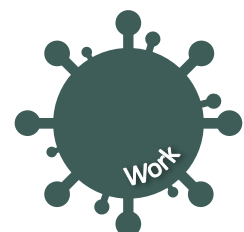
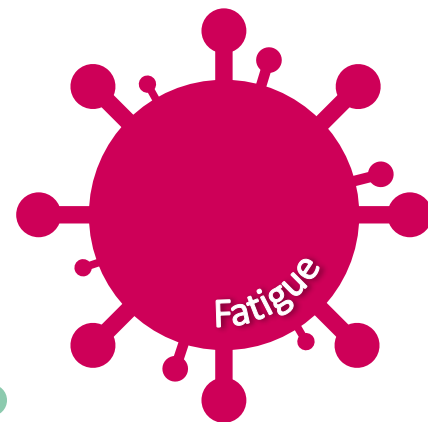
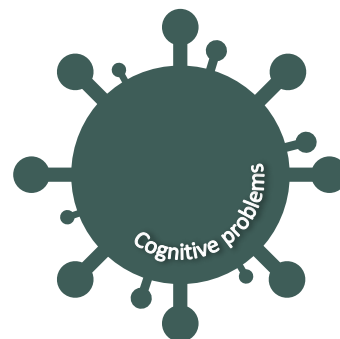


# GUIDELINE OCCUPATIONAL THERAPY FOR CLIENTS WITH POST-COVID-SYNDROME

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## Colophon

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## Disclaimer

This new guideline: '**Occupational therapy for clients with post-COVID syndrome**' follows the fourth version of the guideline '**Occupational therapy for COVID-19 clients in the recovery phase**' published in January 2021. In the past year it has become apparent that many COVID-19 clients suffer from long-term and often erratic complaints. The terms 'Long COVID' and later, 'post-COVID syndrome' were introduced. Because of new medical knowledge and practical experiences of occupational therapists, the need arose to develop a guideline for occupational therapists for the treatment of clients with post-COVID syndrome.

This guideline does not stand alone, but should be used in conjunction with the first guideline.

This guideline, too, is a dynamic document that will be updated as required by current scientific knowledge, new developments in the field of illness and practical experience.

This document is a guide and not a treatment guideline. It does not offer a fully worked-out treatment protocol for occupational therapists, but gives direction with current knowledge and experience.

For the precautionary measures to be able to treat, reference is made to the two documents drawn up jointly by Paramedisch Platform Nederland (PPN)<sup>1</sup>, Koninklijk 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 consulted on the website of Occupational Therapy Netherlands [www.ergotherapie.nl](http://www.ergotherapie.nl). These documents will be updated in case of changes in government policy.

Ergotherapie Nederland, August 2022

*\*In this document, the term Long COVID, which refers to the prolonged complaints after COVID-19 infection, has been replaced by the term post-COVID syndrome. Long-term symptoms after COVID-19 have been defined by the Health Council as post-COVID syndrome since February 2022. This term is now used in several publications, which is also the reason for adapting this document. However, the term Long COVID is now so well established that in practice the terms are used interchangeably.*

## Guideline 'Occupational therapy for clients with post-COVID syndrome: Summary

This new guideline: '**Occupational therapy for clients with post-COVID syndrome**' follows the fourth version of the guideline '**Occupational therapy for COVID-19 clients in the recovery phase**'.

### Introduction

After a COVID-19 infection, long-term and erratic symptoms may occur that can have a major impact on daily functioning. Occupational therapists can play an important role in the treatment of such problems. An explanatory model for the persistent symptoms in combination with increased expertise in the occupational therapy treatment of the target group have led to the development of a second manual: 'Occupational therapy for clients with post-COVID syndrome'. This document will be updated on the basis of new scientific insights, developments in the field and practical experience.

### Purpose

The purpose of this document is to offer a helping hand to occupational therapists in the later phase of the recovery process, if the postinfectious symptoms referred to as post-COVID syndrome persist. This document is suitable for occupational therapists working in primary care who treat clients in the framework of paramedic recovery care COVID-19. In secondary care, this document also provides points of reference for forming the treatment. This document is not a stand-alone document but should always be used in practice together with the first document.

### The post-COVID syndrome

People who have long-term symptoms after a COVID-19 infection experience consequences that affect daily functioning and quality of life. The WHO has introduced the term 'Long COVID or post-COVID-syndrome'. Following the Health Council of the Netherlands, we use the term post-COVID syndrome in this guide. This group of clients is often dominated by fatigue. There are usually no indications of organ damage, insofar as this can be objectified with additional research.

One of the mechanisms that may play a role in post-COVID syndrome is autonomic dysregulation. As long as there are no new scientific insights, this is used in this guide as an explanatory model for the symptoms experienced by clients. An explanatory model provides recognition of the symptoms and the insight can support the client and the therapists in the choices in the rehabilitation or treatment programme.

### Occupational therapy in post-COVID syndrome

Given the problems this target group faces in daily functioning, occupational therapy plays an important role in the recovery of clients with post-COVID syndrome. Occupational therapy is aimed at teaching the client to find a (new) balance in daily activities and in the roles that are fulfilled. Based on expert-based evidence, the treatment process has a number of fixed characteristics that minimise the risk of a relapse in functioning.

Education about the symptoms in relation to daily functioning, a measured build-up of activities and coordination with other care providers are important starting points in the occupational therapy treatment of clients with post-COVID syndrome. When a good balance has been achieved, the activity level can be expanded. It often turns out that this is only possible in small steps.

It is recommended that the COPM and PRO-ergo be administered at fixed intervals, in addition to one or more domain-specific measuring instruments, in order to objectify and evaluate the treatment process.

Promoting self-management and regaining control in changing circumstances are overarching themes in treatment.

The Canadian Practice Process Framework (CPPF) is included as an appendix to support the methodical treatment process when the occupational therapist has little treatment experience with clients with post-COVID syndrome.

### **Domains of occupational therapy treatment**

The treatment domains such as lung problems, cognitive complaints, fatigue and work, which are mentioned in the guideline 'Occupational therapy for COVID-19 clients in the recovery phase', are also addressed in the occupational therapy treatment of clients with post-COVID syndrome. An important difference is that we can now speak of complaints within the various domains and there does not seem to be any organ damage.

In post-COVID syndrome, fatigue symptoms resulting in an imbalance between load and load capacity in daily functioning is the most important treatment indication for occupational therapy. The combination with cognitive complaints occurs frequently. Respiratory problems, sleeping problems, muscle weakness and/or polyneuropathy also influence the ability to carry out daily activities and roles as desired. Psychological and social factors can play a role in the presence and continuation of the complaints and impede recovery.

In practice, it appears important to start the occupational therapy treatment with the symptoms of fatigue and the consequences for daily functioning. Recovering the balance between load and load capacity in daily activities appears to have a positive effect on fatigue as well as on the other symptoms that occur.

### **Domain-specific measuring instruments and interventions**

The specific measurement instruments and interventions in the various domains are mostly applicable to clients with post-COVID syndrome, as described in the first guide. Additional items are described per domain. In addition, each domain discusses the possibilities of building up the activity level. Finally, the cooperation with other disciplines is discussed.

### **Work resumption**

The combination of disease-specific factors of the post-COVID syndrome with (time-related) reintegration and work-related factors can be a barrier to return to work.

Occupational therapy for clients with post-COVID syndrome is aimed at restoring control and developing self-management to enable an appropriate and sustainable return to work. An important characteristic of occupational therapy treatment is that interventions are aimed at both work and daily activities in the home. It is precisely this combined approach towards a work-life balance that contributes to the success of reintegration.

Different possibilities for intervention in the work situation are discussed in order to be able to build up the tasks in complexity, intensity and duration together with the client.

### **Group treatment**

Newly added is a chapter on group intervention. It has been shown that this can be a valuable addition to the individual treatment. In group treatment, the recognition of the issues at stake and the possibility for clients to learn from each other are important additions to a treatment process that are not addressed in an individual course of treatment.

In addition, the use of group treatment can contribute to the reduction of waiting lists. This form of treatment is being experimented with in practice. The tools that are provided can help occupational therapists to put this form of treatment into practice.

