the Municipality and Security Bills which are our greatest costs. Also the salaries!"

As previously mentioned, some homes could not even afford to buy PPE, and one home tragically reported:

"We are in dire need of food, as we have spent money beyond our budget without funding."

Another home, also in an underserved community, reported that:

"The facility's needs have not been met during this time of Covid-19 e.g. There has been a shortage of water from the local municipality. As a result, we only rely on borehole water."

Furthermore, community volunteers who usually provided valuable services and support, were not allowed access to the homes.

Finally, two respondents voiced their concerns about how Covid-19 regulations were impacting on the rights of residents, who were not able to come and go freely, and who were also unable to continue with activities due to the need for physical distancing.

6. What are the most important lessons your facility has been learning from the Covid-19 pandemic?

6.1 The lack of government support made the experience a lot more challenging:

The manager of one care home, reflecting on the lack of government guidance or support, summed up her experience thus:

"In a crisis you're on your own. You have to read, read, read, because nobody in government is coming to your rescue. There's no frail care facility hotline. You're the Manager, Nursing Manager, HR Manager, Infection Control Manager, Training Manager, Safety Manager, Ops Manager and PRO, and you never get time to write all the policies that are required."

Another noted that this lack of support reflected a broader problem, stating:

"We will always be unprepared for a full-blown pandemic due to politics overruling public health ... our public health system is so so broken."

6.2 An unprecedented crisis requires flexibility and adaptability: A number of respondents recognised that in a rapidly and constantly changing situation, it was important to be flexible and able to adapt and quickly implement changes to protect residents. This including developing new rules and amending regulations in response to each new challenge. One respondent observed that people were very adaptable to new ways of operating.

6.3 Be prepared! It was important to be proactive and to have a disaster preparedness plan, and to have practised the existing infection control policy, in order to be prepared for a crisis.

6.4 It was essential to adhere to safety measures: Respondents had internalised the recommended safety measures described previously and reiterated the importance of hygiene in preventing infection. They warned that one should stay focused and never become complacent. It was important to protect oneself and others. *“Awareness – awareness – awareness,”* emphasised one respondent. Another stated that: *“... most protocols we have implemented will remain.”*

6.5 Dedicated staff and teamwork were critical: About half of the respondents commented on how wonderful the care home staff were, and how they never complained but just carried on, for example: *“Loyal, good, and well looked after staff are a blessing.”* Having a team that pulls together was mentioned a number of times; as one person put it: *“Teamwork is dreamwork!”*

There was a strong feeling from a couple of respondents that it was important for the staff to care for one another as well as for the residents. As one put it, *“All must stand together without any discrimination.”* One respondent mentioned that their employee wellness programme was helping staff to cope with the ongoing pandemic.

6.6 Communication is important: Honest communication with staff and residents was important to ensure understanding, and key to developing a successful team.

6.7 Emotional support is needed: It was important to keep checking on how staff members were coping, and to have emotional support available. The emotional impact of the crisis had a huge influence on the residents, who had a real need for physical contact with their loved ones and the personnel. Furthermore, one respondent observed *“... the HUGE impact [of] isolation and change of routine and structure [that] can aggravate dementia and depression.”* People living with dementia needed support to comply with new protocols.

6.8 Take personal responsibility: One respondent observed that she had been *“amazed at how this pandemic has brought the best out in some and the worst in some.”* It was possible to remain positive in the face of a crisis, and each person needed to take responsibility to care for themselves so that they did not bring others down. Two people referred to the

importance of showing patience and understanding with the residents' needs at this challenging time.

6.9 Faith keeps people strong: For many, it was their belief in God that carried them through.

6.10 Never take things for granted again: Finally, *"Things as we know it can change overnight!"* This crisis has taught us to appreciate the small things in life, and never to take hugs, visits, or walking without a mask for granted again.