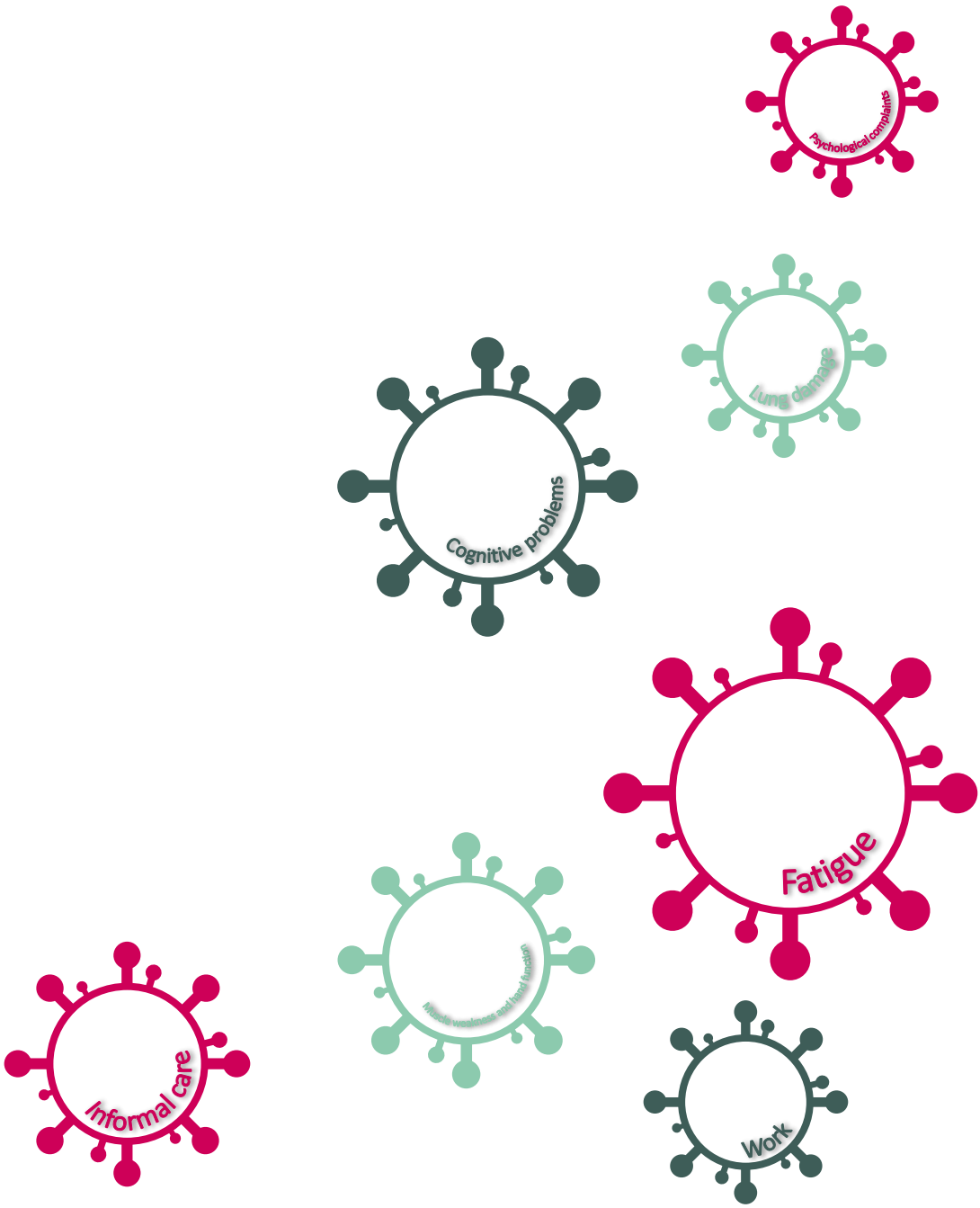
GUIDELINE OCCUPATIONAL THERAPY FOR COVID-19 CLIENTS IN THE RECOVERY PHASE

Version January 2021



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Disclaimer

This guideline is a new revision of the 'Guideline to occupational therapy for COVID-19 clients in the recovery phase' developed in 2020.
This revised guideline, like the previous three versions, is a dynamic document that will be updated as and when required by the latest scientific insights, new developments in the field of the disease and practical experience. The first version of the guide, published in May 2020, was presented as a summary in the form of a webinar on June 10th 2020. After publication of the subsequent versions, more in-depth webinars were presented in the autumn of 2020.

This document is a guideline and not a treatment protocol. It does not offer a fully worked out treatment protocol for occupational therapists but gives direction with the knowledge and experience of today.

For recommendations on occupational therapy for COVID-19 clients during hospitalization, see the guideline: "Occupational therapy for COVID-19 in ICU or nursing ward" (Ergotherapie Nederland, 2020).

For the precautionary measures for treatment, reference is made to 2 documents, which were jointly drawn up by Paramedisch Platform Nederland (PPN)[1], Koninklijk Nederlands Genootschap voor Fysiotherapie (KNGF), Stichting Keurmerk Fysiotherapie (SKF) and Nederlandse Vereniging van Podotherapeuten (NVvP): "Verantwoord verlenen paramedische zorg in de 1e gelatuur tijdens de coronacrisis Version 2.1" (PPN, 2020b) and "Algemene voorzorgsmaatregelen: Guide to hygiene protocol" (PPN, 2020a). These documents can be accessed via the Occupational Therapy Netherlands website www.ergotherapie.nl. These documents will be updated in case of changes in government policy.

Ergotherapie Nederland, 26 January 2021

[1] Paramedisch Platform Nederland (PPN), consisting of Ergotherapie Nederland (EN), Nederlandse Vereniging van Diëtisten (NVD) (Dutch Association of Dieticians), Nederlandse Vereniging van Huidtherapeuten (NVH) (Dutch Association of Dermatologists), Nederlandse Vereniging voor Logopedie en Foniatrie (NVLF) (Dutch Association of Speech Therapists and Phonicians), Vereniging van Oefentherapeuten Cesar en Mensendieck (VvOCM) (Association of Cesar and Mensendieck Therapists) and Optometristen Vereniging Nederland (OVN) (Dutch Association of Optometrists).

Guideline 'Occupational therapy for COVID-19 clients in the recovery phase':

Summary

New insights into the clinical picture, increased experience of occupational therapy treatment of the target group and consultation with occupational therapists with specific and additional expertise have led to additions and adjustments to the earlier versions of the guide. This document will be revised if new scientific insights, developments in the clinical picture and practical experience so require.

Introduction
Meanwhile it is clear from stories of people who have experienced severe COVID-19, the experiences of occupational therapists and from various studies that the consequences of COVID-19 in daily life can be serious and long lasting, not only for clients but also for their relatives. It is also known that there is no direct relationship between hospitalization and experiencing COVID-19 in the home: in both cases, people can experience severe limitations and a (often interdisciplinary) rehabilitation program is needed to resume daily life as usual.

Purpose
The aim of this document is to offer a helping hand to occupational therapists from the first moment in the recovery process in which rehabilitation goals can be set together with the client, aimed at the client being able to function (again as desired) in daily activities and the roles that the client fulfils. This document can be used by occupational therapists working in secondary care as well as primary care.

Target group
Occupational therapy focuses on those clients who, as a result of going through the disease and/or comorbidity, experience long-term or permanent limitations in daily activities and in the roles that individuals perform in life (participation). The clients have been hospitalized, and/or in a cohort department in the elderly care but can also have experienced COVID-19 at home.

Occupational therapy
Occupational therapy enables people to maintain and increase their independence and ability to carry themselves. Occupational therapists do this by evaluating functions, skills and strategies and applying them effectively in an activity. This can be done by training, teaching a different way of acting, deploying a tool or adapting the activity and/or environment. The promotion of self-management and regaining control in the changing circumstances are overarching themes, regardless of the disease or disorder. To be able to determine in the early rehabilitation a partially function-oriented perspective is chosen, especially in this new disease with an unknown course.

Domains of occupational therapy treatment
Seven different domains for occupational therapy are described, based on possible limitations in daily functioning. It is expected that the occupational therapy treatment will at least focus on one or more of these domains. For each domain, the expected problems, the clinimetrics and occupational therapy interventions aimed at optimizing the (own) capabilities in meaningful, daily activities are discussed. The topics should be approached together but can also, depending on the question of the client and/or information needs of the occupational therapist, be consulted per domain.

Lung problems in daily activities

Some of the people who have recovered from severe COVID-19 seem to have permanent lung damage from the virus. Typical for COVID-19 are the rapid decreases in saturation on exertion, without the patient always noticing it. Symptoms of tightness occur with changes in posture. Occupational therapy interventions are aimed at building up the capacity in daily activities. This takes place by teaching energy-saving breathing techniques and postures and applying ergonomic principles for breathing in daily activities which are meaningful to the client. Regaining confidence in one's own abilities is an important objective here. In the context of energy management, interventions consist of informing, advising and coaching clients in order to make adequate choices and to set priorities in daily activities and the roles that the client fulfils.

Consequences of prolonged immobilization in daily activities

As a result of severe COVID-19 there may be physical limitations such as reduced muscle strength, problems with arm-hand function and (risk of) pressure sores, oedema and contractures.

Severe muscle weakness

Severe muscle weakness does not only occur after hospitalization or ICU (Intensive Care Unit Acquired Weakness) admission but is now also known to apply to clients who have experienced the disease at home. A large group of clients indicate that they experience problems in carrying out simple daily activities.

By means of functional diagnostics, the occupational therapist investigates the client's current level of functioning.

The starting point for the occupational therapy interventions is the structured and dosed performance of daily activities, which challenges the client to push back physical limits and restores the energy balance. This enables the client to regain control of his daily activities and the roles he wants to fulfil (again).

Problems with arm-hand function

If movement limitations, loss of strength, sensation disturbances or pain symptoms in the arm and hand occur that affect daily activities, more extensive examination is recommended. Timely identification of the problems is necessary to prevent them from expanding or getting worse.

Hand mobility and strength can largely be regained during the dosed expansion of daily activities. However, carrying out (partial) activities can still be too intensive. Basic exercises and actions that stimulate the arm and hand function can create the right conditions and motivate the client.

If specific symptoms occur or if there is insufficient improvement of the hand function, it is advisable to refer the patient to a specialized hand energy therapist.

Risk of pressure ulcers, oedema and contractures

Prevention is most important in pressure ulcer care and at risk of edema and *contractures*.

Characteristics of the target group are extreme fatigue, muscle weakness and loss of condition. In combination with cognitive problems and/or psychological complaints and possible comorbidity, mobilization and resumption of daily activities can be slow. This increases the risks of developing pressure sores and oedema and developing contractures.

Occupational therapists in intramural and primary care are used to cooperating with informal caregivers and other disciplines regarding these problems. Good observation and individual problem analysis are crucial. Occupational therapy interventions are aimed at activation in daily activities and giving advice on adequate lying and sitting positions. Advice on the use of support aids and anti-decubitus aids, both preventive and curative, can be given to promote recovery and enable the client to resume his daily activities independently.

Fatigue in daily activities

Fatigue is one of the most common symptoms of COVID-19. Severe and prolonged fatigue impairs many COVID-19 clients' ability to function in daily life, and is often the reason for referral to occupational therapy. The experienced fatigue is caused by the experience of COVID-19, but is largely related to personal characteristics, environmental factors and factors at activity level. Both overestimation and underestimation of one's own capabilities are common and can both hinder recovery.
The treatment focuses on strengthening the patient's own control and achieving a balance in daily life so that sufficient energy is available for meaningful activities. Occupational therapists use various measuring instruments and interventions that address the different elements of fatigue in relation to daily activities.

Cognitive problems with daily activities

Occupational therapists can incorporate the principles of cognitive rehabilitation in their treatment programme. It is important to distinguish between cognitive complaints as a result of delirium, or if there are mild to severe cognitive problems. There appears to be no difference between the severity of cognitive problems after a long-term ICU admission or when someone has experienced the illness at home. A wide range of measuring instruments can be used, tailored to the client. An important part of the treatment is to provide the client and his system with insight into the cognitive possibilities and limitations, based on the results of clinical measurements and observations of daily activities. Learning to cope adequately with cognitive limitations by teaching (learning) strategies or compensation possibilities in daily activities can be used to achieve more self-governance in the changed circumstances for the client and the informal caregiver. Sensory overstimulation is briefly discussed. Even well after an ICU admission this can cause problems in daily functioning.

Psychological complaints, sleep problems and the consequences for the execution of daily activities

Clients may suffer from long-term excessive psychosocial stress (including anxiety and depression). It is also known that sleep problems frequently occur after experiencing severe COVID-19. Recognizing psychological symptoms often proves difficult in practice. They can manifest themselves in daily activities, for example, if the balance between necessary and relaxing activities becomes disturbed, there is a loss of initiative, inactivity or the client has difficulty structuring daily activities. Occupational therapists have an identifying role in this.
The occupational therapy intervention offers a number of points for attention and possibilities for influencing psychological symptoms and sleep problems. Giving insight in (the coherence of) the complaints supports a gradual build-up of activities and can lead to (re)finding a balance in meaningful activities and roles of the client.

Work resumption

Work resumption is an important element in the rehabilitation of COVID-19. A large group of clients who have undergone COVID-19 are younger than 65 years old. It is recommended to focus on work at an early stage in the treatment. It offers insight into one's own possibilities within the context of work, legislation and institutions and can be a means to build up one's workload. Resumption of work depends on various factors, such as residual symptoms resulting from the experience of COVID-19, personal characteristics and the client system.
Strengthening self-management is central. A resumption of work plan supports the reintegration and provides a basis for building up the workload. In the first case, the patient is given the opportunity to return to his job. However, the nature of the work and the possibilities for adjustment within the work situation can be complicating factors in this pandemic.

(Over)load of the informal caregiver in daily activities

For informal caregivers too, the period when their loved one has been seriously ill at home, in the ICU or in hospital can be a very uncertain, emotional and stressful experience. As well as the mental impact, the period of illness often places physical demands on the informal caregiver through the help they give with the client's daily activities. Informal caregivers make an essential contribution to the recovery of the client. Occupational therapy can contribute to reduce possible psychological and physical complaints of informal caregivers that affect daily activities and roles, to prevent overburdening and thus promote the recovery of the COVID-19 client.

The informal care situation can be approached as a combination of bearing capacity and bearing burden.

There are various instruments for mapping the burden, coping style and needs of the informal caregiver. Interventions focus on the promotion of the experienced social support, the feeling of appreciation and the meeting of the own participation wishes. In addition, occupational therapists can give advice to make the care and guidance of the COVID-19 client easier.

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Chapter 1 Introduction

The COVID-19 pandemic has profound implications for the lives, health and well-being of individuals, families and communities worldwide (WFOT, 2020). The new virus also creates a new target group in areas where the virus infection has a serious and complicated course. It is not yet possible to determine with certainty how and to what extent the consequences will manifest themselves in the longer term. It is certain that the consequences of COVID-19 can have consequences for the daily activities of clients and their environment. Occupational therapy can play an important role in the recovery of clients with COVID-19 who are expected to experience long-term or permanent restrictions in their daily activities and in the roles the person fulfils in life.

1.1 Purpose of this document

This document can be used by occupational therapists working in both primary and secondary care. The purpose of this document is to offer a helping hand to occupational therapists.
From the first moment in the recovery process in which rehabilitation goals can be set with the client, aimed at the (re)functioning in daily activities and roles that the client fulfills.
Where possible, we base our recommendations on scientific insights and best practices. Based on current knowledge and first experiences with the target group, this document provides an overview of expected problems, intended goals and recommendations for occupational therapy in COVID-19 clients. In the early rehabilitation phase, treatment will be focused on recovery. Based on the experiences of the past few months, it can be expected that for a large part of the clients, the treatment will extend over a longer period of time (Zorginstituut Nederland, 2020).
It is still not known to what extent this new target group will experience complaints in the long term which have consequences for daily activities.
The guide facilitates occupational therapists to draw up an individual treatment plan together with the client and to use this in the development of a product as part of a multidisciplinary or interdisciplinary rehabilitation programme.

1.2 Realization of the guide

The document has been developed by Ergotherapie Nederland in cooperation with a working group of occupational therapists working in inpatient and outpatient settings, primary care and occupational therapy researchers, all of whom have specific expertise about the problems expected after experiencing COVID-19. The first two versions of the manual have also been presented to a sounding board group consisting of occupational therapists and occupational therapy researchers.

1.3 Reading guide

New insights about the clinical picture, experiences with the target group and consulting occupational therapists with specific and additional expertise have led to additions and some adjustments of the previous versions.
After a description of COVID-19 and rehabilitation in general (Chapter 2) and occupational therapy in COVID-19 (Chapter 3), seven different domains of treatment and support are provided in which occupational therapists are involved in the rehabilitation process. Each domain covers a chapter in which the expected problems, clinimetrics, treatment goals and occupational therapy interventions are discussed (Chapters 4-10).
The following are discussed successively:

- Lung problems and their impact on daily activities (Chapter 4),
- The consequences of prolonged immobilization, including severe general muscle weakness, arm-hand function problems and risk of pressure ulcers and contractures (Chapter 5),
- Fatigue and its impact on daily activities (Chapter 6),
- Cognitive problems and the consequences for daily activities (Chapter 7),

- Psychological complaints, sleep problems and the impact on daily activities (Chapter 8),
- Work resumption (Chapter 9),
- (Over)load of the informal caregiver in daily activities (Chapter 10).

The topics should be approached together but can also, depending on the question of the client and/or information needs of the occupational therapist, be consulted per domain.
The consequences of a stroke, as a complication of thrombosis symptoms in COVID-19, are not discussed in this guideline although occupational therapists will be involved in this. For the occupational therapy treatment of stroke clients, reference is made to the Occupational Therapy guideline CVA (Ergotherapie Richtlijn CVA) (Steultjens, Cup, Zajec & Van Hees, 2013).
For the readability of this document, 'clients who have experienced COVID-19 infection' will be referred to as COVID-19 clients.

Chapter 2 COVID-19 and rehabilitation

Meanwhile it is clear from stories of people who have experienced severe COVID-19, the experiences of occupational therapists and from various studies that the consequences of COVID for daily life can be serious, not only for clients but also for their environment. It is also known that there is no direct relationship between an admission to hospital and experiencing COVID-19 at home: in both cases people can experience severe limitations and a (often interdisciplinary) rehabilitation program is needed to resume daily life as clients used to.

2.1 COVID-19

In late 2019, COVID-19 was first diagnosed in Wuhan, China. COVID-19 is the disease caused by the new coronavirus SARS-CoV-2 (WHO, 2020). The virus has spread worldwide. The World Health Organization (WHO) has declared the outbreak a pandemic (Federation of Medical Specialists, 2020; Verenso, 2020).
COVID-19 is a new syndrome that seems most closely related to Severe Acute Respiratory Syndrome (SARS), which broke out in 2003 (Holzapfel, Lammers, Werner & Keesenberg, 2020).
In June 2020, the Lung Alliance of the Netherlands (LAN) defined a provisional definition of COVID-19 Associated Syndrome (CAS): 'It is the collective term for persistent or chronic symptoms and complaints that may remain for a longer period of time after someone has experienced COVID-19' (LAN, 2020). It is not known whether CAS is a separate 'syndrome', what the exact symptoms are that clients experience, what exactly causes them and how they can best be treated and supported. Much knowledge and evidence is currently lacking. That is why we do not speak of a disease but of a 'syndrome' (the joint occurrence of certain symptoms).

Epidemiological situation

It is known that in COVID-19 about 80% of the infected people have a mild course of the disease. Twenty percent become seriously or very seriously ill, requiring hospitalization or admission to the ICU. People aged 60 years and older and people with comorbidity are the group most at risk. They have a significantly worse prognosis (RIVM, 2020; WHO, 2020).
After the first wave of COVID-19 infections in the Netherlands, more attention was paid to aftercare (Federatie Medisch Specialisten, 2020). Since July 18, 2020, a temporary entitlement has been in place for primary paramedical recovery care (physiotherapy, remedial therapy, occupational therapy, dietetics and speech therapy) after severe COVID-19 that is reimbursed from the basic health insurance under certain conditions.