## Table of contents

Colophon	0
Disclaimer	1
Occupational therapy for clients with post-COVID syndrome: Summary	2
Chapter 1 Introduction	Introduction 8
1.1	Purpose of this document ..... 8
1.2	What is new compared to the first guide? ..... 8
1.3	Formation of the guide ..... 8
1.4	Reading guide ..... 8
Chapter 2	The post-COVID syndrome, recovery and rehabilitation ..... 10
2.1	Introduction ..... 10
2.2	Terminology and choice ..... 10
2.3	Retrospective COVID-19 pandemic ..... 11
2.3.1	Lung damage ..... 11
2.3.2	Multi-organ and multi-system disorder ..... 11
2.4	Classification for rehabilitation and treatment ..... 11
2.4.1	Clients with lung damage ..... 11
2.4.2	Clients with other forms of organ damage ..... 12
2.4.3	Clients with persistent complaints without organ damage ..... 12
2.5	Epidemiological situation of post-COVID syndrome ..... 12
2.5.1	Prevalence ..... 12
2.5.2	Who gets post-COVID syndrome? ..... 13
2.5.3	Recognition of the complaints ..... 13
2.6	An explanatory model for post-COVID syndrome symptoms ..... 13
2.6.1	Introduction ..... 13
2.6.2	Autonomous dysregulation ..... 14
2.6.3	Possible causes ..... 14
2.6.4	Forecast ..... 15
2.7	Principles of treatment ..... 15
2.7.1	Classification on the basis of complaints ..... 15
2.7.2	Stepped care ..... 16
2.7.3	Agreement with other conditions ..... 16
2.8	Guidelines and research on long-term COVID ..... 17
Chapter 3	Characteristics of occupational therapy treatment ..... 18
3.1	What does occupational therapy offer? ..... 18
3.2	Methodical handling: Assessment, goal setting and evaluation in daily ..... 18

activities and post-COVID syndrome.....	18
3.2.1    PEO model and education .....	18
3.2.2    Assessment.....	18
3.2.3    Recommended measuring instruments .....	19
3.2.4    Recommended measuring points .....	19
3.3      The course of occupational therapy treatment .....	19
3.4      Completion of occupational therapy treatment .....	20
3.5      Collaboration with other healthcare providers involved with clients with post-COVID syndrome	20
Chapter 4    Breathing difficulties in everyday activities.....	22
4.1      Expected problems.....	22
4.1.1    Introduction.....	22
4.1.2    Hyperventilation syndrome (HVS).....	22
4.2      Occupational therapy directed at hyperventilation.....	22
4.2.1    Clinimetrics .....	22
4.2.2    Occupational therapy intervention .....	23
4.3      Cooperation with other disciplines: .....	23
Chapter 5    Muscle weakness and polyneuropathy .....	24
5.1      Expected problems.....	24
5.1.1    Muscle weakness.....	24
5.1.2    Polyneuropathy .....	24
5.2      Occupational therapy for muscle weakness .....	24
5.2.1    Clinimetrics .....	24
5.2.2    Interventions .....	25
5.3      Occupational therapy in polyneuropathy .....	25
5.3.1    Clinimetrics.....	25
5.3.2    Interventions .....	25
5.4      Aids and facilities.....	25
5.5      Cooperation with other disciplines .....	26
Chapter 6    Complaints of fatigue in daily activities.....	27
6.1      Expected problems.....	27
6.2      Occupational therapy for fatigue .....	27
6.2.1    Clinimetrics.....	27
6.2.2    Interventions .....	28
Chapter 7    Cognitive complaints in daily activities .....	32
7.1      Cognitive complaints in post-COVID syndrome .....	32
7.2      Occupational therapy directed at the cognitive symptoms.....	32
7.2.1    Clinimetrics.....	32



7.2.2	Occupational therapy intervention .....	34
7.3	Cooperation with other disciplines .....	35
Chapter 8	Psychological complaints and sleep problems with consequences for the performance of daily activities.....	36
8.1	Expected problems in post-COVID syndrome .....	36
8.1.1	Wide variation in outcomes .....	36
8.1.2	Risk factors .....	36
8.1.3	Depression and anxiety .....	37
8.2	Occupational therapy directed at psychological complaints and sleep problems.....	37
8.2.1	Clinimetrics.....	37
8.2.2	Occupational therapy intervention .....	37
8.3	Cooperation with other disciplines .....	38
Chapter 9	Work resumption .....	39
9.1	Work problems in post-COVID syndrome .....	39
9.2	Occupational therapy aimed at returning to work .....	40
9.2.1	Clinimetrics.....	40
9.2.2	Occupational therapy intervention .....	40
9.3	Cooperation with other disciplines .....	43
9.4	Funding.....	43
Chapter 10	Group treatment for clients with post-COVID syndrome .....	45
10.1	Introduction.....	45
10.2	Inflow of clients with post-COVID syndrome .....	45
10.3	Group treatment aimed at daily functioning at home and at work.....	45
10.3.1	Structure of the programme .....	45
10.3.2	Clinimetrics.....	46
10.3.3	Occupational therapy interventions.....	46
10.3.4	Experiences.....	46
Realisation of guideline 'Occupational therapy for clients with post-COVID syndrome'.	.....	47
Source list	48	
Appendix 1	A methodical treatment process for clients with post-COVID syndrome.....	53
Appendix 2	Example of occupational therapy group treatment for clients with post-COVID syndrome.....	60
Appendix 3	Self-help tips from Ergotherapie Nederland .....	62

## Chapter 1 Introduction

### 1.1 Purpose of this document

This guideline 'Occupational therapy for clients with post-COVID syndrome' is a follow-up to the guideline 'Occupational therapy for COVID-19 clients in the recovery phase'.

The first guide focuses on the early phase of recovery, while the second guide offers occupational therapists concrete starting points for the treatment of COVID-19 clients with long-term symptoms, the so-called post-COVID syndrome. There are new medical insights about the syndrome and an explanatory model that is often used in rehabilitation for the long-term complaints. These can help occupational therapists in their treatment approach to work together with the client on the goals that are aimed at functioning (again as desired) in daily activities and the roles that the client fulfils.

### 1.2 What is new compared to the first guideline?

In addition to new insights into the clinical picture and the long-term complaints, the extensive treatment experience and treatment results of occupational therapists in recent times ensure that a clear direction can be given to the treatment. An approach that, as it turns out, contributes to achieving treatment goals.

The chapters describing the domains of occupational therapy in post-COVID syndrome supplement the information in the first guideline. This applies to the pattern of symptoms, the use of measuring instruments and suitable interventions.

Where information has not changed or needed to be supplemented, reference is made to the first guideline. For this reason, a chapter on the informal carer has not been included in this guideline. New in this guide is the chapter on group occupational therapy intervention for clients with post-COVID syndrome, which has led to initial experiences. Also included is the Canadian Practice Process Framework (CPPF) that can be helpful in the methodical process when the occupational therapist has little experience in working with clients with post-COVID syndrome.

It is important to emphasise again that this guideline does not stand alone, but should always be used in practice together with the first guideline.

### 1.3 Formation of the guide

The document has been developed by the Dutch Association of Occupational Therapists (Ergotherapie Nederland), again in cooperation with the COVID-19 expert working group consisting of occupational therapists working in (outpatient) clinical treatment settings and primary care. All have up-to-date knowledge of the issues and have gained extensive experience in treating the target group. An important contribution has been made by rehabilitation specialist Dr. Paulien Goossens MD, who describes the current knowledge of post-COVID syndrome and a possible explanation for the complaints.

### 1.4 Reading guide

The handbooks as developed should both be used to help shape occupational therapy treatment in post-COVID syndrome. The first guide can be used as a reference. For this reason the guideline 'Occupational therapy for patients with post-COVID syndrome' regularly refers to the first guideline.

Chapter 2 includes the description of post-COVID syndrome, the commonly used explanatory model and rehabilitation characteristics. This is followed in Chapter 3 by the most important general features and concrete guidance for occupational therapy treatment in post-COVID syndrome.

Chapters 4 to 9 then discuss the various treatment areas, including the expected complaints or problems, the clinimetrics, the occupational therapy interventions and the cooperation with other disciplines:

- Respiratory problems and their impact on daily activities (Chapter 4)
- Muscle weakness and polyneuropathy (Chapter 5)
- Fatigue (Chapter 6)
- Cognitive complaints (Chapter 7)
- Psychological complaints and sleep problems (Chapter 8)
- Resumption of work (Chapter 9)

The final chapter (Chapter 10) sets out to provide group treatment for post-COVID syndrome.

This guide follows the same structure and order as the first guide. 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.