Since September 2020, there has been a second, long-lasting coronas wave. As of 1 June, everybody with complaints can get tested for COVID-19, and as of 1 December, people without complaints but who are at risk of infection can also get tested (Dutch government, 2020). For current figures on the incidence of COVID-19 infections and the current epidemiological situation in the Netherlands, the websites of the RIVM and Stichting Nationale Intensive Care Evaluatie (NICE, for the current situation in the hospitals) can be consulted.

Effects of COVID-19

The natural recovery from COVID-19 takes some time and the course is not yet predictable. Also, at this moment, very little is known about the long term symptoms in survivors. COVID-19, Severe Acute Respiratory Syndrome (SARS) and Middle East Respiratory Syndrome (MERS) are examples of coronaviruses with different characteristics (RIVM, 2020). A number of studies have been conducted into the long-term symptoms in survivors of a (SARS) or (MERS) infection. These studies show that a large proportion of them have permanent residual damage to their lungs. Eighteen to sixty-four percent of survivors have psychological symptoms such as depression, anxiety, avoidance, hyperalertness or post-

traumatic stress. In addition, 40% experience chronic fatigue complaints. To what extent these data can be extrapolated to clients with
COVID-19 is not known but it is expected that a proportion of survivors of COVID-19 will experience physical, cognitive and/or psychological symptoms (Federatie Medisch Specialisten, 2020; Verenso, 2020).
In general (not specifically for clients with COVID-19) it is known that survivors of a long-term ICU admission experience health problems for many years. For COVID-19 clients, the complaints can be more severe because of the relatively long artificial respiration in a sedated state, the relatively common comorbidity, and the drastic isolation measures because of the risk of contamination.

The LAN describes the consequences of COVID-19 Associated Syndrome (CAS) as primarily lung damage, but at the same time there may be other residual damage (cardiovascular, neurological, etc.), Post Intensive Care Syndrome (PICS), as well as cognitive and psychological problems (Lung Alliance Netherlands, 2020a). In a survey conducted by the LAN among corona clients who had registered via various forums, a very large group indicated fatigue and shortness of breath as their main complaints. Almost all clients still experience symptoms after 3 months, regardless of whether they were admitted to hospital. More than half of them need help from their partner, family or others due to functional limitations (Lung Alliance Netherlands 2020b).

COVID-19 is also known to cause other complications besides infections. Thrombotic events occur that can lead to pulmonary embolisms and strokes (Cha, 2020; De Jonge, 2020; Middeldorp et al., 2020; Oxley et al., 2020).
With regard to the physical complaints, it is expected that mainly de-conditioning and loss of muscle mass will be at the forefront. It is still unknown what long-term damage COVID-19 itself can cause to the lungs and/or cardiovascular system. A large proportion of clients who have been hospitalised have comorbidities. (Federatie Medisch Specialisten, 2020; Verenso, 2020).

The cognitive problems after COVID-19 can be explained by the indirect effects of the virus on the brain. These indirect effects are neuroinflammation, blood pressure disruption, hypoxia and thrombosis (possibly resulting in cerebral infarction) (Baker, Safavybia & Evered, 2020; Baig, Khaleeq, Ali & Syeda, 2020; Budson, 2020; Slockers & Magnée, 2020; Verwijk, Geurtsen, Renssen, van Heugten & Visser-Meily, 2020; Wenting, Gruters, van Os, Verstraeten & Valentijn, 2020; Zhou et al., 2020).
Closer examination reveals an inappropriate response of the immune system; immune cells of the innate non-specific immune system become severely disrupted. And these immune cells remain strongly active in clients and cause damage to the brain. This explains why all types of cognitive disturbances can occur after COVID-19 (Schurink et al., 2020). In chapter 7, the possible problems are further explained.
Psychological problems can result from the fact that clients hospitalised with COVID-19 were usually unable to receive visits for days or weeks. The protective clothing worn by the treatment team may have made the environment even more frightening and normal contact with the client more difficult. In addition, they have to deal with an illness that is potentially life-threatening. It is expected that next of kin of clients with COVID-19 may also experience psychological problems, as a result of the limited provision of information, limited visiting opportunities and possible feelings of guilt about contamination. In addition, next of kin may be at risk of being overburdened by the provision of informal care (Federatie Medisch Specialisten, 2020; Verenso 2020).

The LAN has compiled a list of symptoms and/or complaints. The likelihood of developing these and the intensity of the symptoms are expected to depend in part on the severity of the COVID-19 experience and the presence of underlying disorders. It is not yet known whether these symptoms will become chronic or whether complete recovery of the symptoms will eventually occur. The list below is not exhaustive.

Physical

- Shortness of breath
- Coughing
- Thoracic pain
- Reduced (breathing) muscle strength
- Reduced stamina
- General (extreme) fatigue
- Joint pain and/or stiffness
- Muscle weakness, partly as a result of prolonged inactivity
- Unintentional weight loss and/or ornamental mass loss (also in obesity)
- Loss of smell and taste
- Swallowing disorders
- Stomach and bowel complaints
- Dizziness
- Experienced limitations in ADL and/or participation
- (IC-acquired) polyneuropathy and -myopathy
- Disruption of existing comorbidity

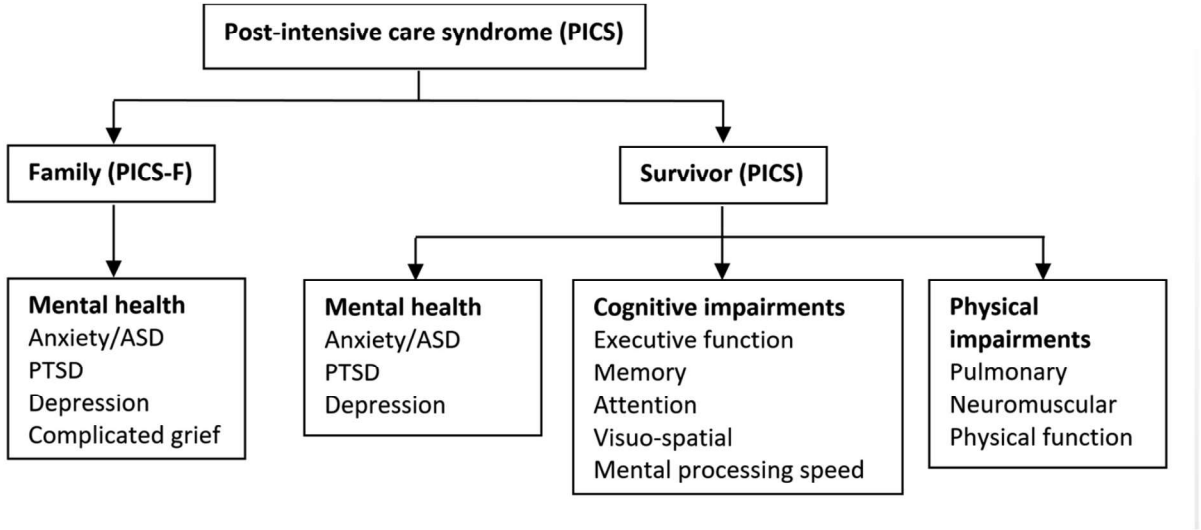
Mental

- Cognitive: memory loss, concentration problems, difficulty with plans and/or dealing with stimuli
- Sleep disorders
- Anxiety, mood complaints, mental overload
- Post-traumatic stress disorder (PTSD)
- Complicated grief (in the next of kin)

Source: 'List of symptoms & complaints CAS' (Lung Alliance Netherlands, 2020a).

2.2 Post Intensive Care Syndrome

The IC-related residual symptoms listed below can lead to long-term limitations in daily functioning and reduced quality of life. The combination of these symptoms is generally also known as Post Intensive Care Syndrome (PICS). The quality of life of family members can also be negatively affected (PICS-F). The nature of these impairments call for interdisciplinary rehabilitation treatment (Dettling-Ihnenfeldt, 2017).
Clients with PICS after COVID-19 will have a largely similar clinical picture to other clients with PICS, however pulmonary problems and psychological/psychiatric morbidity are expected to play a greater role within the COVID-19 group (Graaf, Brouwers & Post, 2020; Holzapfel et al., 2020).



Source: 'Post-intensive care syndrome (PICS) conceptual diagram' (Dettling-Ihnenfeldt, 2017)

2.3 Rehabilitation

During and after hospitalization, functional deterioration often occurs. It is important to prevent this as much as possible. Starting rehabilitation at the earliest possible time can contribute to faster recovery and prevent complications (Davidson & Harvey, 2016).
Rehabilitation usually starts during the clinical admission and should be continued when the client is stable enough to leave the hospital. Due to the unique and complex situation of COVID-19, rehabilitation usually started later. Partly due to the pressure on the ICU and hospital beds, many clients were discharged after hospital admission with relatively severe residual symptoms, without applying for a rehabilitation programme. Fear of transmission of infection and the partial lockdown of regular rehabilitation care during the first wave played a major role in this. This also applies to the rehabilitation of clients who have suffered from the disease at home. Clients start their rehabilitation process relatively late. It is therefore possible that there has already been a decline in functioning and complications have occurred. Practical experiences show that in the second wave there is more awareness and attention for the paramedical treatment options in COVID-19.

Possible forms of rehabilitation

COVID-19 clients have been admitted to a hospital, and/or to a cohort department, for example in elder care, but they can also have experienced the disease at home. The target group an occupational therapist focuses on experiences long-term or permanent limitations in daily activities and in the roles the person fulfils in his or her life, as a result of having gone through the disease and/or co morbidity. The expected long-term limitations usually require an interdisciplinary approach.
Following triage by the specialists involved, patients who have been admitted to hospital are eligible for inpatient or outpatient specialist medical rehabilitation (MSR) or geriatric rehabilitation care (GRZ), depending on the nature and severity of the disability and their age. There may also be an indication for treatment in the home situation. It is recommended that care be provided remotely where possible by means of E-health (Federatie Medisch Specialisten, 2020) .
In view of the complexity of the clinical picture, treatment should be interdisciplinary as much as possible.
Since 18 July 2020, a temporary entitlement has been created for primary paramedical recovery care. It concerns aftercare and rehabilitation support for clients who have experienced severe COVID-19 and still experience severe symptoms and limitations during the recovery phase. There is a temporary extension of the entitlement in the basic insurance for dietetics, occupational therapy and physiotherapy. A condition of the regulation is that an assessment of the required care is made by a doctor. The care

can be provided on a mono-disciplinary basis or as a combination of physiotherapy or remedial therapy, speech therapy, dietetics and/or occupational therapy (Government Gazette, 2020). The care providers involved must make mutual agreements about the treatment goals and progress and, after a period of time, discuss the treatment results and make agreements about who will carry out the treatments at what time and with what intensity. After 3 months, each care provider must report the treatment results to the GP (Zorginstituut Nederland, 2020). To be able to make use of this recovery care, participation in scientific research is mandatory.
Contact between second-line and first-line therapists is important to guide the transition from, for example, inpatient rehabilitation to treatment in the first line and thus offer continuity of care for the client.

When is it safe to start treatment?

For occupational therapists working in a clinical or outpatient rehabilitation setting, the internal agreements are always leading for the moment when the treatment can be started and which, if any, additional hygienic requirements or protective equipment apply.

For primary care, the recommendations of the RIVM (RIVM 2020) apply. The associated measures have been incorporated into the revised document 'Verantwoord verlenen paramedische zorg in de 1e lijn tijdens de coronacrisis 2.1' [Responsible provision of paramedical care in the 1st line during the coronacrisis 2.1] drawn up by PPN, KNGF, SKF and NVvP (PPN, 2020b).
PPN has also drawn up an 'infection prevention protocol guideline for primary paramedical practices'. This guideline describes how the risk of transmission of microorganisms can be reduced by applying hand hygiene and personal hygiene to staff, patients and visitors (PPN, 2020a).
The documents mentioned can be consulted on the website of Ergotherapie Nederland.

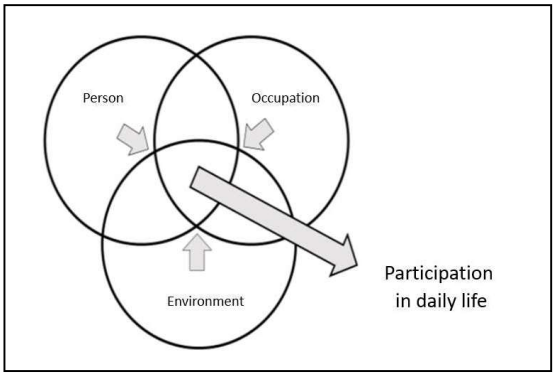
This hygiene protocol has a specific addition for occupational therapists. If there is still a risk of contamination, it is important not to use measuring instruments that use materials that cannot be disinfected or are not disposable.

Chapter 3 Occupational therapy in COVID-19

Occupational therapy can play an important role in the recovery of clients with COVID-19 who experience long-term or permanent limitations in their daily activities and in the roles the person performs in their lives. In the first instance, recovery is aimed for. Even if this is no longer, or not completely possible, occupational therapy can make an important contribution.
Performing daily activities is related to health, well-being and quality of life and is the core domain of occupational therapy (Le Granse, Hartingsveldt & Kinébanian, 2017; Van Hartingsveldt et al., 2010; Wilcock, 2015).

3.1 What does occupational therapy offer?

If clients (and their caregivers) experience limitations in daily activities due to the effects of COVID-19, occupational therapy may be indicated. The aim of occupational therapy is to increase daily activities and participation, and thus the perceived health, well-being and quality of life by addressing the client's own control and ability to adapt. Huber's concept of Positive Health (Huber et al., 2011) that defines health as 'the ability to adapt and take charge in the face of life's social, mental and physical challenges' is consistent with the theories and models of occupational therapy.



Daily actions are determined by the interaction between the person, daily activities and the environment. What distinguishes occupational therapy from other disciplines is that daily activities are seen as the starting point for the intervention. This means that the occupational therapist starts with the request for help in the area of daily activities and investigates which factors in the person, the activity and/or environment are of influence and can be used in the treatment as a starting point to improve activities and participation. This can be achieved by training, learning a different way of acting, using an aid or adapting the activity or environment.

3.2 Self-management, personal control and daily actions in COVID-19

Promoting self-management, regaining control in changing circumstances and drawing on the client's own strengths and resilience are the overarching themes that every occupational therapist will address together with the client in the counselling process, regardless of the clinical picture or the disorder.
Self-management is defined by the national Core Group Self-Management as "the extent to which someone with one or more diseases and / or disabilities is able to maintain control over his or her life as far as he or she wants and is able, by properly dealing with symptoms, treatment, physical, social and psychological consequences of the disease (s) and / or disabilities and associated lifestyle modifications in conjunction with the social environment".
Coping with the consequences of COVID-19 requires self-management on all fronts: both medical management (such as taking into account a limited lung capacity or training for physical recovery), emotional management (for example, dealing with anxiety and stress after experiencing COVID-19 and in a later phase learning to cope with loss of opportunities) and role management (how can I (re)fulfil my roles and daily activities to my satisfaction and potential?) (Satink & Cup, 2014a).
The effects of COVID-19 may be chronic for some of the clients. This means that clients may have to deal with the effects of the disease in their daily lives for the rest of their lives. It is therefore essential to explore with clients how, despite the limitations they experience as a result of COVID-19, they can maintain or regain control over their lives. This involves the development of specific skills such as managing energy, making choices in daily activities, monitoring boundaries, making use of a network and devising solutions for problem situations.

3.3 Goal setting: role management and personal control in daily activities

The approach to occupational therapy for clients with consequences of COVID-19 is based in part on the Goal setting and Action Planning (G-AP) Framework (Scobbie et al., 2011). The individual goals of the client are central.
Occupational therapists begin the introduction and question clarification process with a client. Attention is paid to questions such as: Which daily activities are important, why can I no longer perform them, how can I possibly (still) perform them and how can I retain as much control as possible?
After the joint exploration of goals and goal setting, an action plan and coping plan are established that includes the implementation of the activities and finally the evaluation and feedback on implemented actions (Hees et al., 2015). In practice, the phases of the process will be intertwined, as there are usually multiple requests for help and goals.
The interventions can consist of informing, instructing and trying out strategies, making adjustments, practising or involving the environment. Together with the individual client, the occupational therapist makes a conscious assessment of the various possibilities for achieving goals and solving problems. For example, lung problems and muscle weakness can reduce the energy needed to carry out daily activities. To gain control over the daily activities that clients want to perform (again) (role management), it is important to divide the available energy in a balanced way (energy management).

3.4 Clinical measurement in occupational therapy

Within occupational therapy, observation and measurement instruments are used to evaluate the client's functioning and environment (functional analysis). Measuring client experience with patient-reported outcomes is one of the ways to evaluate the effect of the treatment. Based on the functional analysis, the occupational therapist, together with the client, can formulate wishes, goals and expectations for the treatment.

Measuring instruments for participation in important daily activities

The symptoms after experiencing COVID-19, such as reduced muscle strength or fatigue, can have an impact on the performance of meaningful activities, the level of participation and satisfaction with these activities. Occupational therapists use different tools for functional analysis, some of which are highlighted below.

Canadian Occupational Performance Measure (COPM)

In order to map the extent to which the client is hampered and which activities have priority for the client, the Canadian Occupational Performance Measure (COPM) can be used.
It is desirable to take the COPM early in the treatment process. This measuring instrument provides valuable information about the client, what he does, what he finds important and which questions/wishes there are. In the early rehabilitation phase, the client will not always be able to estimate where and with which activities there are barriers. In this case, the questionnaire can be used to ask the client a perspective of the near future, for example after 6 weeks of rehabilitation. By asking what the client would like to do at that moment, the instrument can contribute to a careful goal setting for the treatment process. The COPM is a reliable and validated measuring instrument. The COPM is also suitable as an evaluation tool (Eijssen, Verkerk & Van Hartingsveldt, 2018).

Activity Card Sort (ACS-NL)

The Activity Card Sort (ACS-NL) is an instrument that uses pictures to map meaningful activities and activity patterns. The target groups of the ACS-NL are native-born elderly people aged 60 and above and is also suitable for people with cognitive and/or communication problems (Grondal & Poerbodipoero, 2013).

Utrecht Scale for the Evaluation of Rehabilitation Participation (USER-P)
The Utrecht Scale for the Evaluation of Rehabilitation-Participation (USER-P) measures the degree of participation, the severity of limitations and the degree of satisfaction. The USER-P can also be used to evaluate the effect of treatment (Post et al. , 2012; Cup & Satink, 2017).

Measuring instruments for self-management, self-efficacy and self-governance
Maintaining or regaining control over life is an important primary goal in occupational therapy treatment. The following measuring instruments are suitable for mapping self-management.

Self Management Screening Instrument (SeMaS)
The SeMaS identifies barriers to self-management and identifies which self-management interventions are appropriate for a particular client (Eikelenboom et al., 2015).

Self-Efficacy Scale (SES)
SES is a measure of self-efficacy for employees with a chronic illness (Varekamp, Verbeek, de Boer & van Dijk, 2011). The questionnaire contains questions about confidence in one's own abilities with regard to illness and work. One of the components concerns load and load capacity (Cup & Satink, 2017). The questionnaire can be found as an appendix in the occupational therapy guideline: 'Q fever fatigue syndrome' (Cup & Satink, 2017).

Measuring tool for evaluation of occupational therapy: the PRO-Ergo
In addition to the instruments mentioned above that can be used to evaluate (changes in) client functioning and the occupational therapy intervention, a professionally specific PROM has been developed, the PRO-Ergo. The Patient Reported Outcome for Occupational Therapy (PRO-ergo) is a reliable and validated patient-reported outcome measure (PROM), specifically designed to evaluate occupational therapy treatment aimed at the performance of daily activities, self-management and participation (Arnoldus et al, 2020). The (PRO-Ergo) can be used to evaluate occupational therapy treatment. To this end, it is important to have the instrument completed both before and after the occupational therapy intervention.

3.5 General approaches to use in occupational therapy intervention
Occupational therapists support the client in self-management and regaining control in daily life. Different approaches and conversation techniques contribute to this and can be chosen throughout the treatment process with the client. Some examples are:

Motivational Interviewing (MI)
MI is a conversation technique which can be used to find out the motivations for change in daily actions (Sassen, 2016). The essence of MI is to get people moving and empowered, to provide insight and prompt them to change their daily actions (Cup & Satink, 2017; Prochaska & Velier, 1997).

Working with solutions

Within occupational therapy, the focus is on competences and placing the emphasis on possibilities, (previous) successes and strengths and as little as possible on problems. The client forms an image of the desired situation. Step by step, the goals are achieved by making use of the available resources: the client's own strengths (skills, characteristics) and those of the environment. During the treatment process, the client develops skills that increase his resilience in dealing with the (chronic) condition (Bannink, 2017).

Resilience

The Resilience Approach focuses on factors that keep a person healthy and find the flexibility needed to get up and walk new paths. The Mini-Activity Approach (MAA) can be used for this purpose. The MAA is based on the resilience approach, by having clients experience resilience activities or resilience enhancers. These resilience activities or resilience enhancers can be divided into 3 categories: (1) enjoyable social activities, (2) positive attitudes, thoughts, and feelings, and (3) good body sense. Mini activities are doable even for people with low energy. Choosing those activities that help them take control can provide a positive boost (Aegler, Heigl & Zischek, 2019; Leenders & Van de Ven 2019)

Strengths approach

Based on positive psychology, the strengths approach assumes successes and personal qualities as the basis for long-term change. It focuses on developing, strengthening and optimizing strengths and not on solving problems or shortcomings (Hiemstra & Bohlmeijer, 2013). Because of this focus, the Strong-Side Approach fits well with the principles of occupational therapy. A short training is needed to apply this approach methodically.

Mindfulness based therapy in daily life

Mindfulness-based therapy is a meditation technique or form of attention training and can be used throughout the treatment process. In it, one learns to focus one's attention, to look at thoughts, feelings and physical sensations with a non-judgmental, mild and open mind (Kabat-Zinn, 2003). In addition to the use of mindfulness for breathing regulation as described in Chapter 5, in occupational therapy practice the technique is also suitable for being aware of body signals and of the load during an activity. This reduces the pace of action and regulates breathing during activities. The loss of energy during an activity is limited and muscle power is used optimally.

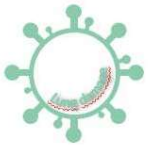
3.6 Domains of occupational therapy treatment in COVID-19

Central to occupational therapy treatment is the optimization of (one's own) capabilities in meaningful everyday activities. In their approach, occupational therapists focus, if possible, on the client's questions, wishes or goals and to a lesser extent on the underlying problems.
However, to be able to determine in the early rehabilitation what possibilities there are for the client in his recovery process, especially with this new syndrome with an unknown course, a partially function-oriented perspective should be chosen.
Moreover, measuring instruments and interventions are (in this phase) largely focused on the specific domains, including functions, to determine what the limiting factors are for daily meaningful action and fulfilling roles (activities and participation). To provide practical guidance for occupational therapists, the possible problems and complaints after COVID-19 that have consequences for daily activities have been taken as a guideline for this manual. Although occupational therapists have received broad training, they do not have extensive expertise in all the areas mentioned. However, occupational therapists are able to include the basic principles of the various domains in their treatment programme. Sometimes additional training is needed to apply certain measuring instruments and treatment methods. In those situations it is advisable to work together with a colleague who has the right knowledge and skills in specific areas.

The following chapters discuss the domains:

- Lung problems and their impact on daily activities (Chapter 4),
- The consequences of prolonged immobilization, including severe general muscle weakness, arm-hand function problems and risk of pressure ulcers and contractures (Chapter 5),
- Fatigue and its impact on daily activities (Chapter 6),
- Cognitive problems and the consequences for daily activities (Chapter 7),
- Psychological complaints, sleep problems and the consequences for daily activities (Chapter 8),
- Work resumption (Chapter 9),
- (Over)load of the informal caregiver in daily activities (Chapter 10).

Chapter 4 Lung problems in daily activities



4.1 Expected problems

Lung damage

So far, it seems that a small group of clients will have residual lung damage after going through COVID-19 infection. This is especially true for people who have been admitted to the ICU and had to use oxygen in the hospital. It is not yet known whether this damage will recover, what is needed to recover and how long this recovery may take (Longfonds, 2020).
Some of the patients with COVID-19 received mechanical ventilation at high pressures. This can lead to ventilator-induced lung damage. Sometimes this damage is temporary and sometimes it is permanent. It is not yet known exactly what lung damage COVID-19 can cause in the long term. It is safe to assume that this damage will mainly consist of a decreased lung capacity and oxygen uptake, as is seen in some other pneumonia caused by a systemic viral infection. In addition to possible lung damage caused by the pneumonia itself and mechanical ventilation, patients who have experienced COVID-19 seem to be at an increased risk of thromboembolic complications. The first complication to come to mind is pulmonary embolism. In the long term, this may lead to chronic thromboembolic pulmonary hypertension, manifested by exercise intolerance and dyspnea. Also, in people who have experienced COVID-19 irreversible damage with scarring may have occurred in the lungs. In that case, it is to be expected that - to a certain extent - the elasticity of the lung tissue has disappeared, resulting in loss of alveoli and less oxygen exchange, which may lead to reduced stamina (LAN, 2020a).

Muscle weakness of the respiratory muscles

The respiratory muscles, including the diaphragm, are not used for a period of time because of the artificial respiration. As with other muscles in the body, this quickly leads to a reduction and shrinkage of the muscle fibres of the diaphragm and other respiratory muscles. Once awake, the client may experience significant tightness even with minimal exertion. Sometimes the weakness of the respiratory muscles makes it difficult to wean the patient off the ventilator. In rarer cases, damage may have occurred in the trachea due to the tube. This can lead to prolonged complaints of tightness (IC connect, n.d.).
Chapter 5 discusses generalized severe muscle weakness due to ICU admission, Intensive Care Unit Acquired Weakness (ICU-AW).

Diaphragm Damage

Patients with COVID-19 often suffer from prolonged shortness of breath. Recent research indicates that this might be caused by damage to the diaphragm. The diaphragm is the most important breathing muscle for us. Researchers from the Amsterdam UMC and the Radboudumc found significant damage in the diaphragm of 26 deceased COVID-19 patients. The researchers found inflammatory reactions and connective tissue formation. Future research will have to show whether the respiratory muscles fully recover after COVID-19 (Shi et al., 2020).

Saturation drops

After a COVID-19 infection, rapid decreases in saturation are still visible in clients, without the client always noticing it or showing any non-verbal signs. This seems typical for COVID-19. Saturation is a measure for the amount of oxygen that is bound to the hemoglobin in the red blood cells. Red blood cells provide the transport of oxygen to tissues (Xiaoneng et al., 2020).

Orthopnea

Clients who have experienced COVID-19 may also suffer from orthopnea. Orthopnea is a form of shortness of breath that occurs when lying horizontally and is often the reason that the client wants to sleep supported with pillows or sitting upright.
In reduced lung function, the increase in shortness of breath occurs due to the sudden change in position, causing the diaphragm and ciliary muscles to lose the mechanical advantage due to the lying down position. Orthopnea can also occur because more blood flows towards the chest from the lower extremity when lying flat. This creates increased pressure in the abdominal and thoracic cavities, which can lead to shortness of breath. In a healthy person the heart can adapt itself adequately to this change, but in a person with a reduced heart function this can cause shortness of breath. In case of a diminished heart function the shortness of breath often occurs after a short lying down period, in case of lung failure it occurs almost immediately. Our lung function also shows a biological rhythm. Early in the morning the lowest lung function is measured. This may mean that in the morning there is a reduced lung function and the client then experiences more complaints (Medarov, Pavlov, & Rossoff, 2008).

A recent study by the Radboudumc shows that in clients struggling with severe COVID-19, lung tissue recovers well in most cases. Residual damage to lung tissue is usually limited and is most frequently seen in ICU patients. The picture is similar to recovery from severe pneumonia or ARDS, where fluid accumulates in the lungs. Recovery from these conditions is generally also long.
After three months, fatigue, shortness of breath and chest pain are the most common complaints. Many people still experience limitations in daily life and a reduced quality of life (Radboudumc, 2020). Even clients with 'mild' COVID-19 will continue to suffer from persistent symptoms for a long time. The most common symptoms are fatigue and dyspnoea. This is true both for clients who have been hospitalised and for those who have had the infection at home (Goërtz et al., 2020).
One striking conclusion from this study is that the group of clients who have experienced the disease at home recover less well than clients who have been admitted to the ICU (Radboudumc, 2020).

4.2 Occupational therapy aimed at lung problems

It is recommended that clients with residual pulmonary impairment be treated by therapists who have experience with and are trained in pulmonary rehabilitation (Spruit, Holland, Singh & Troosters, 2020). That said, occupational therapists are able and advised to incorporate basic principles of pulmonary rehabilitation into their treatment program.

4.2.1 Clinimetrics

During the observation and inventory, it is recommended to evaluate different aspects with the following measuring instruments, specifically for lung problems.
The use of a saturation meter is necessary.

Saturation measurement in daily activities

The saturation measurement is used in combination with the observation of an activity. The oxygen saturation (%SpO2) can be measured with a saturation meter (pulse oximeter), in the form of a 'pinch' that is put on the fingertip. Cold fingers, nail polish on the nails, movement or hanging of the hand can disturb the measurement and give abnormal values. It may take some time before the oxygen saturation is reliably displayed. Oxygen saturation is expressed as a percentage. For healthy people a value of 95-99% oxygen saturation is normal. A value below 90% is called desaturation or hypoxemia. A lower limit of 90% at rest and 85% during physical exertion must be used (KNGF, 2020).

The clinical signs associated with desaturation are shortness of breath, pressure in the chest or around the diaphragm, discomfort in the chest and the feeling that it is more difficult to breathe. The observed desaturation does not necessarily have to be accompanied by these clinical signs.

Observation during meaningful daily activities

At the start of rehabilitation, after getting acquainted, it is important to observe various activities that are meaningful to the client. It is important to pay attention to the performance, the manner of compensation (with breaks, support, standing, sitting), degree of assistance, boundary management and verbal and non-verbal signals that may indicate shortness of breath.
Measure saturation at the beginning and end of the activity. If the client takes a break or in case of clinical symptoms, also measure in between. Before the activity begins, leave the saturation meter on the finger until a stable value is observed. After the activity, the saturation meter remains on the finger until the person has recovered to the value the saturation meter gave before the activity. How long that recovery takes is also an important factor.

Canadian Occupational Performance Measure (COPM)

The COPM can be used to clarify the request for help. It identifies the main problems experienced by the client and measures change. The COPM can also be used later as an evaluation tool (Eijssen, Verkerk & Van Hartingsveldt, 2018). For a more detailed description of the COPM, please refer to Chapter 3.

Lock scale

Shortness of breath and fatigue can be noted using the Borg scale. The Borg scale for shortness of breath and fatigue comprises a scale from 0 to 10, which provides insight into the shortness of breath and fatigue experienced by the client. In the first six weeks after discharge from hospital or symptom-free after COVID-19 treatment at home, clients should exert their energy in a controlled manner, with a maximum score of 4 on the Borg scale from 0 to 10 (KNGF, 2020).
Time registration lists can also be used to analyse the experienced workload and the workload capacity. A version of these has also been made for this target group. The time sheets with Borgscore are attached.

4.2.2 Occupational therapy intervention

Adequate breathing technique when carrying out daily activities

Saturation measurement in daily activities

Saturation measurement in the treatment of various COVID-19 clients has shown that saturation can be at the right level when seated at rest, but that saturation drops significantly during activities. During exercise in daily activities it is important to monitor the saturation and to map out any desaturation in the client. This can be done by measuring at rest, during exercise and directly after exercise. A lower limit of 90% at rest and 85% during physical exertion should be used.
If a saturation meter on the finger does not provide sufficient information because it does not stay in place during the activity, then consider placing a saturation meter on the earlobe or forehead. In this way the course of the saturation during the activity can be registered. This can be of added value when clients become increasingly active and also show many dips in saturation. In the event of a drop in the transcutaneous oxygen saturation level during exercise, it is important that the saturation rises again to the resting level within two minutes. If no desaturation occurs in the first two weeks, intensive monitoring of transcutaneous oxygen saturation is not indicated (KNGF, 2020).

Pacing for shortness of breath

Pacing is part of the 3 P's principle and briefly explained in Chapter 6, on fatigue.

With pacing, the client learns to perform the activity at a steady pace with regular breaks in the activity. Research with clients with Chronic Obstructive Pulmonary Disease (COPD) has shown that this leads to fewer symptoms of shortness of breath and fatigue.
It also appears that the task does not take longer in total. When this method is applied it is easier to control breathing. At the end of the activity, no long rest is then necessary to recover (Prieur, Combret, Medrinal, Arnol & Bonnevie, 2020).
Practical examples for applying pacing to shortness of breath may include:

- Climbing stairs: walk up five steps, rest for 30 seconds.
- Washing/dressing: take a rest after washing/dressing the upper body to then wash/dress the lower body.
- Vacuuming: take 2 minutes rest after vacuuming a room.

Breathing Control: Pursed Lip Breathing

Given the nature of the breathing problems after COVID-19, one would expect that practicing breathing techniques would have no added value. In practice, however, it turns out that the client can benefit from applying breathing techniques or breathing regulation in order to regain control of his breathing. Breathing regulation means that the client is in control of his breathing. This can be done by means of Pursed Lip Breathing (PLB) or by means of PLB in combination with active expiration. Applying PLB while performing daily activities is difficult for many clients, while it can have a very beneficial impact on shortness of breath (Appels, et al., 2016). Make sure that the client does not exhale too much, hyperventilation can occur. In case of dizziness symptoms, PLB should be stopped immediately. By applying these techniques in daily activities the client can regain confidence in his functioning.

Breathing regulation: Mindfulness Techniques

To reduce symptoms of shortness of breath and also to improve well-being, mindfulness exercises could be helpful (Chan, Giardino & Larson, 2015). Relaxation exercises can be supportive in getting a grip on breathing.
Research suggests that there appears to be a complex relationship between breathing, emotions and mindfulness in clients with COPD. The use of mindfulness techniques may be a useful intervention for COVID-19 clients with breathing problems. For example, applying 'the body scan' when lying or sitting, '3 minute breathing space', 'walking meditation', but above all, acting more 'mindfully'. This is about performing a daily activity with more attention, consciously experiencing how it is performed and how the client feels about it (Chan, Giardino & Larson, 2015).

Breathing support postures and ergonomic principles

The diaphragm may have deteriorated significantly following prolonged ICU admission. For clients with a significant decline in function of the diaphragm it is important to be able to make optimal use of the assisting respiratory muscles. The muscles used for supplementary breathing must therefore be spared when carrying out other activities. This can be done, for example, by taking support.
When taking up support, a number of the muscles that help with breathing, such as the pectoral muscles, the trapezius muscle and the sternocleidomastoid muscle, can be used more adequately because the shoulder girdle (and the head) are fixed in this position. A closed circuit is then formed to support breathing. Breathing without support (i.e. in an open circuit) makes use of the diaphragm, the scalene muscles, the trapezius pars descendens and the sternocleidomastoid muscles (Gosselink & Decramer, 2003).
Ergonomic breathing principles make a positive contribution to preventing or remedying shortness of breath and reducing oxygen consumption during everyday activities (Velosso & Jardim, 2006). It makes sense to apply these principles when carrying out everyday activities so that the muscles needed for breathing can be used as optimally as possible during the activity.
One example of applying ergonomic principles to reduce shortness of breath is working with one hand. By supporting yourself with one hand, a closed circuit is created on that side, which makes optimal use of the assisting respiratory muscles. The other hand can then be used for the activity.

Other examples of these ergonomic principles are:

- Supporting on both hands or elbows
- Walking with a rollator or shopping trolley
- Leaning against a wall
- On your knees
- Working more from the legs
- Acting seated instead of standing

Optimize ADL status and improve mobility

If there are problems in carrying out ADL activities, these can be practised. It is important to focus the attention and interventions on working at a steady pace, breathing calmly and, if necessary, adjusting the manner of performance so that the activity is less stressful. This can be done by applying ergonomic principles for breathing and by pacing.

When improving mobility, supportive postures can be used so that ciliary muscles support breathing. Adopting a specific forward bending posture can bring the diaphragm into an extended position, so that more strength can be generated and the ciliary muscles have a chance to make a greater contribution to breathing. This makes it possible to reduce the sensation of shortness of breath. Applying ergonomic principles during activity lowers oxygen consumption (Appels et al., 2016).
When there is a question of very low load capacity and permanent participation problems, the use of aids can be necessary. Think of mobility aids such as a walker, wheelchair, wheelchair and/or mobility scooter.

Advice on lying down

It is known in pulmonary rehabilitation that patients with shortness of breath experience problems as soon as they lie down (horizontally). It is relevant to realise that during the night and particularly in the early morning, lung function decreases, which can realistically lead to an increase in shortness of breath. Clients often tend to sleep upright in bed or in a chair. This is not a desirable posture for the body; it is important to discuss this. Make a distinction between complaints of shortness of breath caused by respiratory problems or by reduced heart function. If there is a reduced heart function, lying horizontally is often not possible.

Shortness of breath increases in a completely horizontal posture

Is there an increased shortness of breath when lying down or did this mainly occur early in the disease period? Sometimes you get used to it and lying down can slowly be made more horizontal. This can be done by positioning the head end of the bed lower and lower or by using fewer pillows.

Shortness of breath increases with rapid change of position

If someone becomes short of breath due to a rapid change of posture, it may be advisable to adjust the pace and first sit on the edge of the bed to regain control of breathing, paying attention to exhaling, before lying down or standing up.

Shortness of breath increases due to fear

Often clients have had a negative experience that has caused them to sleep in a sitting position and no longer dare to lie horizontally. The above advice can help to reduce anxiety. Possibly the client can be taught relaxation or mindfulness exercises, which can be applied before going to sleep.

Chapter 5 Consequences of prolonged immobilization in daily activities

To be able to perform meaningful activities, adequate muscle function and (fine) motor skills are essential. As a result of experiencing severe COVID-19, physical limitations can occur such as general muscle weakness, fatigue, problems with arm-hand function and (risk of) pressure sores and contractures. This chapter discusses occupational therapy treatment for muscle weakness, arm-hand function problems and pressure ulcers and contractures. For these three topics, the clinimetrics and occupational therapy interventions are described separately, as they differ greatly. Fatigue, one of the most frequently mentioned symptoms of COVID-19, is discussed separately in Chapter 6.

5.1 Muscle weakness

Intensive Care Unit Acquired Weakness (ICU-AW)

ICU-AW, muscle weakness acquired in the ICU, is one of the most prominent consequences of ICU admission in COVID-19. client. The cause of muscle weakness can be either in the muscle (critical illness polymyopathy) or in the nerve (critical illness polyneuropathy). Because these disorders often occur simultaneously and are difficult to differentiate, the term ICU-AW is used. The main risk factors are sepsis, Systemic Inflammatory Response Syndrome (SIRS), multi-organ failure (MOF), immobilization and hyperglycaemia (Groeneveld et al., 2012). This muscle weakness has adverse effects on ventilator withdrawal and short- and long-term recovery. The incidence of ICU-AW reported in the literature varies depending on the population studied, from 60% in clients with Acute Respiratory Distress Syndrome (ARDS) to 100% in clients with SIRS combined with MOF (Holzapfel et al., 2020; Sommers et al., 2015).

The average length of ICU stay in COVID-19 was 18.7 days in the first wave and has now been reduced to 14.7 days (RIVM 2020). On a daily basis, clients can lose 0.5-1kg of muscle mass during ICU admission (LAN, 2020). Practice shows that after ICU admission, the loss of muscle strength can be so severe that the client is unable or barely able to move and perform daily activities. Moreover, clients will have to relearn the capabilities of their bodies.

An American study describes peripheral muscle weakness in COVID-19 clients from a post-acute COVID unit. There was muscle weakness in the M. Quadriceps and M. Biceps in 86% and 73% of the clients, respectively (Paneroni et al., 2020).