## Chapter 2 Post-COVID syndrome, recovery and rehabilitation

The variation in symptoms, the sometimes erratic course and the long persistence of complaints after a COVID-19 infection require an explanation in order to adequately shape the treatment of clients with post-COVID syndrome. Rehabilitation specialist Dr. Paulien Goosens MD has in the past year frequently drawn attention to the long-lasting postinfectious symptoms and the importance of rehabilitation. She has been willing to use her accumulated knowledge and experience as an expert for this chapter.

### 2.1 Introduction

This chapter focuses on the symptoms and long-term complaints following the contracting of a COVID-19 infection. The World Health Organization (WHO) provides the following definition:

*"Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time"* (WHO, 2021).

This chapter provides an explanatory model for the complaints associated with post-COVID syndrome. Groups can be distinguished on the basis of the most prominent symptoms. In addition, some general aspects of rehabilitation and treatment are described.

The information in this chapter is based on the literature that has been published in the past year on long-term complaints after COVID-19 infection, but is also based on the experiential knowledge gained in the rehabilitation of the target group in the past year.

### 2.2 Terminology and choice

In a policy letter in February this year, the WHO Regional Office for Europe drew the attention of policy makers to the fact that 1 in 10 people who have experienced COVID-19 still report symptoms after 12 weeks. They introduced the term 'Long COVID' in this report (Davis et al., 2020). Initially, there was confusion about this term in the Dutch language area because people thought it would refer to COVID-19 with specific complaints of the lungs.

We note that the term "Long COVID" is now widely known and used in our country. Therefore, in the earlier version of this guide, we chose to use the term "Long COVID" (RIVM, 2021).

Other terms used to describe the long-term consequences after experiencing a COVID-19 infection are: "Post-Acute Sequelae of COVID-19" (PASC) and "Post-Acute COVID-19 Syndrome" (PACS) (Rajan, Khunti, Alwan, Steves, Greenhalgh, MacDermott, Sagan, McKee, 2021).

Long-term complaints after COVID-19 have been defined by the Health Council of the Netherlands as 'post-COVID syndrome' since February 2022. This is why this term is used in the guideline (Gezondheidsraad Nederland, 2022).

## 2.3 Retrospective COVID-19 pandemic

### 2.3.1 Lung damage

In the spring of 2020, our country was also faced with a persistent and dangerous virus about which very little was known. Hospitals and ICUs were filled to capacity and lung problems seemed to be at the forefront. Patients who had often spent weeks in the ICU were discharged to a rehabilitation centre, nursing home or (their own) home. Nobody knew yet what the right treatment was or how long patients remained contagious. Rehabilitation protocols for these patients were quickly drawn up. Pulmonologists and pulmonary physiotherapists often took the lead. It was assumed that patients would suffer from a combination of Post-IC Syndrome (PICS) and lung damage. The guidelines of the Federation of Medical Specialists (FMS) and Royal Dutch Society for Physiotherapy (KNGF) were therefore partly based on classical pulmonary rehabilitation principles (Federation of Medical Specialists, 2020; NVAB, 2021).

### 2.3.2 Multi-organ and multi-system disorder

In hospitals, it soon became apparent that the SARS-CoV-2 virus not only affected the lungs, but also caused coagulation problems and affected other organs (Pavli, Theodoridou, & Maltezou, 2021). Doctors were concerned about the occurrence of brain damage. Several pathophysiological mechanisms were explained in the literature: stroke, cytokine storm, oxygen deficiency, encephalitis, endothelial dysfunction. Also, critical illness polyneuropathy and myopathy were seen in these ICU patients (Ahmed, Hanif & Ali et al., 2020; Wu, Xu & Chen et al., 2020).

In the first wave of infections, it became clear that not only people who were hospitalised developed symptoms. People who experienced the disease at home were also affected by COVID-19.

It is noteworthy that post-acute COVID-19 symptoms are multisystemic, nonspecific and not associated with the severity of acute COVID-19 infection (Greenhalgh & Knight et al., 2020; Townsend et al., 2020). In the meantime, there is more experience with clients who maintain long-term symptoms after COVID-19 infection.

It remains unclear for the time being why the infection is mildly symptomatic or even asymptomatic in the majority of infected persons, but is serious and often life-threatening in a significant minority (NVAB, 2021).

## 2.4 Classification for rehabilitation and treatment

A large group of people who experience COVID-19 do not experience any residual damage or long-term complaints. With the experience gained in rehabilitation, clusters of clients can be distinguished for the group that did develop long-term symptoms. It is a pragmatic division into three groups that shows which form and place of rehabilitation may be appropriate for which group:

- Clients with lung damage
- Clients with other forms of organ damage
- Clients with persistent complaints without organ damage

### 2.4.1 Clients with lung damage

About a third of clients admitted to hospital experience pneumonia or Acute Respiratory Distress Syndrome (ARDS). They have long-term respiratory symptoms dominated by shortness of breath limited to the respiratory system. In these patients, it is important to be alert for tightness of the chest caused by disturbances in the respiratory system (Guler, Ebner & Aubry-Beigelman, 2021). In addition, COVID-19 infection in clients who are known to have lung disease can lead to exacerbation of their pre-existing

lung problem (Halpin, Criner & Papi et al., 2021). Clinical practice and initial results from screening clinics in hospitals show that lung damage is almost never seen in clients who have not been admitted to hospital (Wassenburg, Keijsers, van de Glind & Meulendijks, 2021). Clients with respiratory symptoms associated with lung damage are usually counselled by the lung specialist and then follow specific pulmonary rehabilitation programmes. If necessary, the lung specialist can refer to one of the five knowledge centres for complex chronic lung diseases for third-line pulmonary rehabilitation.

#### 2.4.2 Clients with other forms of organ damage

After hospitalisation for COVID-19 infection, several forms of organ damage may occur, such as kidney damage, gastrointestinal problems, heart damage and neurological disorders. The symptoms can manifest in different ways. It is important to realise that 90% of patients experience long-term fatigue after hospitalisation, in addition to other symptoms (Behzad, Aghaghazvini, Radmard & Gholamrezanezhad, 2020). Rehabilitation is indicated in any case in patients who have demonstrable brain damage (including stroke) after COVID-19. This is estimated to occur in 3 to 6% of patients who were admitted to hospital or ICU respectively (Elkind, Boehme & Smith et al., 2020). The rehabilitation of these clients follows normal referral patterns. Depending on severity and functional prognosis, clients are treated in specialist medical rehabilitation centres, geriatric rehabilitation or primary care.

#### 2.4.3 Clients with persistent complaints without organ damage

The third and largest group is made up of clients with persistent symptoms, in which fatigue often predominates. There are usually no indications of organ damage, insofar as this can be objectified with additional research. A relatively large number of these are clients who have experienced COVID-19 at home. This third group is known as the group with post-COVID syndrome.

RIVM, among others, is conducting research into the size of the group that developed these long-term complaints and is following people over a longer period of time (RIVM, September 2021).

As a possible classification for the practice, a classification can be made on the basis of the complaints that are in the foreground. This classification is explained in section 2.7.1.

The two groups with demonstrable organ damage can still experience long-term symptoms after a specialist rehabilitation programme, which impede daily functioning at home or at work. They can then follow the same path as the group without organ damage.

## 2.5 Epidemiological situation of post-COVID syndrome

### 2.5.1 Prevalence

By December 2021, more than 3 million confirmed COVID-19 infections will have been registered in the Netherlands, with over 20,000 deaths recorded (RIVM, 2021; CCSE, 2021).

Many people have experienced COVID-19 without becoming (very) ill or testing positive. These people are therefore often not included in a study. From various studies, 50% of patients report long-term complaints (Moreno-Pérez et al., 2021). At least two forms of bias are likely here. Often, patients who were admitted to hospital are over-represented in these studies. Also, no comparison is made with the incidence of complaints in the general population. Even if only a few percent suffer from long-term symptoms after COVID-19 infection, this is a huge number of clients. Only in a few years' time will we know how large the group with permanent complaints is. Previous research on SARS has shown that 1-3% have long-term symptoms (C-support, 2021).

### 2.5.2 Who gets post-COVID syndrome?

It is not well known why some people have long-lasting symptoms after a COVID-19 infection. Both hospitalised and home COVID-19 patients may experience post-COVID syndrome. Clients with pre-existing hypertension and diabetes appear to have prolonged symptoms after COVID-19 infection (Khunti, Davies, Kosiborod & Nauck, 2021). There is evidence that post-COVID syndrome is more common in women and health care workers (Murga, Aranburu & Gargiulo, Esteban & Lafuente, 2021). It is also possible that psychological factors play a role in the emergence or maintenance of the symptoms (El Sayed, Shokry & Gomaa, 2021).