Severe muscle weakness when experiencing COVID-19 at home

The group that has experienced the disease at home can also experience complaints of muscle weakness. A survey of the Dutch Lung Foundation (in collaboration with treatment and knowledge centre CIRO and Maastricht University) among 1622 people with complaints after COVID-19, shows that a large part of the clients still has complaints three months after the first symptoms, such as fatigue, shortness of breath, chest pressure, headache, and muscle pain. Of this group of respondents, 91% had never been to the hospital. As many as 9 out of 10 people indicate that they experience problems in carrying out simple daily activities (Longfonds, 2020).

5.1.1 Occupational therapy for muscle weakness: Clinimetrics

Functional diagnostics

Functional diagnostics are used to investigate the client's current level of functioning.

This can provide insight into:

- The client's actual activity level;

- Safety when performing activities;
- Opportunities to build activity;
- The potential for compensatory strategies;
- Opportunities to re-learn activities.

The daily activities that are important to the client are central to this and could include the observation of daily activities in an ADL situation, a kitchen task or another meaningful activity. Measuring instruments that can be used include the AMPS (Fisher & Bray Jones, 2010) or PRPP (Nott, Chapparo & Heard, 2009).

COPM

Mapping, prioritizing and making choices in meaningful activities can be done by taking the COPM (Eijssen, Verkerk & Van Hartingsveldt, 2018). For a more detailed description of the COPM, please refer to Chapter 3.

5.1.2 Occupational therapy for muscle weakness: Interventions

Mobilization through daily meaningful activities

Based on practical experience it appears that, despite existing muscle weakness and fatigue, it is essential for recovery to encourage the client - as soon as possible - to get out of bed and resume basic daily activities, such as sitting in a chair, eating at the table or taking a short walk behind the rollator. The starting point is that through a dosed and structured implementation of daily activities, the client is challenged to push physical limits and also gets a renewed body awareness.

Daily structure

An intervention that is valuable when resuming meaningful activities is the creation of a daily structure. It is advisable to work with a horizontal schedule, in which therapies, moments of exercise and recovery times are offered at fixed times and are carried out in a time-contingent manner. In the beginning, a mobilization schedule for 'sitting' may be sufficient.
Subsequently, it is important to expand the schedule with activities that are worthwhile for the client and that require little effort. In this, a balance must always be made between what someone does himself and what (partial) actions are taken over. When drawing up a daily structure, account should be taken of the possible overestimation of the client, fear of movement and/or overstimulation.
Experience with the treatment of clients with COVID-19 shows that, after an initial build-up, they regularly experience a relapse. It is advisable to use a calmer build up schedule and to increase the duration and/or intensity of the exercise in smaller steps.

5.2 Problems with arm-hand function

Movement limitations and muscle weakness of the arm and hand have a direct impact on the independence in carrying out (basic) daily activities. If there are movement limitations in the arm and hand and/or pain symptoms that have consequences for daily activities, more extensive examination is recommended.
For example, a lot of prolonged oedema in the hand in the acute phase can cause shortening of the intrinsic muscles of the hand. An ulnaropathy or plexus brachialis lesion can also occur, for example, in or after a long-term immobilization position (such as during ventilation), where there has been pressure/stretch on the peripheral nerves.
Disturbances in sensory feedback also have consequences for the coordinated fine motor skills and the (safe) performance of daily activities.

It is also our experience that clients who have not been touched for a long time or have not been able to use their hands themselves, can have a kind of 'skin hunger', a need to touch and feel again. It concerns the superficial and deep sensibility, but also the experience of movement and body scheme. These problems will need to be identified as early as possible to prevent them from spreading or worsening and to apply the appropriate interventions.

5.2.1 Occupational therapy for problems with hand-arm function: Clinimetrics

Mobility: Range of Motion

Measuring the Range of Motion (ROM) is necessary to get a clear picture of any problems in the tendomyogenic area (Zeeuws Hand & Wrist Centre, 2013). These measurements are repeated regularly during the rehabilitation period. They are also meant to evaluate if the training/deployment of the hand is developing at the right level.

Manual force: hand-held dynamometer

Measuring the maximum hand pinch force gives a good estimation of the muscle function and is related to the total amount of muscle mass in the body. By measuring muscle strength it can be determined if the values of a client are within the norm or how muscle groups relate to each other. Decrease of muscle strength can be a sign of muscle degradation. (Measuring instruments in care, n.d.). To measure hand strength, a hand-held dynamometer can be used (Samosawala, Vaishali & Chakravarthy Kalyana, 2016). Some clients report wrist complaints indicating low load capacity of the wrists after going through COVID-19. This may result in pain symptoms, loss of strength and/or an unstable wrist and restrict/impede performance of daily activities.

Sensibility: Semmes and Weinstein Monofilament Test

In the case of neuropathy, for example due to prolonged pressure or edema, the Semmes and Weinstein Monofilament Test (SWMT) can be administered. Pressure perception is evaluated with this (Fonseca et al., 2018).

Functional level: Patient Specific Complaints (PSK) or Canadian Occupational Performance Measure (COPM)

To record the functional level of the arm and hand, the measuring instrument for Patient Specific Complaints (PSK) (Beurskens, 1996) or the Canadian Occupational Performance Measure (*COPM) can* be used (Van de Ven et al., 2015).

5.2.2 Occupational therapy for problems with arm-hand function: Intervention

Stimulate hand mobility, strength and sensibility

Hand mobility, hand squeezing strength and also the sensibility can largely be regained while performing daily activities. It is important to increase daily activities in a controlled way.
In practice, however, experience shows that in the first period of recovery clients can be so seriously weakened that carrying out (partial) activities is still too intensive. Dosed exercises that stimulate the arm and hand function are often possible and can be motivating for the client.

If clients are given exercises as homework, these are not always carried out according to instructions. Bear in mind that 'over-exercising' can cause a client to develop strain symptoms that were not detected in the first examination.

Basic exercises

Initially, it is important to encourage the client to move the hand and wrist, touch and do repetitions of basic movements such as bending, stretching, spreading, closing and performing basic hand grips. Touching the hand is important for optimizing body schema and therefore sense of movement (Proske & Gandevia, 2012).

Basic operations

By integrating exercises into basic movements, the mobility and load capacity of the hand can be trained. Some examples are:

- Greasing the hands with, for example, a cream. Twisting around each finger and then rubbing the back of the stretched hand again.
- Spread and close the fingers alternately with the 'prayer grip'. From an extended position of the fingers roll up the fingers to a hook grip. This is important for exercising the intrinsic muscles of the hand.
- Picking up and manipulating various objects and materials to improve the stabilisation and manipulation skills of the hand. It creates the conditions for making actions such as buttoning, brushing teeth or turning keys independently possible again (Skirven, Osterman, Fedorczyk, Amadio, 2011).

Building muscle power

To build up muscle strength in daily activities it is important to train the total hand pinch strength as well as the lateral grip (key grip). This is done by performing daily activities (occupation-based). In addition, extra exercise material can be used, such as putty, digiflex or Theraband. Training should follow the normal training recommendations, starting from a baseline with a gradual increase in the number of repetitions and weight. Overloading the tendons and muscles can occur if the total pinch strength is built up too quickly.
The course of the training can be monitored by periodically repeating the hand strength measurement, but also by recording the functional level.
In addition to maximum strength, it should also be assessed during training whether the endurance strength is reduced. This can be trained by specific exercises and periodically measured with the hand-held dynamometer (Skirven, Osterman, Fedorczyk, Amadio, 2011).

Hand occupational therapist

When specific symptoms occur in the arthrogenic, tendomyogenic or neurogenic area or when there is insufficient improvement of the hand function, it is advisable to have an extensive hand function examination done by a specialized hand energy therapist. If specific complaints arise at an early stage, this will have a negative impact on the recovery of normal movement and the building up of load capacity in daily activities.

5.3 Risk of pressure ulcers, oedema and contractures

Decubitus

Pressure ulcers are localized damage to the skin and/or underlying tissue caused by pressure or pressure combined with shearing forces. Decubitus usually arises on a protruding bone, but can also be the result of pressure from medical or other devices.
With pressure ulcers the skin can still be intact or there can be an open wound. Pressure ulcers lead to a high burden of disease and reduce the quality of life for clients and informal caregivers (V&VN, 2020). Besides pain and wound-related discomfort, pressure ulcers affect physical functioning, psychological well-being and social functioning. If the client with COVID-19 has been in the ICU or in the hospital for a long time, the risk of pressure ulcers is high due to loss of muscle mass, reduced nutritional intake, reduced oxygen content in the blood, reduced mobility (resulting in reduced blood flow) and possible sensory limitations. Comorbidity increases the risk of pressure ulcers. Workgroup members who have

contributed to the guide 'Occupational therapy for COVID-19 in ICU or nursing ward' (source text) report that attention is paid to decubitus prevention for the target group during admission. However, as soon as the client is discharged, it is more difficult to control the risk factors that favour pressure ulcers. If the client is sufficiently mobile at home, the risk of pressure ulcers will be low. However, the target group is characterised by fatigue, a decrease in strength (including muscular strength) and fitness, making it difficult to build up activities. If there are cognitive problems, the initiative to move is often reduced and therefore the risk of pressure ulcers increases. Psychological complaints and the presence of pain (caused, among other things, by the pressure ulcer) also have a negative influence on the prevention and recovery of pressure ulcers.
The National Pressure Ulcer Advisory Panel (NPUAP) and the European Pressure Ulcer Advisory Panel (EPUAP) decubitus classification system list the different categories (V&VN, 2020).
Category I: Non-erasable redness in intact skin
Category II: Loss of part of the skin layer or blister.
Category III: Loss of an entire skin layer (fat visible).
Category IV: Loss of entire tissue layer (muscle/bone visible)

Cannot be categorized, not classified:

- Loss of entire skin or tissue layer, depth unknown
- Suspected deep tissue damage, depth unknown.

If there is any doubt about the category, the counsellor should assume the highest category (IV).

Recovery time from pressure ulcers
A start must always be made on the use of preventive measures. If pressure ulcers are present, it is not possible to give a clear recovery time for pressure ulcers. Recovery depends on various factors (location and degree of the pressure ulcer, possibility of removing the cause, personal characteristics of the client, such as food intake, blood circulation, etc.). To monitor recovery properly, it is advisable to take a photo at a fixed time, for example once a week. A photograph can be combined with a 'wound meter' on which the measurements (length, width, depth) of the wound in millimetres or centimetres are noted.

Risk of oedema

In COVID-19 clients, especially after ICU admission, oedema is observed in both the upper and lower extremities as a result of prolonged immobilization. If mobilization and resumption of daily activities is slow, edema can persist and cause contractures. This also has a negative impact on mobility and functionality. Therefore, edema should be prevented and controlled as much as possible.

Risk of contractures

Prolonged immobilization can cause contractures. Contractures can be very limiting and stand in the way of a quick mobilization. Prevention and treatment of contractures are therefore important for the rehabilitation process and the possibility to resume daily activities independently. During the ICU admission, active efforts were made to prevent contractures, among other things by the use of muscle relaxants. It appears that COVID-19 clients developed few contractures after ICU admission. The incidence among clients who have experienced the disease in elderly care or in the home is not yet known. It is important to be alert for factors that aggravate the development of contractures.

5.3.1 Occupational therapy for risk of pressure ulcers, oedema and contractures: Clinimetrics

In practice, the assessment of possible contractures is included in the assessment of possible pressure ulcers and is therefore not mentioned separately.
The NPUAP/EPUAP pressure ulcer classification system mentioned above is used to determine which category of pressure ulcer exists, and at which location. The most common locations of pressure ulcers are:

- In the supine position: toes, heels, tailbone, spine, elbows, shoulder blades and back of head.
- In the lateral position 90 degrees: the inside and outside of ankles and knees, the hip, ribs, elbows, shoulder tips and ears.
- In prone position: instep, shin, knees, ribs, elbow, ear, face, chin, cheekbones.
- When sitting: heel bone, ischium, tailbone (when sitting in a slumped position), elbows and shoulder blades.

COVID-19 clients who have been in the ICU have been nursed in the prone position, so pressure ulcers can also occur in other places, such as the face. Catheters and ventilation tubes can also cause pressure sores.

A number of scales can be used for the assessment and estimation of the pressure ulcer risk: the Braden scale, the Norton scale, the Waterlow scale, the PrePurse and the CBO risk score lists (V&VN, 2020). These instruments are a tool for determining the risk of pressure ulcers in a structured manner. A risk assessment should be combined with the clinical view of a care provider. Pressure ulcers may be more difficult to see in clients with dark pigmented skin, especially in category 1 and when deep tissue damage is suspected with intact skin. Moisture injury can be diagnosed as a pressure ulcer because moisture injury also causes discoloration and changes in the skin and wounds. The cause and interventions of fluid injury are different from those for pressure ulcers. Therefore, it is important to differentiate between pressure ulcers and fluid injuries in the clinimetrics.

5.3.2 Occupational therapy at risk of pressure ulcers, oedema and contractures: Intervention

The outcome of a risk score and individual characteristics of the client give an indication to start or extend preventive and/or curative interventions. By using interventions, pressure ulcers can be prevented or cured and pain can be reduced. The occupational therapy advices for prevention and treatment of contractures correspond in practice to the advices that belong to the prevention and treatment of pressure ulcers and are therefore not mentioned separately in this guide.

Oedema

The stimulation of independent movement is crucial. If this is not yet possible, passive continued movement of the upper and lower extremities may be necessary to reduce oedema and prevent contracture. Active elevation, if necessary with the aid of support equipment, also contributes to the reduction of oedema.

Advice on prevention

Prevention is the most important aspect of pressure ulcer care and the risk of contractures. Occupational therapists in primary care are accustomed to cooperating with informal caregivers and other disciplines such as the general practitioner, district nurse, wound care nurse, dietician and lending centres for decubitus (AD) material. Informing the informal caregivers and other involved disciplines is important to prevent, cure or timely intervene in pressure ulcers. As soon as redness can no longer be pushed away (Category I), or if the client experiences pain that may indicate the development of pressure ulcers, additional (auxiliary) resources must be used immediately. This also applies preventively

to patients with a very high risk of developing pressure ulcers and to the following target groups: patients with pressure ulcers, patients in the ICU, patients in the operating theatre, patients with paraplegia and patients in the terminal phase (V&VN, 2020).
Advice that can be given is:

- Teach the client to adopt different postures and use aids if necessary.
- Minimize shear forces in all situations.
- Mobilize the client as soon as it is feasible.
- Activate the (independent) performance of activities, including eating, drinking and toileting.
- Recommend smooth, supple, dry and clean clothing that does not pinch.
- Limit the number of layers (clothing) below the rump.

Advice on sitting/seating posture, both preventative and curative

- Bear in mind that clients can find sitting up very tiring. Make sure the (wheel)chair is correctly sized so that pressure is evenly distributed across the seat, back, thighs, feet and arms. Prevent shearing forces by maintaining a sitting angle of 90-110 degrees and by tilting the (wheel) chair.
- Alternating between different sitting positions, and therefore varying the pressure distribution, can be created by periodically tilting the (wheel) chair to different positions.
- An anti-decubitus (AD) cushion can be used both preventatively and curatively. When using an AD cushion, make sure that the dimensions of the (wheel) chair remain intact in order to maintain the best possible pressure distribution over the entire body.
- Advise the introduction of midday rest in bed for the purpose of postural variation and shifting of pressure points during the day. In the supine position the knee and hip angle changes, the pressure then shifts from the sitting bones to the coccyx. This variation in posture is also important for the prevention of contractures and ensures that muscles active in the sitting position are relieved (V&VN, 2020).

Advice on lying/recumbent position both preventive and curative

- Alternate between supine and lateral positions on the left and right.
- The prone position is also used in the ICU. A pillow under the chest and hips helps to reduce the risk of damage to the arm and leg nerves.
- Practice turning in bed independently, possibly using a bed rail, bed parrot and/or smooth sheets.
- Prevent shearing forces, both in the supine and lateral positions, and during transfers. In the supine position this can be achieved, for example, by using the semi-Fowler position. Smooth fitted sheets can also be used. To support a good recumbency at home, a high-low bed can be considered. Use a sliding sheet to make transfers.
- Due to the presence of contractures or insufficient possibilities to turn independently to a stable position, it is possible that more support is needed when lying down. The use of additional cushions and supports can therefore be temporarily necessary.
- For decubitus patients, a lateral position of 30 degrees is recommended. In this position, the client does not lie on bony parts. Moreover, in a lateral position of 30 degrees the lungs are less compressed than in a lateral position of 90 degrees.
- A comfortable lying position can vary greatly for COVID-19 patients who are suffering from respiratory distress. An upright sitting position in bed, as mentioned in chapter 5, is often considered comfortable. The aim is to reduce this as soon as possible. The preventive and curative intervention for lying supine is a lying posture in which the head rest and foot rest (semi-Fowler position) are at a maximum of 30 degrees. An upright sitting position in bed should preferably be combined with the semi-Fowler position of the bed in order to reduce the shearing forces to a minimum.

- Alternate postures: sitting, lying, being active as much as possible. Due to muscle weakness, clients sometimes have too little energy at the start of rehabilitation to perform transfers independently, such as turning over in bed (V&VN, 2020).

Advice on AD facilities

AD cushions and mattresses can be used both preventatively and curatively. There are many types and brands of AD cushions and mattresses available that can be used both intramurally and extramurally. Follow the protocol of the institution or consult a wound nurse at the lending centre.

Individual counselling

Different factors such as the location and category of pressure ulcers and personal characteristics must be taken into account with each client. It is therefore not possible to give one single piece of advice, intervention or type of AD material. Good observation of lying and sitting posture and a good problem analysis remain crucial to discovering the causes.
The table is included in the appendices and shows different intervention options, based on the localization of pressure ulcers.

Chapter 6 Complaints of fatigue in daily activities

Experiences of occupational therapists:

"In practice, it appears that 'working hard' at recovery and continuing when tired does not lead to build up of energy but rather exhausts clients."

"Because practical experience shows that the energy level in COVID-19 varies greatly from client to client and from day to day, and that recovery from COVID-19 is often erratic, it can be difficult for clients to determine their 'baseline level', which is what the Activity Weigher, for example, assumes."

"Fatigue is not (only) related to shortness of breath. Estimating predictors of recovery is often difficult, partly because of the frequent occurrence of relapse."

"In practice, it appears that clients do not adequately consider that physical recovery after a serious illness such as COVID-19 also requires energy."

6.1 Expected problems

Severe fatigue

Fatigue is one of the most commonly reported symptoms of COVID-19 (Adhikari et al., 2020; Chan et al., 2020; Pascarella et al., 2020). Severe and prolonged fatigue impedes many COVID-19 clients' functioning in various life areas .

It is well known that clients are often intensely tired after ICU admission. Even the smallest activity demands a lot of effort, such as sitting up straight in bed or holding the telephone. The length of stay, the treatments in the ICU and the possible experience of delirium can influence this. Severe fatigue not only affects COVID-19 clients after hospital or ICU admission, but also occurs in people who have experienced COVID-19 at home (Keulemans, 2020).

Following malaise and fatigue in the acute phase of COVID-19, chronic fatigue occurs with a prevalence of over 50% after 10 weeks (Townsend et al., 2020) and 10% after three months (Williams et al., 2020). The 'Occupational therapy guideline fatigue in MS, CVA or Parkinson's disease' defines chronic fatigue as "fatigue that, regardless of the time of day, is present on more than half of the days for a period longer than six weeks consecutively" (Evenhuis & Eyssen, 2012, p. 16).

Sleep problems

Admission to the ICU can disrupt your day and night rhythm. This may also make it more difficult to go to sleep, which in turn leads to fatigue. The quality and quantity of sleep can also be affected by psychological symptoms (such as tension, nightmares, flashbacks and pondering), lung problems (difficulty breathing) or the need to adopt a different lying posture due to pressure sores or contractures.

It is important to have your GP or specialist assess whether medication has an influence on sleep problems. Sometimes taking the medication at a different time can already lead to an improvement. Keep in mind that psychological complaints can also seriously disrupt sleep. See the chapter on psychological problems.