Experiences from occupational therapy practice show that some of the post-COVID syndrome clients had difficulty in balancing the (many) tasks and roles in daily life before the infection. A relatively large group of people with post-COVID syndrome experience symptoms that affect their quality of life.

### 2.5.3 Recognition of the complaints

Globally, there is a call (from the WHO) for recognition of the symptoms associated with the 'post COVID-19 condition' also known as 'long COVID', which affect work opportunities and quality of life (Rajan et al., 2021). The persistent symptoms have a significant impact on the daily lives of these people, who are also called 'long haulers'. They struggle to return to work and family responsibilities, which may include secondary financial consequences (Davis et al., 2020).

It is recommended that an appropriate approach be created in the form of rehabilitation and treatment in primary care and that this be coordinated with the client and their family (Rajan et al., 2021).

## 2.6 An explanatory model for post-COVID syndrome symptoms

### 2.6.1 Introduction

The aetiology and pathophysiological causes of post-COVID syndrome symptoms are still unclear. There is also no global consensus on the definition of post-COVID syndrome.

More research is needed to understand the underlying mechanisms by which post-COVID syndrome develops (Rajan et al., 2021). Nevertheless, it is important to use an explanatory model based on the most common symptoms. Clients with post-COVID syndrome, in addition to numerous other symptoms, almost all suffer from fatigue (Rajan et al., 2021).

The complaints have a great influence on the functioning in daily life. An explanatory model provides recognition of the symptoms and the insight can support the client and the therapists in the choices made in the rehabilitation or treatment programme.



*Fig. 1 Overview of post-COVID syndrome symptoms (Rajan, et al., 2021)*

### 2.6.2 Autonomous dysregulation

One of the mechanisms that may play a role in post-COVID syndrome is autonomic dysregulation. The complaints that clients experience may fit with a dysregulation of the autonomic nervous system (Dani, Dirksen, Taraborelli, Torocastro, Panagopoulos, Sutton & Lim, 2021). The autonomic nervous system, which is regulated by the sympathetic and parasympathetic nervous systems, ensures that the activities of the organs are appropriate to the efforts a person makes.

#### Sympathetic

The sympathetic system is active during exertion and stress. It is this system that activates the 'fight, freeze or flight' response. The heart rate increases, blood vessels in the muscles dilate, pupils dilate, breathing frequency increases, digestion is inhibited. The attention is focused, so that ultimately only little sensory information gets through to the brain.

#### Parasympathetic

The parasympathetic system is active at rest. It facilitates digestion, improves the function of the kidneys and reduces heart rate and respiratory rate. Attention is often lowered and sensitivity to sensory stimuli is variable.

#### Dysregulation

To function properly, a balance between sympathetic and parasympathetic nervous system is necessary. When this balance is disturbed, people suffer from all sorts of complaints, such as palpitations at rest, disturbed breathing, cognitive complaints, difficulty estimating exercise capacity, sleeping problems, fatigue, and so on.

The symptoms of post-COVID syndrome can be easily recognised in it.

### 2.6.3 Possible causes

The cause of the autonomic dysregulation is not well known and may be multifactorial. Immunological processes, long-term infection, endothelial factors and thromboembolic processes, but other factors,



such as anxiety and depression, may also play a role in the development or persistence of the symptoms (Stella, Furlanis, Frezza, Valentinotti, Ajcevic & Manganotti, 2021).

Moreover, the intensive physical training prescribed to this group of clients during the first wave of the corona pandemic seems to have maintained the symptoms with a counterproductive effect on recovery.

There is evidence that an imbalance in the autonomic nervous system can be identified. Tests performed in studies of this include blood pressure measurements after postural changes, sweat production measurements, tilt tests and heart rate variability measurements (Goodman, Khoury, Blair & Grill, 2021; Kaliyaperumal, Rk, Alagesan & Ramalingam, 2021). The results in clients with post-COVID syndrome were often abnormal on one or more tests, but not on all tests. In daily practice, these tests are not easy to perform.

#### 2.6.4 Forecast

There is little literature on the course of the disease. The experience of healthcare professionals who have treated many clients with post-COVID syndrome is that the vast majority of clients recover well. Recovery can sometimes be quite fast, but it can also take many months (Davis et al., 2020).

Keeping to the advice to build up gradually proves difficult. In addition, clients indicate that they have to keep an eye on their workload, even when they are functioning reasonably again. There is often a very fragile balance that can quickly become disturbed and can lead to temporary relapses.

### 2.7 Principles of treatment

#### 2.7.1 Classification on the basis of complaints

Based on the complaints that are in the foreground, a classification can be made in practice. This classification also determines which interventions appear to be suitable or not.

#### **Reduced effort possibilities**

Some clients suffer from a serious loss of condition, but can build up their condition through physical training. Clients in this group sometimes need help to build up their condition. It is estimated that three weeks after the experience of COVID-19 about 80% of the people belong to this group. Based on the characteristics of recovery, this group might not belong to the group with post-COVID syndrome. However, there is currently no generally accepted definition and no consensus as to whether this population should be included in this group or not.

#### **Autonomous complaints**

In these clients, deep fatigue is the most prominent symptom, combined with numerous complaints that are hard to define, such as shortness of breath, coughing, chest pain, palpitations, dizziness, post-exercise fever and gastrointestinal complaints (Poenaru, Abdallah, Coorales-Medina & Cowan, 2021; Taribagil, Creer & Tahir, 2021). During exercise tests, these clients sometimes score remarkably well, only to suffer a prolonged relapse afterwards. This relapse is called post-exertional malaise (PEM). The course of the symptoms is erratic, with many bad days and sometimes a good day. After fitness training, clients seem to get worse rather than better. There is often a great lack of understanding from the environment. The incidence of these symptoms could be around 25% (Stella et al., 2021).

### Cognitive complaints

In addition to fatigue, cognitive complaints such as forgetfulness, attention and concentration problems and (sensory) overstimulation symptoms occur in this group. These are not cognitive disorders. At good times, the intellectual capacity and cognitive abilities are intact. However, the client makes mistakes, is forgetful and suffers from so-called 'brain fog'. Brain fog is often described by clients as the feeling that there are cotton wool in the head, which prevents stimuli from entering properly and also prevents adequate reactions.

It is not yet clear whether the group experiencing (physical) fatigue and autonomic complaints and the group with fatigue and cognitive complaints are two separate groups, or whether fatigue and autonomic complaints evolve into cognitive complaints.

Many clients indicate that initially they suffered particularly from fatigue, and that during their recovery a shift occurred towards cognitive complaints.

A possible explanation for this is that clients are very tired at first and therefore do not undertake many activities. As soon as they start doing more activities that require cognition (capacity and skills), they notice cognitive complaints.

#### 2.7.2 Stepped-up care

The treatment of clients with post-COVID syndrome follows the principles of stepped care as long as there is no evidence of other methods. The principle of stepped care is that the client is not treated more heavily than is strictly necessary. This means that the simplest intervention appropriate to the client's symptoms is used. This principle is reflected in the decision to start treatment in primary care. Referral to occupational therapy in primary care is indicated for clients with participation problems due to fatigue and/or cognitive complaints if there are no indications of organ damage. If, despite adequate treatment, there is little or no recovery after about 3 months, it is advisable to propose to the GP that a referral be made to a rehabilitation specialist or neuropsychologist. Multidisciplinary treatment may then be necessary in the second line.

#### 2.7.3 Similarity to other conditions

The intervention in post-COVID syndrome leans on the treatment that is common in other conditions involving autonomic dysregulation, such as chronic pain and post-commotional syndrome (PCS) (Verbunt, Swaan, Schiphorst Preuper, Schreurs, 2019). For the occupational therapy treatment of these conditions, education, a dosed build-up and coordination with other care providers are important principles. These may also apply to the client with post-COVID syndrome:

- Give recognition to the complaints.
- Provide a logical explanation model, such as the dysregulation of the autonomic nervous system described above.
- Explain that the symptoms are temporary and recovery is likely.
- Point out the self-help tips from Ergotherapie Nederland (see Appendix 3).
- Focus on a gentle build-up, aimed at avoiding an increase in complaints after exertion (PEM).
- Explain that overburdening often leads to relapse or can make symptoms worse.
- Make steps in the build-up small and allow enough time to consolidate the steps.
- Explain the biopsychosocial model and the influence of stress on delaying recovery.
- Tailor the treatment to the person and their situation. The PEO model provides good guidance in restoring personal balance (see Chapter 3).