Influencing factors on fatigue

Because of ICU admission and/or (often) prolonged bed rest, there is a substantial decrease in muscle mass, muscle strength and condition. The Intensive Care Unit Acquired Weakness (ICU-AW), the muscle weakness that is discussed in more detail in Chapter 5, is well known.
Swallowing problems can occur after (prolonged) ventilation. Sitting down, especially in combination with eating or drinking, takes a lot of effort. Crowds in the environment, watching television or taking care of yourself can also be very stressful. Moreover, fatigue is related to personal factors (whether or not caused by medical problems), to environmental factors (for example, overloading by the environment or a stimulating environment) and to factors at the activity level (for example, wanting to take on too many tasks (Cup & Satink, 2017). These factors can cause energy to recover only slowly. It can take months and sometimes even longer for the client to get back to their old energy level (IC Connect, n.d.).

Recognize and respond to body signals

Many COVID-19 clients have difficulty recognizing signs of fatigue. As a result, they may overestimate themselves, they may be prone to overexertion, or they may lose faith in their bodies. In addition, they may underestimate their own capabilities and fear a relapse. This is not the case for the first time.

Physical, mental and emotional energy

Literature on fatigue shows that it is important to distinguish between physical and mental energy (Buunk et al., 2018). In daily practice, activities demand not only physical and mental energy but also emotional energy to varying degrees. The degree to which activities demand energy or give energy can vary per person. Clients can experience a discrepancy in this compared to the period before COVID-19. Practical experiences also show that our expectations, habits, motivation, previous and early experiences about how we (should) behave towards illness and health can influence the level of energy. Therefore, it is important to ask clients with COVID-19 about these aspects or to be alert to them, especially when recovery is stagnant.

Transdiagnostic factors

Transdiagnostic factors are not related to the disease but involve personal aspects such as age, sex, motivation, concentration, pain, sleep problems, reduced activity and low self-efficacy in dealing with fatigue. Severe fatigue is common in people with a chronic condition. Only 11% of the severity of fatigue can be explained by the diagnosis. When combined with transdiagnostic factors, this percentage increases to 55% (Menting et al., 2018).
People with severe fatigue are therefore likely to benefit from a transdiagnostic approach that focuses on the individual needs of clients rather than the specific illness (Menting et al., 2018).

Chronic fatigue syndrome

Some people develop chronic fatigue syndrome after SARS infection - similar to COVID-19. Chronic fatigue is also a common obstacle for Q fever patients (Perrin et al., 2020). To prevent chronic fatigue syndrome after going through COVID-19, early fatigue intervention is advocated (Lamprecht, 2020; Perrin et al., 2020). In terms of occupational therapy treatment, the 'Occupational therapy guideline fatigue in MS, CVA, or Parkinson's disease' (Evenhuis & Eyssen, 2012) and the 'Occupational therapy guideline QVS - Coaching in activities of daily living' (Cup & Satink, 2017) can be used.

6.2 Occupational therapy directed at fatigue complaints

Occupational therapy for fatigue focuses on strengthening control and achieving a balance in daily life so that sufficient energy is available for meaningful activities. Occupational therapists can use different measuring instruments and interventions that address different elements of fatigue in relation to daily activities.

6.2.1 Clinimetrics

Coping, habits and expectations

In order for the interventions to be well suited to the person, it is important to map out individual habits, coping and expectations.

- What was the energy level like before COVID-19? A visual presentation of the energy level can help.
- How and at what moments does recovery occur when there is an energy shortage?
- What are habits regarding sleeping, eating, recovering or relaxing?
- What are cognitions, thought patterns and expectations regarding fatigue and activities?
- What are signs of fatigue?
- Are former recovery activities still experienced as recovery? Or do these activities now cost (too) much (mental) energy?
- What is the motivation to carry out certain activities and what has changed COVID-19 in this respect?

Impact of fatigue on daily life

A number of occupational therapy guidelines recommend various Dutch-language measuring instruments for assessing fatigue complaints and the impact of fatigue on functioning.

Modified Fatigue Impact Scale (MFIS)

The Modified Fatigue Impact Scale (MFIS) examines the impact of fatigue on physical, cognitive, and psychosocial functioning in the 4-week period preceding the administration of the list.
The MFIS is a self-scoring list that describes the impact of fatigue on daily activities using 21 items. (Cup & Satink, 2017).

Individual Tension Checklist (CIS20R)

The Checklist Individual Tension (CIS20R) is a questionnaire that measures the degree of fatigue experienced by the client (Vercoulen et al., 1999). It also measures the behavioural aspects related to this fatigue. The CIS20R examines how the client has felt over the past two weeks and focuses on the severity of fatigue, concentration, motivation and physical activity (Rietberg et al., 2010).

Pain and fatigue charts

Pain and fatigue graphs provide a graphical overview of fatigue during the day. These have been developed in clinical practice to give clients and occupational therapists insight into the peaks and courses of pain and/or fatigue during the day and the possible relationships with the activities during the day. The relationship between workload and symptoms can then be discussed during therapy (Janssen et al. submitted).

Borg scale for shortness of breath and fatigue

The Borg scale for shortness of breath and fatigue comprises a scale from 0 to 10, which provides insight into the shortness of breath and fatigue experienced. The chapter on lung problems in daily activities elaborates on the use of the Borg scale.

Performance of daily activities

ADL diary

Based on the manual 'Rehabilitation after IC admission', an ADL diary is available for the target group that has undergone Post Intensive Care Syndrome (PICS) (Amsterdam UMC/Rehabilitation Fund, 2020). By filling in this diary, the burden can be estimated and the progress on the activity level can be monitored. The ADL diary has been added as an appendix.

Activity scale (Activity Weigher)

The activity scale maps activity level and workload using points that are assigned to the subjective heaviness of activities (Hulstein & ten Hove, 2008). It is a method to obtain a balance in load and load capacity in daily activities and if possible to increase the load capacity.

Activity monitor

An activity monitor, activity tracker or smartwatch is a useful tool for clients with a demand for physical activity, for clients with sedentary behaviour or clients who are overexerting themselves. An activity monitor registers activities such as sitting, standing, walking and sleeping. Based on the activity level, the occupational therapist, together with the client, can give specific advice to achieve a good balance between physical exertion and rest. Subsequently, an activity monitor can support the build-up of load capacity in activities. The activity monitor's direct feedback on progress can be motivating (Bouma & Baars, 2019).

Sleep problems

Because fatigue and sleep problems often occur together, it is advisable to map out the sleep pattern in addition to the activity pattern. In Chapter 8, on psychological complaints, clinimetrics and interventions in case of sleep problems are elaborated.

Other measuring instruments

Occupational Balance Questionnaire (OBQ)

The Occupational Balance Questionnaire *(*OBQ) is a questionnaire that addresses several dimensions of balance. Like fatigue, balance has several dimensions. Balance is related to the number of activities, the importance of activities and whether the client experiences a good mix of activities. The questions from the OBQ make it possible to explore the different forms of balance. The questionnaire was developed in Sweden (Wagman & Håkansson, 2014) and has been translated into Dutch as: ' the Activities balance questionnaire' (Leenders et al., 2018).

Self-Efficacy in Performing Energy Conservation Strategies Assessment (SEPECSA)

The Self-Efficacy in Performing Energy Conservation Strategies Assessment (SEPECSA) is a measurement tool for self-efficacy in energy conservation strategies. The instrument provides insight into whether people feel competent to apply energy-saving strategies in their daily lives (Liepold & Mathiowetz, 2005). This instrument has been translated into Dutch.

6.2.2 Occupational therapy interventions

This section describes specific techniques, interventions and strategies for coping with fatigue in daily activities. Intervention usually starts with education. For the recognition of body signals and to experience which actions are appropriate, metaphors can be used such as a stoplight, rechargeable battery, wallet or colour wheel.

In addition, the power of occupational therapy is to let people experiment with techniques and strategies in practice and to let them experience what does and does not work to increase energy levels. Focusing on what is going well (see chapter 3) can support the continued use of success strategies.

Education of client and relatives

Clients often have no idea at the beginning of their recovery how more energy can be obtained and what are effective strategies to increase energy levels. Many strategies that were used before going through COVID-19 are no longer effective. Clients often do not know where their limits lie and often expect to be able to resume all their activities as they did before the illness.

- Education on the following topics is then desirable:
- Energy and fatigue, effort and relaxation, change by COVID-19
- Relationship between fatigue and overstimulation, cognitive complaints, psychological complaints and physical complaints
- Distinction between physical, mental and emotional fatigue
- Influence of coping, cognitions, socialization and values on fatigue and energy

The Radboudumc has produced a video on fatigue. This visual education is based on the programme 'Coping with Fatigue' and is a translation of the group programme 'Managing Fatigue' (Packer et al., 1995; Cup, Packer, 2018).

The spoon theory

Using the Spoon Theory, severe fatigue is easy to explain. The spoon theory represents the daily energy supply as a certain amount of spoons. Every activity requires one or more spoons of energy. Many chronically ill people start the day with fewer spoons and require more spoons for daily activities than healthy people **(**Miserandino, 2003). It is a way to provide insight into the impact of fatigue (Cup & Satink, 2017).

Observing, recognizing and responding to body signals

Traffic light method

The metaphor of a traffic light or thermometer can be used to recognize body signals and to experience what the appropriate actions are and to adjust the activities accordingly. It provides insight into the structure of body signals, categorized into green, orange and red. To prevent 'red' alternatives are described. Orange plays an important role as a warning.
The inventory is followed by the experimentation phase, in which clients try out helping activities, thoughts or reactions. Recognizing and taking into account the limits, COVID-19 supports clients in having confidence in their bodies and thus in building up energy in daily activities.

Strategies aimed at energy management

Energy management is aimed at optimizing the balance between load and load capacity. The distribution of available energy is necessary in order to maintain control over daily activities.
get. There are various interventions to improve energy balance.

Pace, Plan and Prioritise (3 P's principle)

The 3 P's principle is about adjusting the pace, planning and prioritizing daily activities with the aim of saving energy.

- Pacing

The client learns to perform the activity at a steady pace while taking regular short breaks during an activity. With pacing, the client also does not become overloaded while performing strenuous activities (Prieur, Combret, Medrinal, Arnol & Bonnevie, 2020).

- Plan(s)

The client learns to make a schedule of the activities usually performed in a day or week and spreads them out (differently) throughout the day and/or week to save energy. Adjusting the time at which the activity is carried out can be useful. It is important to prepare an activity well and to ask for help if necessary.

- Prioritise

The client learns to assess the need and urgency of tasks and to determine what can be postponed or moved. This is recorded in the schedule, possibly supported by a priority table (Royal College of Occupational Therapists, 2020).

PRET strategy

PRET stands for Pause, Find Quiet Environment, Do One Thing at a Time, and Adjust Pace. The advantage of the PRET strategy is that it is an easy to remember strategy that has a positive influence on cognitive complaints as well as on energy levels. The PRET strategy is often used by people who suffer from fatigue as a result of brain injury. Also people who have difficulties with planning and organizing often apply this strategy (Hersenz, 2017).

Alternating between effort and relaxation

COVID-19 often involves a combination of physical, mental and emotional fatigue. Occupational therapists note that many COVID-19 clients find that relaxation is no longer the same as before the disease. Previously relaxing activities (such as reading or watching TV) now consume (too much) mental energy. It can be different for each COVID-19 client what is relaxing and what gives energy. The strategy to achieve a good balance is one of constant experimentation: "try, monitor, evaluate". Condition is that the client is aware of the physical signals, how (de)tension feels and can notice, recognize and acknowledge signals of (de)tension.

The activity scale

The activity scale can be used to build up the general load capacity The activity scale has been developed primarily as an intervention. Using a basic level of activities, it is determined whether the load capacity can be built up or whether energy-saving strategies are needed to make activities lighter or shorter (for a longer period) (Hulstein & ten Hove, 2008). For COVID-19 clients, it is important to increase the number of points in small steps.

Don't run but plan

The treatment programme: "Niet Rennen Maar Plannen" (Dutch translation of “don’t run but plan”), developed for people with brain injury, includes a training module focused on fatigue that seems to be suitable for COVID-19 related fatigue (Baars-Elsinga, Geusgens, Visser-Meily & Van Heugten, 2014). The method is further explained in Chapter 7.

Group programme 'Managing Fatigue’

To gain control over daily activities, clients with severe fatigue can use energy-saving strategies. The occupational therapy group programme: 'Managing Fatigue' is an education and training programme aimed at this (Packer et al., 1995).
This programme has been translated into Dutch as the group intervention: 'Coping with fatigue' (Cup, Tebarts, Josten, 2010).

The 6-week program aims to promote personal control, learn to make choices and use available energy efficiently. The sessions are based on principles of behavioural change. By learning and experiencing how to put these strategies into practice, participants gain confidence in their own abilities, which helps them to apply these strategies in everyday life (Packer et al., 1995). The group program can also be offered via teleconferencing (Cup et al., 2010; Finlayson & Cho, 2011; Garcia Jalon et al., 2013;). Recently, the group program has been adapted to an individual program and expanded to include sleep problems and cognitive and mental fatigue. It is expected that the programme will be made available via a special website for occupational therapists working with people with chronic conditions and fatigue.

Treatment of sleep problems

For clients who have experienced COVID-19 and are severely fatigued, it is important to still stay awake and engage in activities during the day. This can help build up sufficient sleep pressure. Sleeping during the day can hinder falling asleep and therefore increase fatigue. The occupational therapy treatment of sleep problems is discussed in more detail in chapter 8.

Chapter 7 Cognitive problems with daily activities

7.1 Possible cognitive problems

Clients may experience cognitive impairment after a period of illness due to COVID-19, both in the acute and recovery phases (Holzapfel, et al., 2020; Liang et al, 2020).
COVID-19 can cause damage to the brain in several ways:

- As the patient's lungs are affected, there can be a lack of oxygen in the brain. This causes damage in the brain areas for attention, memory and planning.
- Long-term hospitalization in the Intensive Care unit increases the risk of damage to the brain. This can include attention and memory problems, overstimulation, behavioural changes or extreme fatigue.
- Blood clots occur more frequently than normal. Especially in the lungs, but also in the blood vessels to the brain. This can lead to strokes.
- There is evidence that the coronavirus can cause viral encephalitis. Inflammation of the brain can lead to serious brain damage.
- The disrupted immune system of severely ill COVID-19 patients causes damage to all organs, and most strikingly, also to the brain. At the Amsterdam University Medical Centre, researchers have discovered that brain damage is caused by a runaway immune system in severe COVID-19 infection (Hersenstichting, 2020; Schurink, 2020).

The cognitive symptoms can vary from mild to severe. Researchers worldwide are collecting data on the cognitive consequences of COVID-19 in order to make treatment recommendations (Weir, 2020).
The cognitive problems after COVID-19 can be explained by the indirect effects of the virus on the brain. These effects explain that all types of cognitive impairment can occur after COVID-19.
As far as research now indicates, cognitive impairment can occur as a result of COVID-19 regardless of where the disease has been experienced, the severity of the disease and the age of the client. Cognitive problems that occur are problems with attention, concentration and memory. However, problems with stimulus processing, information processing, visio-spatial functions, word finding and planning also occur (Slockers & Magnée, 2020). These disorders affect the quality of life, daily activities and the possibility of returning to work. Cognitive problems also influence the (mental) capacity of the clients.
As a result of COVID-19, two specific causes of cognitive complaints can be identified, namely delirium and post-intensive care syndrome (PICS). These are briefly discussed below.

Delirium

Delirium often occurs in clients with COVID-19, or develops during the disease process. A higher age, a serious infectious disease, artificial respiration and (long-term) sedation are known risk factors for delirium, which often occur simultaneously in clients with COVID-19 (Edwards, 2020). Delirium involves acute confusion. Clients can develop hyperactive delirium with increased vigilance, restlessness and aggression, but also a hypo-active form, also called silent delirium, with decreased vigilance, sparse speech and apathy. A mixed form also occurs. The hypo-active form is more often overlooked, but may occur more frequently, particularly in people in the ICU. There is strong evidence that clients with delirium in the ICU have a greater risk of cognitive problems in the longer term.

The length of delirium is the most important predisposing factor. The isolation measures that had to be taken in clients with COVID-19 can be a maintaining factor for delirium, even if the symptoms of COVID-19 improve (Dutch Association for Clinical Geriatrics, 2020).

Post Intensive Care Syndrome (PICS)

A proportion of people with COVID-19 are treated in the ICU for long periods of time. The clients who have been admitted to the ICU for a long time may experience Post Intensive Care Syndrome (PICS) (Dettling-Ihnenfeldt et al., 2017). PICS is the collective term for the physical, cognitive, and psychological problems that arise from the critical illness and the ICU treatment required for it. We only name the cognitive problems of PICS here. After IC admission, 40% of clients continue to have cognitive problems (Simpson & Robinson, 2020). This is true for both older and younger clients, regardless of their previous condition and regardless of the reason for their admission. The severity of PICS depends on the duration of the ICU admission, age, pre-existing suffering and duration of ventilation (Herridge et al, 2013). The symptoms can be very subtle or very obvious. Because mild cognitive dysfunction is difficult for the environment to see, these disorders will also often be underestimated.

Complaints occur with respect to:

- Attention,
- Memory (in 30-40% of people after ICU admission),
- Speed of information processing,
- Visuo-spatial features,
- Executive functions,
- Word finding,
- Over-stimulation.

The cognitive complaints are probably explained on the one hand by exhaustion and on the other by a change in the functioning of the brain. This may be due to a combination of the serious illness, the necessary medication and treatment in the ICU. Clients in critical condition experience high levels of physical and psychological stress during ICU admission. This can result in cognitive complaints. Often this pattern of complaints recovers (partly) in the first year, but sometimes (annoying) limitations remain (Holzapfel, et al., 2020).
Clients can be quickly overwhelmed by stimuli such as crowds, noise and light and, partly as a result, quickly lose the thread of a conversation (Edwards, 2020; Innoue, 2019; Hoogstraat, 2020; Pandharipande, 2013; Rawal 2017; Simpson & Robinson, 2020; Stam, 2020).

7.2 Occupational therapy directed at cognitive problems

It is recommended that clients with cognitive complaints be treated by occupational therapists who have experience with and have been trained in cognitive rehabilitation. However, occupational therapists without this background are also able to include the principles of cognitive rehabilitation in their treatment programme.

7.2.1 Clinimetrics

To assess the presence or absence of cognitive problems and their severity, various instruments can be used in the occupational therapy examination.
A selection of available instruments has been made for this guide. In the additional information after the reference to the source, references to the various instruments are included. When administering each measuring and/or screening instrument, possible secondary pathology and/or limitations which may influence the test should be taken into account.
Clients with observed visuospatial problems should be referred to occupational therapists specialized in the field of visual impairment for additional diagnosis. For the group of clients after ICU admission,

extra alertness will be required in connection with additional problems such as stress, anxiety, flashbacks and depression (see also Chapter 8).

Observation of daily activities

An observation of daily activities is an important first step in mapping the cognitive abilities and limitations of the client. This can be an open, semi-structured or structured observation or on the basis of an observation instrument. The choice depends on the situation, the possibilities of the client and the therapist and which question is central at that moment.

Assessment of Process and Motor Skills (AMPS)

The AMPS is an occupational therapy, standardised and validated observation instrument with which the occupational therapist can assess the client's actions in everyday domestic and self-care tasks. The occupational therapist uses this instrument to make a judgment about the degree of effort, efficiency, safety and independence of the client's actions, and can thus support the clinical judgment about independent functioning in society with scientific evidence (Fisher & Bray Jones, 2010a; Fisher & Bray Jones, 2010b). To be able to use this assessment, a course must be followed. It is important to consider having a trained colleague do the assessment if possible or to do a (structured) observation yourself.

Perceive, Recall, Plan and Perform System of Task Analysis (PRPP) Assessment

The PRPP Assessment is an observational instrument that can be used to assess the effectiveness of applying information processing strategies while performing everyday actions in a realistic environment (Nott, Chapparo & Heard,2009). For this assessment a course has to be followed as well.

Screening of cognitive problems

In addition to observing daily actions, various measuring instruments are available to screen for cognitive problems. The choice depends on the situation, the possibilities of the client and the therapist, and which question is central at that moment.