- Teach the client to use cognitive compensation strategies (temporarily) if necessary.
- Cooperate with other healthcare providers and coordinate periodically.

## 2.8 Guidelines and research on long-term COVID

New guidelines from the Federation of Medical Specialists (FMS) on the treatment of long-term COVID-19 have been published, such as the guidelines 'Rehabilitation' and 'Long-term complaints after COVID-19'. Currently, several studies are conducted on the course and optimal treatment of long-term COVID complaints, such as the PARACOV study by the research consortium led by RadboudUmc. Clients are often asked to participate in research, to take certain tests or to fill out questionnaires. Encourage your clients to participate! In time, this will lead to determining the most appropriate treatment methods for post-COVID syndrome.

## Chapter 3 Characteristics of occupational therapy treatment

The ability to perform daily activities is related to health, well-being and quality of life and is the core domain of occupational therapy (Le Granse, van Hartingsveldt & Kinébanian, 2017; Van Hartingsveldt et al., 2010).

### 3.1 What does occupational therapy offer?

In the past year, many clients have been treated by an occupational therapist, partly due to the Paramedic Recovery Care COVID-19. Considering the problems this target group faces in daily functioning, occupational therapy plays an important role in the recovery of the client. This is true both in early rehabilitation after COVID-19 infection and in post-COVID syndrome. Occupational therapy focuses on participation, daily activities and the roles the person fulfils (or wants to fulfil again) in life. Since the beginning of the COVID-19 pandemic, occupational therapists have gained a lot of experience and new knowledge. The treatment domains as described in the previous handbook have indeed been addressed in occupational therapy. This also applies to the measuring instruments for functional diagnostics and evaluation and the various interventions.

### 3.2 Methodical handling: Assessment, goal setting and evaluation in daily activities in post-COVID syndrome

#### 3.2.1 PEO model and education

In chapter 3 of the 'Handreiking Ergotherapie bij Covid-19 cliënten in de herstelfase' (Guideline Occupational Therapy for Covid-19 clients in recovery), the input of occupational therapy is described based on the PEO-model. This model is suitable as a basis for the methodical process in occupational therapy treatment and (in its simplicity) also suitable in dialogue with the client and with other care professionals.

The factors of person, occupation and environment have a great influence on the functioning of the client in daily life. Because there are so many variations in these factors, there are also so many differences in recovery at

clients. For occupational therapists, this is obvious, but it is essential to include in the information provided to clients.

Providing information on post-COVID syndrome to the client and those around him can also lead to greater understanding of their own symptoms. This can also contribute to greater understanding on the part of those around them, and with regard to, for example, returning to work and daily activities.

#### 3.2.2 Assessment

In occupational therapy treatment, the sustaining factors of the symptoms are methodically identified. Observation and measuring instruments are used for the assessment in order to map the functioning and the environment of the client: the functional analysis. Based on this, the occupational therapist, together with the client, can formulate wishes, goals and expectations for the treatment.

However, this is a new and often erratic condition. The complaints may persist for a long time and recovery is often slow. As a result, treatment processes can be lengthy. In order to get a better grip on this and to objectify the (interim) results of the treatment, it is important to use measuring instruments at various measuring points.

The same measuring instruments are also used to evaluate the treatment and to communicate the (interim) results to clients, their relatives and other practitioners involved.

The measuring instruments that can be used in the treatment of post-COVID syndrome largely correspond to the measuring instruments in the previous guide.

### 3.2.3 Recommended measuring instruments

It is recommended that the following measuring instruments are always used:

- *Canadian Occupational Performance Measure (COPM)*  
When using the COPM, it is important to determine the performance and satisfaction scores and to repeat this periodically.
- *Patient Reported Outcome for Occupational Therapy (PRO-ergo)*  
This was specifically developed to evaluate the occupational therapy treatment aimed at the performance of daily activities, self-management and participation (Arnoldus et al, 2020). It is important to have the questionnaire completed both at the start and at the end of occupational therapy treatment.
- *A domain-specific measuring instrument*  
If it is clear in which domain the client has complaints, that domain-specific measuring instrument is added to this minimal set.

### 3.2.4 Recommended measuring points

A structured "measurement protocol" helps to compare and/or collect data. It is recommended to carry out an evaluation at the following moments:

- At the start of occupational therapy treatment
- 3 months after the start
- 6 months after the start
- 12 months after the start and/or at the end of treatment

By evaluating periodically, the results can be objectified and the treatment adjusted, if necessary. Also at a later point in time, when the treatment is completed or even a period after the completion of the treatment, it can be valuable to schedule another appointment for the evaluation of the functioning and experienced problems of the client, which also gives the client the opportunity to discuss any new questions.

## 3.3 The course of occupational therapy treatment

After the functional analysis, the occupational therapist uses client-oriented interventions based on best practice. The interventions take place as much as possible in the context of the client.

Occupational therapy is aimed at teaching the post-COVID client how to find a (new) balance in daily functioning. This balance is disturbed by the (physical and mental) symptoms of fatigue in combination with other symptoms associated with post-COVID syndrome that differ per client. The treatment is aimed at recovering from the viral infection by balancing the load and load capacity in the activities and roles that he fulfils and to prevent over- or under-loading. Once a good balance has been achieved, the activity level can be expanded.

It turns out that many clients can only build up their activity level in very small steps.

Based on expert based evidence, occupational therapy treatment in post-COVID syndrome follows a number of distinctive steps.

1. Providing information about the clinical picture and about recovery after illness. The explanatory model described in Chapter 2 is a useful concept for this.
2. Providing insight into the complaints in relation to the current level of functioning in daily activities and roles.
3. Experiencing new possibilities, such as doing things in a less stressful way, distributing them differently and/or making other choices in the activities.
4. The client gains insight into (parts of) his daily functioning and learns to recognise his own influence on this.
5. A basic level of daily activities has been achieved that is adapted to the client's load capacity and over which the client has control. Activities can now be built up.
6. Experiencing a controlled build-up of activities. This is usually done in 3 steps:
  - a. Try and experience
  - b. Consolidate successful experiences (some control over one's own situation now emerges)
  - c. Securing the success experience (sustainably) with room to build up activities (in duration/number of tasks/frequency and complexity).

A process of controlled build-up of activities can be expressed in periods of weeks. It can thus give direction to the process of accrual, but more often the periods are individual, depending on the amount of recovery time the client needs.

By using this step-by-step plan, the experience is that progress can be made and the risk of relapse is small. Should there nevertheless be a relapse, this step-by-step plan also helps to adjust the structure. As soon as the "action and reaction" pattern is recognised and acknowledged by the client, he can be deemed capable of learning to apply the principles himself in his daily life. The accompaniment of the occupational therapist can then be phased out.

### 3.4 Completion of occupational therapy treatment

As soon as the client has regained sufficient control over his activity pattern, is able to convert the possible signals of the viral infection into adequate actions and has learned to make choices in his activities and roles, it is often possible to reduce the frequency of treatment and to phase out the treatment. Ultimately, the client learns to manage and resume his daily life with all the activities and roles that go with it.

### 3.5 Collaboration with other healthcare providers involved in post-COVID syndrome clients

Clients with post-COVID syndrome often experience symptoms in multiple domains. As a result, several care providers are often involved. The overview below outlines, in alphabetical order, the possible deployment and role of the various care providers. Periodic coordination between the care providers is essential, if only to prevent overburdening by a pile-up of advice.

Company doctor: The company doctor accompanies return to work in case of long-term COVID-19.

Dietician: Many clients have difficulty maintaining a healthy diet, partly due to altered perception of smell and taste. Dieticians advise on healthy nutrition aimed at maintaining weight and muscle mass during the recovery phase.

Physiotherapy: A physiotherapist can, if the load capacity is sufficient, help to improve the condition. A psychosomatic physiotherapist often takes more account of autonomic dysregulation. Pulmonary physiotherapy can be of added value in clients with a disturbed respiratory coupling. Psychosomatic

physiotherapy or haptotherapy can also be of added value, for example in patients with reduced confidence in their bodies.

GP: Recognise and explain, identify 'flags' such as focal neurological deficit, reduced O<sub>2</sub> saturation at rest, abnormal ECG, changed voice or swallowing problems.