Cognitive Complaints-Participation measure (CoCo-P)

The CoCo-P is a validated questionnaire translated into Dutch, intended to be administered to the client and any informal caregiver at the start and as an evaluation at the end of treatment. The outcomes provide insight into cognitive symptoms in relation to performing daily activities and participation (Spreij, Sluiter, Gosselt, Visser-Meily & Nijboer, 2019a; Spreij, Sluiter, Gosselt, Visser-Meily & Nijboer, 2019b; Spreij, Sluiter, Gosselt, Visser-Meily & Nijboer, 2020).
The original questionnaire was developed for people with brain injury, but is also suitable for COVID-19 clients with (suspicion of) cognitive problems.

Montreal Cognitive Assessment (MoCa)

The Montreal Cognitive Assessment (MOCA) is a brief screening instrument to measure cognitive decline and consists of 8 domains. It was developed to measure mild cognitive decline. This instrument can be used for assessment and screening (Thissen, van Bergen, de Jonghe, Kessels & Dautzenberg, 2010).

Checklist for cognitive and emotional consequence of Stroke (CLCE-24)

The aim of the Checklist for cognitive and emotional consequence of Stroke (CLCE-24) is to identify cognitive, emotional and behavioural consequences. It is a questionnaire that first the client and then the informal caregiver completes. This reflects any differences of opinion which can provide information about the client's level of disease understanding (Fens et al., 2013) and it is a way to communicate differences in perception of the consequences.

Checklist for cognitive consequences after ICU admission (CLC-IC)
The Checklist for Cognitive Consequences after ICU Admission (CLC-IC) is a checklist for cognitive complaints after ICU admission. It consists of 10 yes/no questions about cognitive symptoms and two open-ended questions designed to assess cognitive symptoms following ICU admission (Van Heugten, Visser-Meily & Verwijk, 2020).

Allen Cognitive Level Scale (ACLS)
The Allen Cognitive Level Scale (ACLS) is a valid and reliable screening instrument to map functional cognition. Based on the execution of three (unknown) visual motor tasks the occupational therapist gets a quick impression of the learning and problem solving capabilities of the client. The ACLS is based on the Cognitive Disabilities Model (CDM) of Claudia Allen (Allen, 1992) and gives tools for advice on guidance, the learning strategy to be used and the design of the physical environment. The ACLS should always be combined with an observation of a meaningful activity (Steultjens, et al., 2013). The client should have sufficient hand function to be able to carry out the assignments.

Clinimetrics in case of delirium

First of all, it is important that delirium is diagnosed by a doctor. If delirium is suspected, the occupational therapist must contact the referring physician immediately. It is very important that the delirium is properly supervised with the main aim being that it clears up as quickly as possible. Two measuring instruments can be used for clinimetrics.

Delirium Observational Scale (DOSS)
The Delirium Observation Scale (DOSS) is an instrument consisting of 13 observations of behaviour that reflect symptoms of delirium and is usually completed by nurses (Schuurmans, 2001).

Confusion Assessment Method for her Intensive Care Unit (CAM-ICU)
The Confusion Assessment Method for the Intensive Care Unit (CAM-ICU) is a measuring instrument for diagnosing delirium in the ICU and can be administered by any healthcare professional in a multidisciplinary team (Ely et al., 2001; Ely & Truman, 2001). The CAM-ICU has also been translated into Dutch (Heeren, Kat & Stek, 2002).

These are the only measuring instruments that are reliable in delirium. In addition, the occupational therapist can form a picture of the current possibilities and limitations for action by observing daily activities. Because COVID-19 is associated with fatigue and attention problems, among other things, it is important that the actions of small, feasible daily activities are observed. The Perceive, Recall, Plan and Perform System of Task Analysis (PRPP) Assessment (Nott, Chapparo & Heard, 2009), or the Arnadottir Occupational therapy ADL Neurobehavioral Evaluation (A-ONE) can be used for this (Arnadottir, 1990; Steultjens, 1998).

Measuring instruments for specific cognitive skills

As a result of the observation and screening of cognitive problems, there may be a need to assess specific cognitive skills as well. Various instruments are available for this purpose.

Attention Process Training Test (APT test)
The Attention Process Training Test (APT) can be used to identify the type of attention problems that occur. With the APT test, the starting level can be determined and thus the approach of the training can be determined (Sohlberg & Mateer, 2001).
Contextual Memory Test (CMT)

The Contextual Memory Test (CMT) can be administered when memory problems appear on the basis of (one of) the above instruments or from observation. This screening test was developed to assess whether clients have insight into their own memory problems and/or whether they have the ability to apply memory strategies (Gil & Josman, 2001).

Weekly Calendar Planning Activity (WCPA)
In addition to the above instruments, the Weekly Calendar Planning Activity (WCPA) can be administered. It examines how subtle problems in executive functioning influence the performance of the multistep activities in daily life (Weiner, Toglia & Berg, 2012). The WCPA can be administered when the above instruments cannot provide any information, but the client does experience problems in daily living or when this has been observed.

Adolescent/Adult Sensory Profile (AASP-NL)
The Adolescent/Adult Sensory Profile (AASP-NL) is an instrument for mapping the sensory profile of sensory sensitivity. This questionnaire is completed by clients and provides insight into the influence of these stimuli on daily functioning and also offers tools for intervention. The questionnaire is scored by a trained expert (Rietman, 2007).

7.2.2 Occupational therapy interventions

General points of interest
The treatment goals depend on the client's request for help and his/her capabilities and limitations. Some general points of interest for treatment are:

- Providing insight to the client and his or her system in their cognitive abilities and limitations.
- Improving attention through training.
- Adequate coping with cognitive limitations in daily life by learning strategies.
- Conscious use of cognitive abilities in daily activities.
- Compensating for cognitive limitations by adapting and actively involving the environment.
- Adapting approach in case of psychosocial stress and possibly developed co-morbidity such as depression, anxiety, Post Traumatic Stress Disorder (PTSS).

If the observations have revealed cognitive problems that impede the client in daily functioning, a selection of interventions and treatment methods that can be used is described below (per group).

Interventions for cognitive problems
Determine learning strategy
Firstly, determine which learning strategy can be used based on the results of the clinical measurements and observations. It is essential to coordinate this interprofessionally (also in primary care), so that all disciplines involved with the client use the same learning strategy. The various forms of learning are described below, along with the appropriate interventions.

- Semantic learning (learning based on facts and concepts)

The interventions that can be used are:
    - psycho-education
    - information
    - counselling or coaching
- Episodic learning (learning by experience)
  The interventions that can be used are:
    - strategy training
    - error-free learning, here and now and in context
    - trial and error, here and now and in context
- Procedural learning (learning based on repetition of sub-steps of a task and on the ingraining of an action)
  The interventions that can be used are:
    - functional activity training by backward or forward chaining
    - error-free learning, here and now and in context
- Process training, recovery of cognitive processes (attention)
  (Van Schouwen, 2017).

Process training to improve attention

Process training of attention includes practicing the cognitive process where graded stimuli are added for the purpose of functional improvement for example using Graded Activity (Van Schouwen, 2017). It is important to combine process training with psycho-education, training of daily tasks and change techniques (Barfia, Markovic, Sargenius Landahl & Schult, 2014).

Cognitive treatment program Do not run but plan (NRMP)

The 'Don't run, but plan' treatment programme (NRMP) consists of 5 modules in which the brain damaged client learns to deal with the cognitive consequences of the injury through information, education and strategies provided. The problem at hand determines which module is most appropriate.
The five modules are:

1. Information module: Types of brain injury and possible consequences
2. Training module : Fatigue after brain injury, what now?
3. Training module : Dealing with time pressure - delayed information processing
4. Training module : Working on memory problems
5. Training module : Grip on planning

(Baars-Elsinga, Geusgens, Visser-Meily & Van Heugten, 2014)

PRPP Intervention

In addition to the PRPP Assessment, the PRPP system also provides a treatment methodology, the PRPP intervention. The aim of this treatment method is to improve strategies of information processing and task control. In this, the occupational therapist supports the client in his or her development by applying a series of cognitive strategies that are necessary for the performance of the task. For the application of this intervention a course has to be followed (Nott, Chapparo & Heard, 2008).

Giving insight in reduced cognitive skills

Insight into one's own abilities and limitations can be increased by training functional skills in realistic situations in combination with multiple forms of feedback (such as verbal, visual, audio-visual) (Van Heugten, Bertens & Spikman, 2017).
In addition, insight can be increased by applying insight-giving techniques to specific behaviors to be observed such as anticipating, predicting, checking and evaluating, questioning, time evaluation, and role reversal (Van Schouwen, 2017).

Involving the environment

It is important to involve the environment in the treatment of cognitive problems. This can be done by adapting the physical environment and/or instructing the social environment. Interventions that can be used in instructing the social environment are counselling, coaching, training on the job, functional activity training, strategy training and psycho-education.

Treatment of sensory sensitivity

General points of interest in sensory sensitivity where interventions can be used are:

- Finding a balance between load and load capacity and learning to guard your boundaries.
- Use the Activity Weigher or the Don't Run, Don't Plan treatment programme. Explanations of the methods are included in the chapter on fatigue (H 6).
- Learning to 'arm' oneself against stimuli, such as consciously looking at an auditory stimulus, shutting oneself off from external stimuli or distracting oneself from an irritating stimulus.
- Compensation can be achieved by eliminating or dampening the stimuli. For example, by using external aids such as ear protectors or a cap or sunglasses. Also adapting activities (such as taking a different position in the room), limiting overstimulating activities (such as reducing computer or telephone use), or adapting the physical environment such as reducing light in the room, can reduce overstimulation.
- Involving the social environment. This can be supportive, such as making appointments with the family, moving away from an over-stimulating situation, or arranging more time for the doctor's appointment, for example.

Specific occupational therapy interventions aimed at reducing or learning to cope with sensory sensitivity are the 'Adult Sensory Integration Timmerman Treatment' (ASITT) treatment (Occupational Therapy Gouda, n.d.) and the 'Process Training for Improving Attention' (Van Schouwen, 2017). Additional training is required to apply these methods.

Psycho-education

It is important to provide psycho-education to the client and his family and friends. This increases insight into and acceptance of cognitive problems and overstimulation symptoms (Brain Foundation, 2020; Van der Perk, Mortel & Komduur, 2017). This also applies to psychological complaints. See Chapter 8 for this.

Interventions in delirium

In the event of delirium, it is important to observe the client carefully and then to determine the most appropriate approach. It is important to advise the environment about appropriate supervision and approach to the client that is focused on clarity and structure. This can be done, for example, by using a clock, calendar or familiar items from home. Determine within the possibilities if and how the treatment can be started.

Chapter 8 Psychological complaints, sleeping problems and effects on the performance of daily activities

This chapter is mainly based on best practices of occupational therapists working with clients with psychological problems, among others as a result of ICU admission. It is now known that sleep problems also frequently occur after COVID-19. This chapter pays attention to that.
If the client's psychological symptoms are prominent and this hinders treatment in other areas, referral to a POH-GGZ or first-line psychologist is recommended.

8.1 Expected problems

Psychological complaints

In most COVID-19 clients, in addition to physical and cognitive complaints, there may also be psychological and social complaints or problems (Verenso, 2020).
Psychological complaints often have a strong impact on daily life and can therefore undermine the self-confidence of clients. Clients will often not express their complaints because of their own or others' shame and lack of understanding. Furthermore, psychological complaints influence the course of the treatment and the recovery.
When psychological symptoms are present, the balance between necessary activities and pleasurable activities, between relaxation and strenuous activities and also in the performance of different roles can become disturbed, and a person may have difficulty structuring their day (Spijker et al., 2013).
Inactivity can also be a manifestation of psychological symptoms, sometimes out of fear, gloom or ignorance. A lack of meaningful activities or energy can make people depressed. Timely detection is therefore essential, also because there is an interaction with physical complaints, fatigue, sensitivity to stimuli and cognitive complaints.

Risk factors for the development of psychological complaints in COVID-19

Although a stay in hospital or in the ICU ward are already risk factors for the development of psychological symptoms, a number of specific risk factors are mentioned for COVID-19 such as prolonged ventilation, social isolation, barrier due to protective clothing worn by healthcare staff and concerns about shortages of staff and resources (British Psychological Society, 2020). Continuous media coverage can re-trigger trauma.
Psychological complaints can also occur in people who have experienced COVID-19 at home. In addition, it can happen that someone has lost a loved one to COVID-19 and because of their own period of illness has hardly had the time to deal with their grief.

Behavioral changes that could potentially indicate underlying psychological suffering include:

- fretting, not being able to stop thoughts, getting 'stuck' in a particular thought;
- anxiety symptoms: stress, tension, agitation, irritability, fearful feelings;
- depressive symptoms: sudden mood swings, gloomy thoughts, listlessness;
- Signs of traumatic experiences such as increased tension, irritation or stress reactions, nightmares, poor sleep, startle reactions, physical or emotional reactions to triggers reminiscent of the IC time.

In daily life, this can be expressed in a change in personal manner, for example, loss of initiative, inactivity, apathy, anhedonia, not being able to stop or not going on long enough, reacting very slowly, agitation and a lack of confidence in one's own abilities. During the therapy, behavioural changes may be noticeable, for example, due to an increase in tension, because someone avoids tasks, avoids situations, keeps talking about things instead of doing them, withdraws or is sombre due to a relapse caused by too intensive exercise.

Fear of illness

Anxiety about illness is specific to COVID-19, because much is still unknown about long-term recovery. This can cause uncertainty about the future, hyper alertness to physical symptoms (focus on saturation) or fear of stigma and possible new infection.
Delirium often occurs as a result of heavy sedative medication, and after ICU admission, a client may continue to suffer from hallucinations for a long time.

Fear of movement

In the early phase of rehabilitation, post-IC clients also show fear of movement. Clients have difficulty trusting their own bodies. They did not feel very ill when they were brought to the ICU and woke up completely weakened after a long period.

Mourning

Grief in the form of anxiety, fretting or gloom is certainly to be expected after a potentially traumatic event such as ICU admission or after severe COVID-19. It is a normal reaction to an abnormally stressful or sometimes life-threatening situation. Uncertainty about the future plays a role here. Normally, grief symptoms decrease over time. Psychological symptoms last longer, and can interfere with health and recovery.
Regarding COVID-19, uncertainty about recovery and about the future complicates grief. Questions such as: What are my chances of recovery, Will I get back to my old self, What do I need to consider in the future, can affect a person's mental health and resilience. Grief can also be about the sudden loss of the 'old self' or the loss of the naturalness with which people carried out their roles and activities. Peer contact can be important for clients in the grieving process, to feel that they are not alone.

Sleeping problems and day/night rhythm disturbance

In COVID-19, sleep problems are common (Nalleballe et al., 2020). In addition, other complaints after the experience of COVID-19 influence the (objectively or subjectively experienced) sleep quantity and sleep quality, such as psychological complaints (tension, nightmares, flashbacks, pondering), lung problems (difficulty breathing) or the need to adopt a different, perhaps more uncomfortable lying position due to pressure sores or contractures.
It is known that sleep plays an important role in resting, relaxing our muscles, storing events and memories, in physical health and the immune system. Furthermore, sleep has an influence on how we feel. Too little sleep can make us irritable (Cranenburgh, 2013; Marshall, & Born, 2007; Verbeek, 2014). Adequate and proper sleep is therefore essential in recovery from COVID-19.

8.2 Occupational therapy aimed at psychological complaints and sleep problems

For occupational therapists who are familiar with treating mental health problems, there are treatment options described in the fact sheet: 'Occupational therapy, also for people with mental health problems' produced by the knowledge network for primary occupational therapy in mental health (ETP-Net, 2019). Not every occupational therapist feels equipped to evaluate and treat possible mental health problems or sleep problems. When appropriate, it is important to identify the symptoms in a timely manner and refer back to the treating clinician with the aim of referring to a colleague who is more knowledgeable in this area where possible.

8.2.1 Clinimetrics

Inventory of psychological complaints

Recognizing psychological complaints often turns out to be difficult in practice. Care workers sometimes have trouble interpreting the complaints. Especially when clients do not openly discuss these symptoms or do not recognize them as such. Some clients are adequately able to describe changes in habits, personal style of acting, coping style or behaviour. If this is not possible, informal caregivers can be consulted.

In general, it is important during the diagnostic phase:

- By asking about psychological symptoms;
- letting the client tell his or her story;
- discuss the consequences of psychological symptoms for multiple areas of life such as work and relationships;
- explaining what mental health problems can entail, and in doing so, making it possible to discuss the client's image of mental health problems (Spijker et al., 2013),
- motivation, coping strategies and self-confidence. This clarifies possible bottlenecks in the treatment and can give direction to the treatment (Graaf, Brouwers & Post, 2020).

For anxiety, depression and Post Traumatic Stress Disorders (PTSD), there are some measuring instruments available that can be used by occupational therapists as well as other disciplines.

Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS) is an instrument for measuring anxiety and depression without including any physical complaints. It is a short questionnaire that looks at feelings in the past 4 weeks (Pouwer, Snoek & Van Ploeg, 1997).

Primary Care Post Traumatic Stress Disorder Screen for DSM 5 (PC-PTSD-5)

The Primary Care Post Traumatic Stress Disorder Screen for DSM 5 (PC-PTSD-5) can be used to screen for PTSD symptoms. There is a long version and an abbreviated version specifically for COVID-19. When there is doubt about someone's mental health, occupational therapists can give these questionnaires to clients, or use them to gain knowledge about the signs themselves (Bakker, Van der Meer & Olff, 2020; Boeschoten et al., 2020).

Influence of psychological complaints on daily activities

The Occupational Performance Questionnaire (QOP)

The *Questionnaire Occupational Performance (QOP)* can be used to examine the influence of psychological symptoms on daily activities. This measurement instrument is a self-assessment and has been developed to map out the experienced quality of life and satisfaction about the ability to carry out daily activities. The instrument can also be used for clients who have difficulty expressing their needs in words. The QOP can also be used as an evaluation of the treatment offered (ETP-Net, 2019).

Canadian Occupational Performance Measure (COPM)

The COPM identifies the main problems the client experiences in daily activities and it measures change (Eijssen, Verkerk & Van Hartingsveldt, 2018). Supplementary to the use of the COPM, a weekly schedule can be used to specifically address the relationship between mood and performance of the relevant activities.

Sleeping problems and day/night rhythm disturbance

It is always important to contact your GP or specialist to assess whether medication has an influence on sleep problems. Sometimes, for example, taking the medication at a different time can already lead to an improvement.

Activity monitor

Because fatigue and sleep problems often occur together, it is advisable to map out the sleep pattern in addition to the activity pattern. With an activity monitor app, insight can be gained into sleep habits, sleep patterns and sleep quantity.

Questionnaires and sleep diary

Various instruments investigate the quantity and quality of sleep and the consequences of sleep problems. The Pittsburgh Sleep Quality Index (PSQI) specifically examines the nature of the sleep problems and has been translated into Dutch (Buysse et al., 1989). A sleep diary maps sleep routines, sleep rhythm and resting moments (Buuren & de Roode, 2013a; Buuren & de Roode, 2013b).

8.2.2 Occupational therapy interventions

Treatment of psychological complaints

General points of interest for the treatment

For occupational therapists who are less familiar with the treatment of psychological complaints in daily life, there are general points of attention for the treatment, based on practical experience:

- Make grief and psychological symptoms discussable, but do not get stuck in talking about it. Focus on daily activities: that is what occupational therapy is all about.
- Use the triad of listening, validating and normalizing: listen to what the client says, validate their experiences and normalise the reaction, as much as possible, as a normal reaction to an abnormal situation.
- In the treatment, keep the balance between motivating the client to go a step further and maintaining boundaries. To do this, examine the relationship between the various symptoms and explicitly evaluate someone's options, such as helpful coping strategies. How does the client deal with the changed circumstances? Does the client overstep his boundaries or is there a question of avoidance? Does someone experience enough meaningful activities?
- The client is the owner of his process. This means that the therapist sometimes asks questions 'like a curious ignoramus'. Visualize together with the client how he/she sees his/her goals.
- The client must build up confidence in his own abilities. Strengths and resources can be used for this. This applies to the client, family members as well as the therapist.
- As a therapist, offer trust and safety, including emotional safety. Celebrate progress, take smaller steps if necessary, and facilitate experiences of success.

Psycho-education

It may be sufficient to explain the prevention, development and recovery of mental health problems and what the client and those close to him can do to promote recovery. Explaining the relationship between different complaints, for example that they maintain each other, and the influence of mental health on daily functioning can provide insight and support for the treatment.

Education, activation and construction of activities

A lack of meaningful activities or lack of energy can make people depressed. Together with the client, map out the relationship between mood and activities in order to build up activities on that basis. When activating, also take into account the fear of carrying out activities due to, for example, shortness of breath or low saturation. Education about lung problems is important in reducing this fear.

Signaling plan

A first step towards reducing the influence of tension or anxiety on daily functioning is to map out, preferably together with the client's relatives, the following

- The triggers: the risk situations that can provoke the complaints (aggravation).
- The signals: where, when, how, and how do the signals build up.
- The possible actions by the client himself and/or by others.

This approach is derived from the signaling plan as used in the GGZ to identify signs of relapse (GGZ Nederland, 2019).

Acceptance and Commitment Therapy (ACT)

Occupational therapists who have received specific education or training can apply ACT to reduce the influence of psychological symptoms on actions (A-Tjak 2015).
ACT is aimed at dealing flexibly with obstacles that clients find in their path (acceptance) so that they can continue or start using their energy for the things they really find important (commitment) (Batink, et al., 2016). Acceptance of going through a serious illness with possible chronic symptoms is complicated when there is still so much uncertainty about the course of the illness and recovery. Accepting the reality of the complaints is often essential for changing behaviour.

Treatment of sleep problems

Occupational therapists have a number of interventions at their disposal to promote the quality of sleep (Van der Veen & Satink 2018). If serious sleep problems do not improve with occupational therapy interventions, referral via the GP to, for example, a sleep coach, an occupational therapist specializing in sleep problems, POH-GGZ, GZ psychologist or specialist doctor is recommended.

Interventions based on the model of insomnia

A widely used model of insomnia (Morin, 1993) assumes several, modifiable, factors that can negatively or positively affect sleep (AOTA, 2017; Buuren & de Roode, 2013a; Buuren & de Roode, 2013b; Ho & Siu, 2018).

An occupational therapist can use the following interventions:

- Apply habits:
  - applying the regular sleep hygiene rules,
  - Develop helpful sleep routines, such as set sleep-wake times, apply sleep preparation activities,
  - find the right balance in activities and build up sufficient sleep pressure,
  - Avoid using the smartphone, tablet or laptop in the bedroom.

- Reduce voltage level:
  - prior to the sleep ritual, write a 'head blank page' in a journal, as a release from the tension at the end of the day (by writing down in a few minutes all the thoughts that come up),
  - Applying activities such as meditation, yoga, breathing exercises, relaxation exercises and massage,

- Mapping the build-up of tension
- Keeping a positive journal or gratitude journal.

- Helping thoughts form:
  - Investigate the thoughts together with the client and ask whether a thought is realistic and helpful.
  - Testing thoughts about sleep against reality, by formulating more realistic thoughts.
  - Learning techniques from cognitive behavioural therapy or cognitive restructuring, such as getting out of bed when sleep deprived and returning when tired and developing helpful self-talk about sleep,
  - Improving coping skills and stress management,
  - Providing sleep education to clarify the relationship between thoughts and sleep quality,
  - prevention of sleep-sabotaging thoughts, by visualising positive (sleep) memories vividly.

- Influencing effects of insomnia:
  - address underlying problems, such as pain, depression, anxiety, or in COVID-19 also tightness of the chest or apnea, or overstimulation,
  - psycho-education of clients and caregivers about sleep patterns, sleep needs, sleep beliefs and the consequences of insomnia,
  - Health promotion measures such as stopping smoking, reducing caffeine intake, healthy diet, adequate adequate exercise.

Adapting environment and advice on aids

Aids such as changing the sleeping position, a comfortable bed, using a special pillow, earplugs, white noise devices or an eye mask can be considered. There is limited evidence for the use of these aids.
In addition, it may be advised to adjust the environment, such as limiting noise and light and regulating the ambient temperature (maximum 18 degrees).

Chapter 9 Work resumption

9.1 Expected problems

A large number of clients who experienced COVID-19 are adults of < 65 years of age (Spruit, Holland, Singh, Troosters, 2020). This means that a large group of COVID-19 clients is still in the working age. Performing work is important for a client's financial security, but also for self-esteem, social bonding and the feeling of being useful (Kuiper & Van Houten, 2017).
Work resumption can therefore be an important part of the rehabilitation after experiencing COVID-19. Some of the COVID-19 clients will have resumed work independently. Those more seriously affected will be in the process of rehabilitation and will make a start on resuming work during the course of the treatment.
Whether a client with COVID-19 can resume his/her work to the full extent depends on various factors, such as the complaints resulting from the experience of COVID-19, the personal characteristics and the client system. The nature of the work and the possibilities of adjustment within the work situation also play an important role.

Factors concerning the client and the client system

COVID-19 related

In practice, COVID-19 does not always show a relationship between the severity of the disease experienced and the eventual recovery.
In addition, the recovery and the build-up of the capacity often follow an erratic pattern. Even when the build-up is fast in the beginning, it can be followed by (not always explainable) relapses and stagnation of the rehabilitation process. These are important factors to take into account when returning to work

Personal characteristics

Coping and self-management skills, self-confidence and confidence in one's own effectiveness influence return to work. The impact of the symptoms, the erratic course of the recovery and the uncertain prognosis of COVID-19 can influence the confidence in oneself and in the future. As recovery takes longer or is delayed, the consequences for the client's life will increase. These include cognitions regarding the symptoms, cognitive-emotional consequences, behavioral and/or physical consequences. This can create a vicious circle that can hinder recovery and/or maintain the symptoms. When the recovery takes longer, the financial consequences for the client increase and the chance of job preservation decreases. The client is often more insecure and stressed, which does not help the recovery.
Values and norms about work can also change. A profound IC experience can give a different perspective on life. Being suddenly confronted with one's own mortality often affects a person deeply and can suddenly put life as it was in a different perspective (IC Connect, n.d.). This can influence the attitude towards work, the motivation to return or can be a reason to want to go in a different direction in work.
In practice, clients, especially care workers, also have feelings of guilt towards their colleagues. Feelings of guilt because they have become ill and have dropped out, fear that colleagues may be infected and feelings of guilt if colleagues have to take over tasks (for a long time). Many clients experience their recovery as too slow and want to build up their strength more quickly than is perhaps desirable in terms of the degree of recovery.

Client system

The roles and tasks that someone has in his job but also outside of work play a role in the return to work. Because recovery after COVID-19 takes a long time for some of the clients, restoring a good

work-life balance will require a lot of attention. For example, a client with a young family or care responsibilities for family members may experience less space to build up his work. In addition, the effects of the treatment on the patient's cognitive development can be felt more strongly.
Also for family members of clients with COVID-19 the illness, treatment and rehabilitation is a stressful period. This has an effect on the 'space' the client experiences to build up in his work.
It is also true that during the acute phase of the illness there is usually a lot of understanding and support from the environment, but this can diminish as the symptoms persist and become less 'visible'.

Factors in the work situation

Whether someone can return to their own work has a great deal to do with the workload in relation to the client's situation. There are a number of factors in the work that can be distinguished here (Kuiper et al., 2017) .

- Job content (the type of work or position, physical and mental demands);
- Labour relations (relationship with superiors and colleagues, forms of consultation);
- Working conditions (amount of breaks, working hours, childcare, etc.);
- Working conditions (workplace ergonomics, ambient temperature, etc.).

The fact that there are possibilities to regulate working hours and rest times, to work from home and to adapt the pace of work, the tasks and the working environment all play an important role in work resumption.

COVID-19 measures and impact on business

This period, in which several companies suffer heavily from the corona measures or even go bankrupt, can have an impact on work resumption. As a result, the focus may be more on keeping the company afloat than on getting an ill employee back to work.
It may happen that the work of the client has come to a complete standstill as a result of the corona measures, making reintegration in his own work practically impossible. In this case, the client is not able to make use of the corona measures, which makes it practically impossible for him to re-integrate into his own work.

Working from home and reintegration

Many employees are forced to work from home and the contact between colleagues is less and different now that they are mainly contacted via mail, telephone and video. For many people, having conversations online is more intensive than at the workplace, especially for COVID-19 clients who are prone to sensory overstimulation. The degree of understanding, support and acceptance of the complaints by employers and colleagues is also hampered by the reduced contact.

Working from home can sometimes also be conducive to reintegration, provided that the working conditions are arranged properly. Think, for example, of the absence of commuter traffic, being able to plan the time yourself, taking a break in between, doing household chores as a change from computer work, a quiet workplace at home instead of a busy office garden.
The creation of a quiet and good ergonomic workplace at home is a point of attention. Because of the reduced capacity of the client, posture and movement problems as a result of an incorrect working posture are lurking, as well as overexcitation problems due to crowding or too many roles being mixed up.

Employment

If you are in paid employment, the compulsory steps of the process are laid down in the Wet Verbetering Poortwachter (Absenteeism Reduction Act). An employer is obliged to go through these steps in time. In particular, the outcome of an employment test (within 6 weeks after 1 year of absence) can have far-reaching consequences for the client. This determines whether the second year of absenteeism is focused on the client's return to work, other work with the employer, or other work with another employer. The timely start with the work resumption is crucial and can influence the decision. It is

important to pay attention to this now that the circumstances of the pandemic may also make it more difficult to return to work.

9.2 Occupational therapy aimed at returning to work

9.2.1 Clinimetrics

Taking one or more measuring instruments gives the occupational therapist insight into the value of work and how work can be adapted to the physical, psychological and cognitive capabilities of the client.
Measuring instruments such as the COPM (Eijssen, Verkerk & Van Hartingsveldt, 2018), the PRPP (Nott, Chapparo & Heard, 2008) and the *Self-Efficacy Scale (SES)* are suitable for this purpose (Varekamp, Verbeek, de Boer & van Dijk, 2011). These instruments are explained in Chapter 3, section 3.4.
In addition, some other measuring instruments are suitable to be used if work resumption is one of the treatment goals.

Utrecht Scale for the Evaluation of Rehabilitation Participation (USER-P)

The USER-P is a measuring instrument that records the level of participation with regard to frequency of activities, experienced limitations and satisfaction. It gives a global picture of the activities in the area of productivity and leisure time use. The USER-P is recommended to determine the starting level when the client starts working again. The USER-P can be repeated during and after the reintegration process (Post et al. , 2012).
The results offer good information about the consequences of returning to work for the activity level, the experienced limitations and satisfaction. No specific training is required to administer the survey.

Questionnaire Work Limitations

For clients who resume work and still seem to have problems, it is advisable to take the 'Work Limitations Questionnaire'. This is the adapted, Dutch version of the Work Limitations Questionnaire (WLQ-mdlv) (Verhoef, Miedema, Bramsen & Roebroeck, 2012).

PRPP@Work

The PRPP@Work is used to map out, in a structured manner, the client's actions when carrying out his work tasks in his own work environment. The PRPP@Work consists of an analysis of the job description, an interview with the employee, an interview with the employer and an observation of the client's actions. The instrument will be translated into Dutch in 2019 (Jansen, 2020).

9.2.2 Occupational therapy intervention

Early return to work

It is preferable to start with a form of work resumption as early as possible, fitting in with the possibilities of the client. In this way, return to work becomes a means of building up the client's workload. The chances of job retention are considerably higher if the resumption of work is started at an early stage (UWV, 2020a).
Various studies of clients with neurological disorders have indicated that those affected want to be informed at as early a stage as possible of the possible consequences of their illness for their work (Minis, 2013; Sturkenboom, Storm van's Gravesande & Meijer, 2012). This also applies to clients with Q fever fatigue syndrome (Cup & Satink, 2017). It can be expected that this is also true for the COVID-19 client.

Education

It gives clients with COVID-19 and the treating occupational therapist clarity when the context is known of work, income, benefits agencies, absenteeism insurance companies and the laws and regulations.
Clients can then request and be offered the right support at different moments during their return to work. Experience shows that the application of laws and regulations in the field of labor is complex

and differs per case. The most important information for people with an employment contract and for independent entrepreneurs is presented.

Points of attention for employees with an employment contract

People with an employment contract who are absent due to illness are subject to the Wet Verbetering Poortwachter (Absenteeism Reduction Act). This law states that the employer must continue to pay (part of) the salary during the first two years of absence. During the first year of absenteeism, efforts are focused on resuming work.

The process steps of the WVP may come too early for the client. A problem analysis is drawn up by the company doctor after 6 weeks, and the plan of approach by the employer after 8 weeks of absence. It is important to inform the client that these are legal process steps and that they are not seen as pressure to get back to work quickly.

The Uitvoeringsinstituut werknemersverzekeringen (UWV) has developed a step-by-step plan for resuming work (UWV, n.d.a) and a special addendum in connection with COVID-19 (UWV, 2020b).

The COVID-19 measures have a lot of influence on the design of the reintegration. It does not relieve the employer of his (effort) obligations. If after two years of absence a WIA application is submitted to the UWV, the assessment of the re-integration report and the efforts of employer and employee will take into account the possibilities and impossibilities of the situation. The proper motivation and recording of all choices and changes made remains very important to prevent sanctions (UWV, 2020b).

Points of attention for independent entrepreneurs

Independent entrepreneurs, including ZZP-ers, must make their own arrangements in case they become disabled. They have the choice between an occupational disability insurance (AOV), a mutual fund and the choice not to insure.

An AOV can be concluded with a private occupational disability insurer or with the UWV. In general there is a waiting period of for example one month before the insurer pays out.

A brood fund is a mutual disability insurance for (mostly small) entrepreneurs, who determine the rules together. The duration of that payment is maximized. A brood fund does not provide reintegration efforts.

Meanwhile, more and more intermediate forms are created. A legally compulsory AOV for the self-employed is in development.

Self-employed entrepreneurs who are not insured against incapacity for work can, if they are at risk of falling below the poverty line, apply to the municipality for an allowance under the Income Support for Older and Partially Incapacitated Former Self-Employed Persons Act (IOAZ) (central government, no. b) or the Besluit bijstandverlening zelfstandigen (BBZ) (central government, no. a). It is not a matter of course that a self-employed person will receive income/benefit when he falls ill. This can mean that financial problems arise in the very short term. This can mean that financial problems arise in a very short period of time. Thinking along with the client and his relatives in time can be supportive.

You will be able to make a decision about whether you want to go back to your job or not. This can be both an obstacle and a stimulant to recovery.

Points of attention for clients without work and with a desire to work

It is possible that these clients will eventually benefit from applying to the UWV for an assessment of their work capacity. For this group, additional support possibilities and facilities are available to mediate them towards suitable work (UWV, n.d. a).

Building up the load capacity

Within the WVP it is the joint responsibility of the employee and the employer to make use of all possibilities to return to work. Resumption of work can often be used as a means to build up work capacity. The occupational physician can play an independent supporting role in this. The occupational therapist can draw up a work resumption plan together with the client based on the individual possibilities.
When there is a discrepancy between the demands of the job and the client's capacity to cope, it is important to (temporarily) reduce the workload. The (sometimes unexplained and recurring) relapse in the build-up of the workload puts extra demands on the reintegration plan.
The treatment focuses on the possibilities of (temporarily) adapting the content of the work to the physical, psychological and cognitive capabilities of the client. In addition, the occupational therapist can advise the client on how to communicate with the employer and the company doctor. The therapist can also refer clients to professionals in the field of work if there are signs that specific support is needed.

Work resumption plan

In this case, the patient has to be given the opportunity to return to his or her job. In the case of fatigue and cognitive problems, the strategies learned in the treatment should be applied. As a result of lung problems the pace of work can be low and/or remain so.

- In the initial phase, make sure you take enough breaks. Installing a break program on the computer can support taking breaks.
- Keep a fixed order and structure in work tasks when building up the work.
- In the beginning, choose work tasks that are not urgent, that fit in with the possibilities of the client in his rehabilitation process, and that are also meaningful for the employer or client. In case of a relapse, the consequences are less drastic for the continuity of the work.
- Together with the client, make a low-dosed, step-by-step build-up in time, weight and scope of the tasks as the workload increases. Frequently alternate thinking and doing tasks, followed by moments of rest. This often enables the client to keep on working longer.
- First build up work in hours (the number of time blocks thinking/doing/resting).
- Then adjust the ratio of doing/thinking/resting within the time blocks. That is to say: hold on to a task longer and reduce the rest moments.
- Finally, work can be done to increase the intensity of the work (such as deadlines, expanding span of control, physically demanding work).

In the event of a relapse it is advisable to go back a number of steps in the resumption of work plan and then to build up the plan again gradually.

Labour relations

You will be able to make a selection from the list of treatments that you will be offered. It is important, because of the unknown and uncertainty about the course of the disease and the recovery, but also because of the many home works or even work stoppages, to pay attention to the communication of the client with his company doctor, employer and colleagues. You can also make a list of all the things you want to do in your job, and you can make a list of all the things you want to do in your job. If the client can properly formulate what he needs to be able to reintegrate, it becomes easier for the employer and colleagues to support the client and think along in solutions. Looking at what is possible and in what way promotes participation in a positive way.

If the client finds it difficult to convey the information properly, the occupational therapist can play a facilitating role by simulating and preparing communication moments together.

Terms of employment
Together with the client, propose working hours that fit in with the client's capacity, the rehabilitation programme and the home situation. In the course of time, the working hours may more and more follow the original rhythm.

Working conditions
Physical factors such as accessibility of the workplace and the ability to get to work are prerequisites for returning to work. In case of lung problems, it is important to look at the climatic conditions. It is important to be aware of the fact that the lung is a very fragile environment, and that extreme temperature differences or an environment with dust, smoke or fumes can have a negative influence on this. In the case of cognitive complaints, it is helpful to start from a quiet, low-stimulus workplace.
In these times of frequent working from home, it is important to pay attention to an ergonomic home office.

Matching work resumption to the treatment programme

Together with the client a proposal can be formulated to match the return to work as closely as possible to the rehabilitation and recovery. The client can use this proposal when visiting the company doctor and employer in order to come to an optimal plan. The discussions with the employer and company doctor can be prepared together. There are two suitable intervention options.

Method: 'Back to work
The starting point of the 'Back to work' method is the strengthening of the client's self-management during resumption of work. The method offers ten work materials aimed at treatment and legislation. In this way the therapist is able to provide the client with the necessary support to be able to return to work. To be able to apply the 'Back to Work' method, a training course is required (Brocken, 2019).

Guide to participatory approaches in the workplace
The multidisciplinary guideline: 'participative approach in the workplace' offers a short-term intervention consisting of a number of defined process steps, which are supervised by a process supervisor, such as an occupational therapist. In the approach, those directly involved reach consensus on the most important bottlenecks in the work as well as the solutions to tackle these bottlenecks. The process counsellor guarantees an equal and active contribution of all those involved. The multidisciplinary Participatory Approach in the Workplace guideline was developed by the EMGO Institute for Health and Care Research (Huysmans, Schaafsma, Viester & Anema, 2016).

Financing

Work resumption in early rehabilitation will usually take place from the occupational health and safety service / company doctor of an employee. There is no guideline for independent entrepreneurs. In many cases, rehabilitation and occupational therapy can pay attention to work resumption. When more support is needed to get back to work, this can be paid by the employer or the insurance company for sick leave. If there is no employer, in some cases the UWV can take care of the costs. Since laws and regulations can change, it is important to ask the paying agencies about the possibilities.

Chapter 10 (Over)burdening of the informal caregiver in daily activities

This chapter focuses mainly on the needs of the informal caregiver and the monitoring of his/her own balance of roles (participation). A family care situation with COVID-19 can be extra complicated when both client and family caregiver have experienced COVID-19. There is then a greater chance of over-burdening.