Speech therapy: Clients who feel oppressed or have a dysfunctional breathing connection often benefit from speech therapy, which can help them to restore their natural breathing pattern. There are indications that singing can also help in this respect. Speech therapy is also recommended for swallowing problems, both for diagnostics and for advice and treatment. Sometimes a referral to an ENT doctor will be necessary.

Psychological support: Sometimes counselling by a psychologist, social worker or POH-GGZ is desirable for psychological or emotional problems that may arise from the period of illness, or from the consequences of the long-term COVID-19 symptoms on daily life. A (neuro)psychologist identifies the cognitive, mental and personality aspects that play a role and, in this capacity, provides advice for the continuation of the treatment.

Rehabilitation specialist: If a client does not make progress despite good supervision in primary care, referral to a rehabilitation specialist can be considered. The rehabilitation specialist collaborates with the patient and the first-line treatment providers on the treatable aspects (rehabilitation diagnostics) and on the treatment plan. Sometimes, the treatment will then be continued from the rehabilitation centre, but often the treatment can be continued from the existing treatment team.

## Chapter 4 Respiratory problems in daily activities



### 4.1 Expected problems

#### 4.1.1 Introduction

Research shows that 74% of COVID-19 survivors complain of persistent dyspnoea (shortness of breath) and excessive fatigue after 3 months of leaving hospital. This while abnormal lung functions are seen in only 10% of cases (Arnold et al. , 2020).

The largest group with persistent symptoms is those who have developed a mild form of COVID-19 without visible damage. There appears to be little correlation between the severity of the complaints experienced and the symptoms found medically.

In post-COVID syndrome, we usually speak of respiratory problems rather than lung problems.

#### 4.1.2 Hyperventilation syndrome (HVS)

When post-COVID clients report breathing problems, this is usually due to hyperventilation, an unconscious dysregulation of breathing. Hyperventilation involves breathing so quickly and/or deeply that more CO<sub>2</sub> is expelled than absorbed. When these complaints occur frequently and are present for a long time, we also speak of hyperventilation syndrome (HVS). The origin of this HVS may be related to a deviation in the breathing mechanism. This can possibly be explained by hyperactivity of the autonomic and cortical activation systems or by the failure of the inhibition system (endorphins) in the recovery period of a lung infection. The hyperventilation that occurs on exertion is an important limiting factor in clients with post-COVID syndrome.

There are several somatic and psychogenic causes that can lead to hyperventilation. HVS only has a psychogenic cause (Folgering, 1986). Anxiety plays an important role in hyperventilation.

### 4.2 Occupational therapy directed at hyperventilation

#### 4.2.1 Clinimetrics

The clinimetrics for respiratory complaints as described in the previous guide is also applicable for clients with post-COVID syndrome:

- Saturation measurement in daily activities
- Observation during meaningful daily activities
- Canadian Occupational Performance Measure (COPM)
- Borg scale for shortness of breath

#### Observation of daily activities

In addition to these measuring instruments, attention should be paid to the possibility of HVS and the associated symptoms in the analysis and observation of daily activities.

These are the following signals:

- Dyspnoea (shortness of breath)
- Chest pain and/or pressure
- Tingling in the hands
- Fatigue
- Dizziness and syncope (fainting) on exertion
- Fear

(Motiejunaite et al, 2021)



### **Saturation measurement in daily activities**

Rapid decreases in saturation when performing activities seem to occur less often in clients with post-COVID syndrome. However, saturation is rarely measured in occupational therapy treatment, so it is not possible to establish with certainty whether this is the case and to what extent. Because drops in saturation can occur, it is advisable to measure saturation at the beginning of the treatment process. Complaints such as tightness of the chest are not always perceived by the client or observed by the therapist. If no rapid drops are measured (any more) during an activity, no additional interventions are necessary. If there is a rapid drop in saturation during activities, the interventions described in chapter 4 of the first guide are applicable.

### **4.2.2 Occupational therapy intervention**

#### **Points of attention**

The occupational therapy interventions for lung problems, as described in the previous handbook, can also be used for clients with respiratory problems.

The core of the treatment is the awareness of body signals in everyday activities. Many clients are not aware that their breathing problems can be traced back to HVS.

Many clients tend to increase their activity level too quickly. It is important to ensure an adequate and gentle build-up in the activities. This allows the client to maintain and perpetuate the feeling of control over their breathing and reduces the risk of a relapse in activity levels.

#### **Education**

Education about hyperventilation is necessary, how the signs can be recognised and what the influencing factors might be. The fear factor often plays an important role in HVS.

#### *Adequate breathing technique when carrying out daily activities*

The application of breathing techniques in daily activities is important in hyperventilation. There are various breathing techniques with which the client can regain control over breathing and which can reduce the symptoms. In HVS, the breathing techniques described in the first guide are also applicable:

- Pacing, to learn to perform activities at a steady pace and take breaks in time
- Pursed Lip Breathing, to regain control of breathing in the event of dysfunctional breathing
- Mindfulness techniques
- Breathing support postures and ergonomic principles in everyday activities. This allows the auxiliary respiratory muscles to be used optimally for breathing during activity.

It is important to practise the techniques with the client first and to discuss with the client when and how the techniques can be applied at home.

### **4.3 Cooperation with other disciplines:**

Cooperation with the physiotherapist and speech therapist is recommended in the treatment of respiratory problems. Jointly coordinating the education, exercises and structure can contribute to the client's confidence and offer tailor-made care. Timely coordination can reduce the risk of relapse.

If fear persists or the client experiences little confidence in his/her body, this will impede progress in the occupational therapy treatment. It is then advisable to involve the referring party and work together with, for example, a psychologist.

## Chapter 5 Muscle weakness and polyneuropathy



Post-COVID syndrome symptoms, especially fatigue, lead to reduced activity. This can lead to muscle weakness. The muscle weakness in turn causes additional fatigue when performing daily activities that require physical effort. This then often leads again to reduced activity. A circle is created that can be broken by addressing the appropriate activity level for the client in occupational therapy treatment. Cooperation in the treatment process between the physiotherapist and the occupational therapist is of crucial importance here.

### 5.1 Expected problems

#### 5.1.1 Muscle weakness

Post-COVID syndrome clients often suffer from severe fatigue and physical overload. In order to recover, (part of) the physically strenuous activities will have to be reduced or temporarily suspended. Muscle weakness and loss of condition are secondary to fatigue. Enquiries made to physiotherapy reveal that, unlike after ICU admission, there is no evidence of primary muscle weakness or loss of condition. A low activity level, however, causes loss of muscle mass. This subsequently also leads to fatigue and, moreover, can entail risks for the performance of daily activities. Think of the risk of falling and dropping (heavy) objects.

Severe fatigue can make it difficult for clients to perform many activities.

#### 5.1.2 Polyneuropathy

Polyneuropathy can occur as a result of prolonged compression. This phenomenon can occur when clients have been immobilised for a long time during hospitalisation, as described in chapter 5 of the first guide. However, there are also various practical examples of clients with peripheral polyneuropathy symptoms in their hands and feet who have experienced the disease at home. Based on the explanatory model, these complaints may also be part of the autonomic dysregulation. There are indications that COVID-19 acts on the nociceptors and that, under the influence of an active immune system, this makes the brain more sensitive to this information, which may explain the increase in pain complaints (Mosley & Butler 2017; Siers et al, 2020). In any case, it is important to rule out co-morbidity in these complaints. The emotional disturbances and pain symptoms can have a major impact on the performance of daily activities and on the client's recovery options.

### 5.2 Occupational therapy for muscle weakness

#### 5.2.1 Clinimetrics

Using the functional diagnostics described in the first guide, the impact of the muscle weakness on the level of functioning of the client with post-COVID syndrome can be mapped out. This can provide insight into:

- The actual activity level of the client;
- Safety in carrying out activities;
- The possibilities of building up activities;
- The possibilities of using compensation strategies;
- The possibilities of re-learning activities.

The daily activities that are important to the client are the main focus of this, and could include the observation of daily activities in an ADL situation, a kitchen task or another meaningful activity.

### 5.2.2 Interventions

#### **Mobilise through daily meaningful activities**

Important for recovery is the advice to resume (partial) activities, however small, as soon as possible. A dosed and structured performance of daily activities helps to discover the physical limits. As soon as the client gets a grip on this (see chapter 3) and the flare-up of symptoms diminishes or stays away (see chapter 2), the client can be challenged to push his limits.

#### **Gaining confidence through experience**

In many practical examples, fear of taking on more physical work plays a major role. Many clients have experienced a serious relapse due to a too rapid build-up of activities or an overly intensive physical training programme, which makes them conceivably afraid of relapsing again as soon as they increase their activity level. Under the guidance of the occupational therapist, it is possible to build up in gradual steps. The experience ensures that a new body awareness can develop so that the client can have more confidence in his body.

The advice is that the occupational therapist, when increasing the load capacity by building up the physical load, should strive together with the client to achieve the healthy exercise behaviour indicated in the Dutch exercise guideline ( Kenniscentrum sport & bewegen, nd).

## 5.3 Occupational therapy in polyneuropathy

### 5.3.1 Clinimetrics

Using the functional diagnostics described in the first guideline, the impact of the polyneuropathy symptoms on the client's level of functioning can be mapped out. It is important to continue to monitor the symptoms and, if they get worse, to refer the patient back to the referring physician in good time.

### 5.3.2 Interventions

As with the other complaints that can possibly be explained by the autonomous dysregulation, it can be expected that also in polyneuropathy, the activity level should be adjusted in such a way that the complaints no longer occur and/or get worse. A clear boundary management and careful build-up of activities contributes to this. In addition, it is important to encourage the client to use normal movement patterns and to be alert to signs of recovery. Practical experience confirms this approach. When in doubt about the influence of polyneuropathy on hand function, a referral to an occupational therapist specialized in hand care can be considered.

## 5.4 Aids and facilities

It is to be expected that clients will recover both conditionally and in terms of muscle strength with a dosed build-up of load capacity in daily activities. In a number of situations, the capacity can be so low at the beginning that, for example, moving outside the home is not possible and clients cannot be active enough at home to build up their capacity.

In those cases, the temporary use of aids can be indicated, whereby explicit consideration is given to the extent to which the use of the aids supports the performance of meaningful activities indoors and outdoors on the one hand and contributes to increasing load capacity through activation on the other. As an occupational therapist, it is important to find a good balance, together with the client.

## 5.5 Cooperation with other disciplines

The 'KNGF point of view physiotherapy at COVID-19, recommendations for physiotherapeutic action in primary care (KNGF, 2022) mentions the cooperation with occupational therapy.

In primary care, valuable collaborations between occupational therapists and physiotherapists have already been established with this target group.

Several physiotherapists act according to the characteristics of post-COVID syndrome. They start with a physical exercise programme in close cooperation with the occupational therapist. In principle, this takes place after the occupational therapist has been able to establish together with the client what the basic level of functioning is in his daily activities and a balance has been achieved between load and load capacity. The advice is that the occupational therapist, in the build-up of the load and thus the increase of the load capacity, together with the client should aim for a healthy exercise pattern as indicated in the Dutch exercise guideline (Kenniscentrum sport & bewegen, nd).

Accurate coordination is required when building up the physical load. If a client stagnates in the build-up of fitness, physiotherapy should be called in. Once the client has regained control of his daily functioning, even though this is often not yet the level of functioning prior to the infection, he can usually continue to build up and expand his activities independently and thus continue to fulfil his roles.

## Chapter 6 Complaints of fatigue in daily activities



Fatigue is the main complaint of many post-COVID syndrome clients.

Practical experience shows that it is important to include occupational therapy in the treatment.

start with the fatigue and the consequences for daily functioning. Regaining the balance between load and load capacity in daily activities appears to have a positive effect on fatigue and on the other symptoms that occur.

### 6.1 Expected problems

Approximately 10% of people who have experienced COVID-19 infection maintain fatigue symptoms for a long time (NVAB, 2021). Of the COVID-19 symptoms, fatigue has been found to be one of the most persistent and debilitating (Rudroff et al., 2020). It is notable that it mainly affects middle-aged women (Twomey et al., 2021).

The explanatory model that dysfunction of the autonomic nervous system (dysautonomia) underlies the symptoms of people with post-COVID syndrome also provides a framework for thinking about the extreme fatigue and the erratic and unpredictable course of recovery in post-COVID syndrome. In practice, fatigue also occurs some time after exercise, in the form of a setback such as Post-Exertional Malaise (PEM). PEM poses a challenge in practice for the client, professionals and researchers (Twomey et al., 2021).

In addition to the physical explanation of the fatigue symptoms, psychological and social factors may also play a role in the presence and maintenance of the fatigue and may hinder recovery.

In occupational therapy practice, it appears that many clients become worried when recovery is slower than hoped for. They start to doubt themselves and, for example, they say they have less confidence in their own bodies. They also become uncertain about their own abilities to do the right things to aid recovery or about their own perseverance. Many clients have experienced relapses when trying to increase their activity level. This can lead to stress reactions and worrying, which can become maintenance factors for the fatigue.

### 6.2 Occupational therapy for fatigue

Fatigue in daily activities is always part of the occupational therapy treatment in primary care, according to the survey that Ergotherapie Nederland periodically conducts among its members. However, there is little literature available on valid and reliable clinimetrics and interventions when fatigue is present in post-COVID syndrome. The information below is based on practical experience and is also based on occupational therapy treatment in other target groups, where severe and similar fatigue symptoms may occur. These include Q fever, chronic fatigue (CFS/ME), consequences of cardiac disorders and fatigue due to brain injury.

#### 6.2.1 Clinimetrics

In addition to using the 'biological' explanatory model of autonomic nervous system dysregulation to explain fatigue, it is important to assess psychological and social factors in fatigue. These factors may also play a role in the presence and maintenance of fatigue and may impede recovery.

- The degree and severity of fatigue;
- The activity pattern and activity level;

- Sleep/wake pattern;
- Personal values and interests;
- Cognitions regarding post-COVID syndrome and fatigue;
- Others' reaction to post-COVID syndrome and fatigue;
- Premorbid functioning.

### Measuring instruments

It has been established that all fatigue assessment instruments listed in the guide 'Occupational therapy for COVID-19 clients in the recovery phase' are still up to date and suitable for the treatment of people with post-COVID syndrome. These are, successively:

- Mapping Coping, Habits and Expectations
- Modified Fatigue Impact Scale (MFIS)
- Individual Tension Checklist (CIS20R)
- Pain and fatigue graphs
- Borg scale for shortness of breath and fatigue
- ADL diary
- Activity scale
- Activity monitor
- Occupational Balance Questionnaire (OBQ)
- Self-Efficacy in Performing Energy Conservation Strategies Assessment (SEPECSA).

When selecting measuring instruments, it is preferable to choose an evaluative measuring instrument as well. The Dutch Multifactor Fatigue Scale may be suitable for the target group (Visser et al, 2015).

### Observation of action

An observation of the client's actions, preferably several observations of activities in the client's own environment, is a valuable addition to, for example, filling in registration lists to map out the activity pattern. It provides insight into the tempo of action, the degree of strength and dosage, the cognitive aspects, but also provides insight into the physical and/or social environment in which the client acts and the demands that this places on the client. The evaluation of these observations provides the client with insight into his own abilities and limitations.

### 6.2.2 Interventions

In addition to the interventions described in the guideline 'Occupational therapy for COVID-19 clients in the recovery phase', a number of new insights and treatment strategies for the treatment of clients with post-COVID syndrome can be identified.

## Education

With respect to the persistent fatigue and the erratic course of the symptoms, it is valuable to name the explanatory model of the dysfunction of the autonomic nervous system. Education is a first step in regaining control over one's own energy level and one's own load and load capacity in activities.

Practical experience shows that the following aspects are often points of discussion:

- The influence of stress and insecurity (e.g. at work).
- The possible changed subjective experience of the activity pattern; activities that were experienced as relaxing before COVID-19 may now be (too) strenuous, for example.
- The relapse is part of the erratic course of recovery that can occur unexpectedly and is often a sign of a (one-time) overload with Post-Exertional Malaise (PEM) as a result, rather than a sign of 'not trying hard enough'.
- Educate important loved ones and, for example, employers or colleagues. This can increase understanding and thus reduce external pressure (Chu et al., 2020).

## Establishing a basic level of activities

It is important, on the basis of the explanatory model, to look for a level of activity at which the dysfunction of the autonomic nervous system does not yet occur, or at which the limit of the maximum load capacity is not exceeded. Balance in daily activities can then be achieved. From there the activity level can be gradually built up again (NVAB, 2021).