10.1 Expected problems

Symptoms Post Intensive Care Syndrome-Family (PICS-F)

For family care givers too, the period when their loved one has been seriously ill at home, in the ICU or in hospital can be an uncertain and stressful experience. Research shows that three months after ICU admission one third to half of all relatives of ICU patients experience symptoms of PICS-F, namely anxiety, depression or PTSD (Matt, Schwarzkopf, Reinhart, König & Hartog, 2017). In addition, feelings of helplessness and uncertainty appear to be common stressors. Fatigue and overwork are seen as factors that can be related to depression and poor sleep, among others (Choi et al., 2014). Feelings of overload in family caregivers during the ICU period even appear to be an important predictor for PTSD. Thus, several factors play a role in the development of PICS-F, including the individual coping style of the family caregiver, a threatening IC environment, and lack of information by IC professionals (Matt et al., 2017). Due to the particular situation of COVID-19, some normally protective factors such as support for informal caregivers and unrestricted access to visit the client may also have been lacking.

Physical strain on informal care givers

In addition to the mental impact, the period of illness also makes physical demands on the informal caregivers. If the client is in poor condition, the informal caregivers may have to provide support, for example in making transfers or washing and dressing. This can be a considerable physical burden and increase the risk of physical problems (Vilans, 2020).

Severe fatigue of the client can also have a major effect on the informal caregivers. Many tasks must be taken over. Overburdening the informal caregivers is then a risk and can subsequently lead to over-burdening of the client because he may be less inclined to ask for help. Moreover, because of the Corona measures there is often less help from others available and people seem to have difficulty asking for help.

10.2 Occupational therapy aimed at the (over)load of the informal caregiver

Occupational therapy can help reduce possible psychological and physical complaints in informal care-givers that affect daily activities and roles, to prevent overburdening and thus promote the client's recovery.
Occupational therapists usually have a detecting role with respect to the specific symptoms of PICS-F. If the occupational therapist has no experience or additional training with the treatment of these prob-lems, it is advisable to work with a colleague who has the right knowledge and skills. If this is not possible, referral to a colleague with appropriate expertise is advised.

10.2.1 Clinimetrics

Bearing load and bearing capacity

In a conversation with the volunteer aid provider, the volunteer aid situation is mapped out. This can be approached as a combination of carrying capacity and carrying load. The burden of informal caregivers can be visualized as the balance between both. Whether the balance is in place, is determined by several factors.

The following factors are taken into account in order to draw up an inventory of the burden on informal caregivers: the illness, the presence of other stressful life events, the quality of the relationship with the person in need of care (both past and present), living with a family member in need of care, possible problems in the relationship with the family and relatives, the gender of the informal caregiver and practical and financial problems.

The following factors are usually taken into account in order to draw up an inventory of capacity: health of the informal caregiver, social support, motivation to care, appreciation, knowledge of the illness and expectations of the client and coping style (Kennispunt Mantelzorg, n.d.).

Insight in expectations of recovery trajectory

Asking both client and informal caregiver about their expectations of recovery is essential. It may happen that the expectations of the client and the informal caregiver are contradictory. For example, where the informal caregiver wants to resume 'normal' life, the client does not yet feel able to do so (Maasstad Hospital, 2019).

In discussions with informal caregivers, attention will be paid to the uncertainties in the rehabilitation and recovery of COVID-19 in the longer term. It is important to inform both clients and next of kin about the possibility of a long-term and intensive recovery and treatment process that may also have consequences for, for example, returning to work (see Chapter 9).

To measure the burden on the informal caregiver, a number of measuring instruments are available. These map the risk of overburdening, the given support and professional guidance and are a means to evaluate the interventions (Evenhuis & Eyssen, 2012).

(Measuring) instruments

The Caregivers Strain Index (CSI)

The *Caregivers Strain Index* (CSI) (Post, Festen, Port & Visser-Meily, 2007) is a frequently used instrument for assessing the burden experienced by informal caregivers. Both the Occupational Therapy Guideline on fatigue in MS, CVA or Parkinson's disease (Evenhuis & Eyssen, 2012) and the 'Occupational Therapy Guideline QVS - Coaching in activities of daily living' (Cup & Satink, 2017) advocate the use of the CSI. It is recommended to use the CSI to initiate the conversation about the experienced burden of the informal caregiver (Cup & Satink, 2017), including inquiring about possible positive effects of informal caregiving and using the measuring instrument as a start for interventions to reduce the burden of the informal caregiver where possible.

The Hospital Anxiety and Depression Scale (HADS)

It is important to be alert for anxiety and mood symptoms in the informal caregiver. A screening instrument such as the Hospital Anxiety and Depression Scale (HADS) can also be used for the informal caregiver to identify symptoms such as anxiety and depression (Pouwer, Snoek & Van Ploeg, 1997).

The ethnographic interview

The ethnographic interview can be used to form a picture of the roles, activities, tasks and responsibilities of the informal caregiver. It gives insight in the perception and perspective on the care tasks. In addition, it can provide insight into the future expectations of the volunteer aid worker and any problems experienced. It can be assumed that, based on practical experience, the guiding questions for an ethnographic interview from the EDOMAH-program can be used (Graff, Van Melick, Thijssen, Verstraten, & Zajec, 2010).

The guiding questions from the EDOMAH program can also be used to assess the caregiver's coping style.
Coping style is the way a person thinks about, reacts emotionally to, and deals with problems and stressful events. Each coping style offers opportunities but also carries risks. Acceptance of a situation can lead to a certain nonchalance. If the coping style is adequate, the informal caregiver will actively intervene in the situation, but there is a risk that informal caregivers will take over too much from the client.
A motivated informal caregiver, who takes care for granted, sometimes has difficulty handling boundaries (Graff et al., 2010).
In the case of a dysfunctional coping style, supervision by a psychologist or social worker may be desirable.

Measuring instrument aimed at treatment problems

Canadian Occupational Performance Measure (COPM)

The use of the COPM can be a way of mapping the experienced action problems of both the client and the person close to the client (informal caregiver) in their daily actions. (Eijssen, Verkerk & Van Hartingsveldt, 2018).
A neighbour can act as:

- the client's 'advocate': from the client's perspective. If the client is not (yet) able to verbalize the problems he/she experiences or has insufficient insight into the problems in the daily situation, then a neighbour can act as an advocate and, putting himself/herself in the client's place, can express his/her wishes or problems as the neighbour thinks the client experiences them;
- co-client: from the perspective of the person close to the client. The person close to the client can express his/her wishes or problems in the client's actions, or their own perceived problems in dealing with the client (Eijffinger & Eijkelkamp, 2020).

10.2.2 Occupational therapy interventions

Attention to the quality of life of informal caregivers

Occupational therapy treatment pays attention to the quality of life of the informal caregiver. Interventions focus on improving the perceived social support, both emotional, instrumental and professional. In addition, on feeling appreciated and one's own participation wishes (Cup & Satink (2017).
Recommendations for support of the informal caregiver as included in the occupational therapy guideline for QVS are expected to also apply to COVID-19.

Family education and information

Informal caregivers make an essential contribution to the recovery of the client. Therefore, it is important to provide education to remove as many questions and uncertainties as possible from the informal caregiver. These include education about PICS, PICS-F and recovery expectations (Inoue, 2019; Matt et al., 2017).
Uncertainty about the future and financial uncertainty can be a major stressor. Offering support in contacting a company doctor, the UWV or a trade union can limit the negative influence of the work stressor.

Other occupational therapy interventions for the informal caregiver

The following interventions can be expected to support the informal caregiver in the recovery of clients with COVID-19 and to enhance their own load capacity (Cup & Satink, 2017).

Supporting the client

- Advice on and training in client care and support skills. Instructional films are available online for this purpose.
- Advice on relevant aids that can ease care and support the client in meaningful activities.
- Advice on activities or experiences that have a calming or soothing effect and which the informal caregivers can use to support the client in the event of (long-term) overstimulation symptoms.

Strengthen own load capacity

The approaches and interview techniques used to support the client in self-management and regaining control can also be adopted in the treatment of the informal caregivers (see Chapter 3).
Other possibilities are:

- Stimulate and guide the search for possibilities to maintain or regain the execution of 'own' activities. Also think about the importance of relaxing activities and asking for help where necessary and possible.
- Advising on local initiatives where people can ask for (practical) or emotional support.
- Supporting or teaching other coping styles or learning to manage negative emotions (Matt et al., 2017).
- Stimulating contact with fellow sufferers.

Realization of the guideline ‘Occupational Therapy for COVID-19 clients in the recovery phase'.

The guideline 'Occupational Therapy for COVID-19 clients in the recovery phase' has been developed with the cooperation of a large group of active members. The members of the working groups are involved in various consultation groups of Ergotherapie Nederland or have been approached for their specific expertise. The reading groups consist of occupational therapy researchers and individual members.

Working group 'Occupational therapy guidelines for COVID-19 clients in the recovery phase' version January 2021

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Chapter 10 (Over)load of the informal caregiver in daily activities

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Additional Information

COVID-19

https://corona.nhg.org/
https://www.esculaap.nl/zakkaartje/covid19
https://www.esculaap.nl/zakkaartje/covid19-ouderen
https://www.rivm.nl/documenten/triage-klantclient
https://www.rijksoverheid.nl/onderwerpen/coronavirus-covid-19
https://fcic.nl/post-intensive-care-syndroom/

COVID-19 and cognitive effects

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7324344/
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7445105/
https://bjanaesthesia.org/article/S0007-0912(20)30849-7/fulltext
https://www.health.harvard.edu/blog/the-hidden-long-term-cognitive-effects-of-covid-2020100821133

Occupational therapy and COVID-19

Webinar Guidance on Occupational Therapy with COVID-19 clients in the rehabilitation phase June 10, 2020:
https://www.youtube.com/watch?v=IsZ3uoicI4s
https://www.npi.nl/ergotherapie?fbclid=IwAR0pYRd1ALo4wGR0bzooD4QtBgszyf7uSUa1jlWwjf4BuOeyPQWcIgW9fcI
http://www.prpp.nl
http://www.thecopm.ca/
https://meetinstrumentenzorg.nl/

Lung problems in daily activities

www.longfonds.nl, geraadpleegd op 22 april 2020
https://meetinstrumentenzorg.nl/instrumenten/borg-rating-of-perceived-exertion-scale/

Consequences of prolonged immobilization in daily activities: pressure ulcers

https://qcare.nl/professionals/decubitus-info-voor-de-professional/
https://www.wcs.nl/wp-content/uploads/Depth-unknown-verdieping-van-onbekende-diepte-1.pdf
https://www.nursing.nl/3-veranderingen-in-de-nieuwe-richtlijn-decubitus-2694714w/

Severe fatigue

CIS20R: https://meetinstrumentenzorg.nl/instrumenten/checklist-individuele-spankracht-checklist-individual-strength/
MFIS: https://meetinstrumentenzorg.nl/instrumenten/modified-fatigue-impact-scale/
FSS: https://meetinstrumentenzorg.nl/wp-content/uploads/instrumenten/FSS-meetinstr.pdf

Cognitive problems with daily activities
https://etpnet.net/wp-content/uploads/2018/09/Questionnaire-Occupational-Performance-QOP-2018.pdf
https://meetinstrumentenzorg.nl/instrumenten/montreal-cognitive-assessment/
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https://multicontext.net/contextual-memory-test
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https://www.howtotest.eu/functiedomein-testfiches/mental-slowness-observation-test
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Psychological complaints, sleep problems and consequences for the execution of daily activities
https://etpnet.net/wp-content/uploads/2019/05/Factsheet-ETP-Net.pdf
https://www.psychotraumadiagnostics.centrum45.nl/ptss
https://www.rijnstate.nl/media/12293/adviezen-om-beter-te-slapen.pdf

Work resumption
https://www.nvab-online.nl/content/participatieve-aanpak-op-de-werkplek
https://www.kcrutrecht.nl/producten/user-p/
https://www.prpp.nl/het-prpp-systeem/work/
https://ergotherapie.nl/wp-content/uploads/2018/10/171206-Ergotherapierichtlijn-Q-koorts-vermoeidheidssyndroom-QVS.pdf
https://www.werk.be/sites/default/files/Fiches%20Huis%20van%20werkvermogen%20LR.pdf

(Over)load of the informal caregiver in daily activities
Measuring instruments for the occupational therapist
https://www.zorgvoorbeter.nl/docs/PVZ/vindplaats/mantelzorg/CSI-meetinstrument-overbelasting
https://www.vilans.nl/docs/producten/Care%20giver%20strain%20index.pdf
mantelzorger.pdf
https://meetinstrumentenzorg.nl/wp-content/uploads/instrumenten/424_1_N.pdf (coping)
https://familiealsbondgenoot.nl/
https://wijzijnmind.nl/

Websites to support informal caregivers
Platform for people with lung complaints after corona
https://coronalongplein.nl/

Practical help and support
Overview of support websites and apps: https://mantelzorg.nl/pagina/voor-mantelzorgers/thema-s/delen-van-de-zorg/steun-uit-je-omgeving/websites-en-apps-voor-delen-van-de-zorg/overzicht-van-gratis-apps-voor-mantelzorgers
https://www.rodekruis.nl/hulp-in-nederland/ready2help/
See www.samenbeterthuis.nl/ for instructional videos on client care and support.

Emotional support during and after intensive care admission
https://www.psychosocialezorg.info/naasten/informatie-voor-naasten-na-een-opname-van-uw-dierbare-op-de-intensive-care
https://icconnect.nl/coronavirus/ voor patiënten en familieleden, over coronavirus
https://fcic.nl/onze-projecten/ic-hulplijn/ voorlichting, lotgenotencontact (patiënten en familieleden)

General information about next of kin and corona

https://naasteninkracht.nl/nl/corona

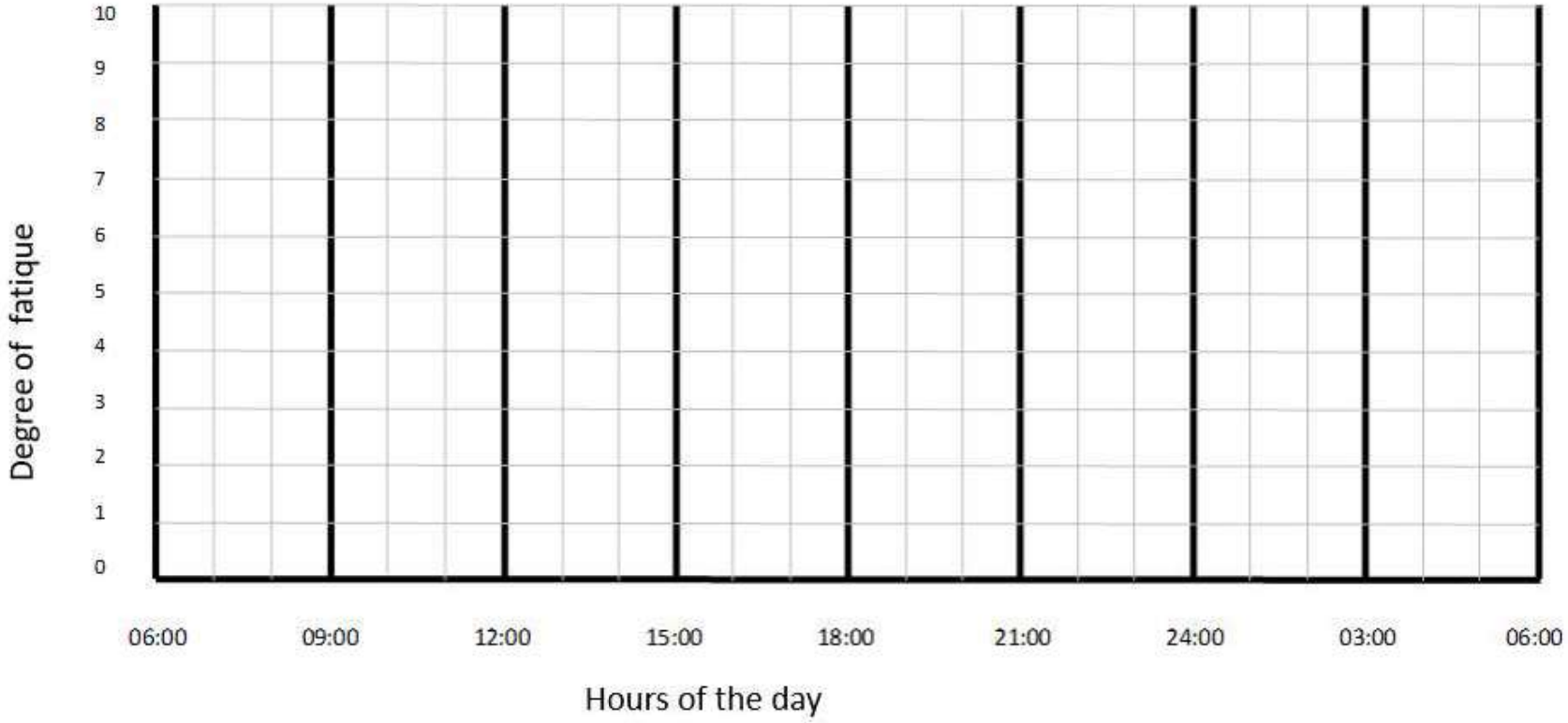
General support for informal caregivers
https://mantelzorg.nl

About work and informal care, and respite care
https://www.zorgvoorbeter.nl/mantelzorg/respijtzorg

Support with regulatory affairs
https://www.regelhulp.nl/ik-zorg-voor-iemand/mantelzorgondersteuning

Appendix 1 Fatigue graph

Graph complaint pattern fatique



Appendix 2 ADL diary

Activity diagram (diary)

Please tick if you can do the following activities independently (without assistance).
Please indicate how strenuous you find carrying out these activities and whether the exertion makes you short of breath. You can indicate this with the help of the deposit scales (see below).

Daily activities checklist Date: ..... - ..... -	Can you do this?	Shortness of breath	Fatigue
Dressing and undressing			
Personal care (washing, shaving, brushing teeth, etc.)			
Turning over in bed			
Getting up (from a chair)			
Bend over			
Squat			
Walking in the house			
Climbing stairs			
Outdoor walking on level ground			
Outdoor walking on uneven terrain			
Run			
Bicycles			
Gardening			
Doing the shopping			
Vacuuming			

Lock scale

For each activity, indicate how short of breath you experienced and how tiring you found the exertion. The table shows the experienced shortness of breath and the exertion level in numbers.

Shortness of breath		Fatigue	
0	Not at all.		Not perceptible
0.5	Hardly any	0.5	Very light
1	Very little	1	Very light
2	Little	2	Light
3	Moderate	3	Moderate
4	Quite strong	4	Reasonably heavy
5	Strong	5	Heavy
6		6	
7	Very Strong	7	Very Heavy
8		8	
9		9	
10	No breath at all	10	Very heavy, Max

Appendix 3 Time sheet for fatigue and shortness of breath

..... day .....-.....-2020

	activity	Fatigue	Shortness of breath
00.30			
01.00			
01.30			
02.00			
02.30			
03.00			
03.30			
04.00			
04.30			
05.00			
05.30			
06.00			
06.30			
07.00			
07.30			
08.00			
08.30			
09.00			
09.30			
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19.30			
20.00			
20.30.			
21.00			
21.30			
22.00			
22.30			
23.00			
23.30			
24.00			

Appendix 4 Pressure ulcers, location, cause and intervention

Location decubitus	Possible cause	Possible interventions
Tailbone	Sitting upright in bed without semifinished position Sitting in a slumped position in bed or wheelchair Sliders Lie on back Folds in clothing, mattress cover	Lying on your side 30 degrees in bed, use for example a horseshoe cushion Supine with semifowler stance Tilt wheelchair. Alternate position AD mattress and pillow Smooth bed linen Use of sliding sheet
Inside of knees	Pressure from knees in lateral, supine and seated positions High muscle tension due to uncomfortable posture Not properly adjusted leg supports	When supine: pillow between legs to prevent pressure or under knees to reduce muscle tension Side position: position your knees behind each other with a pillow between them Sitting position: adjust leg supports, cushion between knees
Heels	supine friction forces folds and/or hard mattress cover too small shoes (oedema!)	When supine, heels free with cushion under entire lower legs Preferred side position Dressing slippers AD mattress
Auricle	Pressure in lateral or prone position Oxygen hose Pleats Moist/warm due to saliva for example	Alternate back and side positions When lying on your side: lay the auricle free Moving the hose Preferably not on the side of the affected ear
Outer ankle	Sideways position with 2nd leg on top Shear forces and pressure	Ankle free in lateral position Sideways position on other side Footwear without pressure on the wound Dressing slippers, possibly with cutout