Usually, the registration lists for the activity pattern are used for this, as mentioned in the previous guide. It is important to ask about the subjective appreciation of activities in terms of energy. Attention should be paid to possible changes in energy balance that have occurred after COVID-19 infection. For example, an activity that previously provided energy may now be energy consuming after experiencing COVID-19.

## Building up activity levels

The next step is to build up activity in a dosed manner, such that the autonomic dysregulation does not manifest itself. Because activities can be more taxing now than before COVID-19 infection, a different activity pattern will be feasible and desirable, at least temporarily. It is important to pay explicit attention to the use of relaxing activities that do not require significant energy now and that are necessary to find and maintain a balance in the activity pattern.

A measure of adequate balance is that a client must still have energy at the end of the day (NVAB, 2021). The activity scale can be used for this, whereby the goal is not to exceed 3 for activities. The activity scale is also a suitable instrument for monitoring and subsequently expanding a feasible activity pattern. In many cases, it seems important that the client is alert to the fact that he does not exceed the predetermined activity level during the day. Moreover, avoiding an abrupt increase in activities also seems to be essential for this target group.

It is important to maintain the period of balance for some time before taking the next step in construction (see also chapter 3).

When building up daily activities, attention should be paid to the presence of sufficient activities of value to the client in the daily and weekly planning.

### Relaxation through mini-activities

Practical experience has shown that the Mini-Activities Approach is suitable (chapter 6 of the first guide). A characteristic of a mini-activity is that it provides more energy than is needed for its implementation. Such an activity is easy to carry out for the clients, without using specific means. The activities can be valuable for the client, even if they only last a short time. Mini activities contribute to increasing self-direction and resilience (Aegler, Heigl & Zischeck, 2019).

### Strategies for energy management

In addition to the energy management strategies in Chapter 6 of the first guide, such as the PRET method and the 3 Ps principle, the following rules and strategies are suitable for teaching post-COVID clients to use in their daily activities. These are widely used in current practice.

### 'ELVOSICO' rules

The Elvosico rules contribute to a critical analysis of daily activities and how they can save energy.

Elvosico (Dutch) stands for:

- Eliminate
- Change order
- Simplify
- Combine

By applying these rules in daily activities and in the activity pattern, the client can experience if and which change leads to energy saving (Amsterdam UMC, n.d.).

### The 'SHOULD I DO THIS NOW' rule

In order to make choices and set priorities in daily activities, the client can be taught to ask himself five times: 'SHOULD I DO THIS NOW?'

The emphasis is placed on a different word each time:

**SHOULD** I do this now? – Should I do this now? – Should I **DO THIS** now? – Should I do this **NOW**?  
Should I **DO** this now?

### 'Don't run but plan'

This treatment programme is intended for people with cognitive problems as a result of brain damage. The following strategies from the programme appear to be suitable for use in the treatment of clients with post-COVID syndrome:

1. Spread out; distribute activities throughout the day, alternate between relaxation and activity.
2. Variety/ alternation: alternate mental (THINK) and physical (DO) activities
3. Pause; regularly schedule short breaks, even when you are not tired.
4. Planning: day-to-week planning
5. Relaxed

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



### **'Powernap'**

In the case of disturbed day and night rhythms, the advice not to sleep during the day remains valid. However, some nuance is desirable. A short 'powernap' during the day of maximum 20 minutes can contribute to recovery or energy building. A short sleep includes only light sleep, phase one and phase two.

These sleep phases create a:

- Reduction of sleepiness;
- Improvement of concentration;
- Improving mood;
- Improvement of alertness;
- Improving motor skills.

The advice is not to let the client take a short 'power nap' after 2pm so as not to disturb the quality of sleep during the night (Fleming & Vollebregt, 2016).

### **Traffic light method**

Chapter 6 of the previous guide already explained the use of the traffic light method, which teaches the client to observe and recognise body signals when carrying out activities. The method is now widely used in the treatment of clients with post-COVID syndrome, so a brief addition to the information is appropriate.

Working together with the client to concretise where, when and how the build-up of red-orange (warning) and green signals occurs, helps the client to (re)learn to experience his body signals and to learn to set limits in his daily activities. It is important to continue this until the client gets some routine. It has been shown to be important to also take stock of the signals of a 'green phase'. Clients are more likely to associate these signs only with the time before the COVID-19 infection.

Information from relatives about signals is a welcome addition, it is important to involve them in this method.

### **Acceptance and Commitment Therapy (ACT)**

ACT is, as stated in chapter 6 of the previous handbook, a form of treatment that does not aim to reduce complaints but to adopt an accepting attitude towards complaints, thoughts and feelings.

Because the recovery process of post-COVID syndrome is still unclear, ACT can be a valuable approach to treatment. It also helps to reduce stigmatising thoughts about oneself (Masuda et al., 2007).

Continuing to fight and resist can aggravate the client's symptoms and can also drain the (already limited) energy for daily activities.

### **Graded activity**

Only if clients have become (too) anxious to increase their activity level even though this is possible due to a relapse, can Graded Activity be used; however, this method is not generally suitable in post-COVID syndrome.

If there are any maintaining factors that prevent progress in the occupational therapy treatment, it is recommended, in consultation with the referrer, that another healthcare professional be involved.

## Chapter 7 Cognitive complaints in daily activities



In addition to fatigue, many post-COVID syndrome clients experience cognitive symptoms such as forgetfulness, attention and concentration problems, and sensory overexcitability.

### 7.1 Cognitive symptoms in post-COVID syndrome

Research shows that the risk of brain damage after COVID-19 is small. The risk is 6% after ICU admission, 2% after hospital admission and 0% after COVID-19 treated at home (Puccioni-Sohler, Rodrigues Poton, Franklin, da Silva, Brindeiro & Tanuri, 2020). Still, clients experience cognitive complaints after COVID-19. The complaints include concentration problems, memory problems and hypersensitivity to light and sound (NVAB, 2021).

A frequently mentioned phenomenon is the so-called 'brain fog'. Although it is not a medical term, brain fog describes the feeling that there is not full mental clarity and that it takes more effort to remember something or to concentrate. The complaints are similar to those of patients who are undergoing or have undergone chemotherapy for cancer (chemofog or chemobrain). This also applies to clients with myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS) or mast cell activation syndrome (MCAS). The cause of brain fog in these conditions is still unknown (Theoharides et al., 2021).

There is as yet no scientific explanation for the cognitive symptoms after experiencing COVID-19. It is possible that the autonomic dysregulation, as described in Chapter 2, plays a role in maintaining the complaints. Occupational therapists see in practice that as soon as the (mental) fatigue diminishes, the cognitive symptoms also diminish. The fatigue causes the executive functioning in activities to be (temporarily) less good.

Because in most situations there is no cognitive impairment or brain damage, the complaints can usually be expected to be temporary.

### 7.2 Occupational therapy directed at the cognitive symptoms

#### 7.2.1 Clinimetrics

In occupational therapy treatment, the extent to which cognitive symptoms affect meaningful daily activities is assessed.

### Cognitive hierarchy

A model that provides an overview and insight into cognitive complaints is: "The cognitive hierarchy", by Reif & Allen.

The pyramid shows what the cognitive functions need and how they affect each other. Attention is needed to process information. Memory is needed to remember and plan. The higher cognitive functions, called executive functions, are necessary to be able to direct and control activities in addition to, for example, planning. The more complaints someone experiences, the 'higher up the pyramid' and thus the more complicated the complaints manifest themselves in daily activities. (Reif & Allen, 1992; Toglia & Kirk, 2018)



The mental capacity of a person is the basis for cognitive functioning and the use of cognitive skills. A lower mental capacity, such as having little energy, makes it more difficult to access cognitive functions.

To identify and evaluate the presence or absence of cognitive symptoms in post-COVID syndrome and their severity on daily functioning, observations of daily activities and a number of screening tools can be used in the occupational therapy assessment.

### Observation of daily functioning

It is essential to observe the actions in addition to using a measuring instrument. This can be done by means of an open observation, a (semi) structured observation by means of the Perceive, Recall, Plan and Perform System of Task Analysis (PRPP) Assessment or by means of the Assessment of Process and Motor Skills (AMPS).

The choice depends on the capabilities of the client, the context and the occupational therapist's own capabilities or preference.

### Measuring instruments and questionnaires

Because the cognitive symptoms experienced by clients with post-COVID syndrome may be caused by (mental) fatigue, it is important to also administer fatigue measurement instruments and questionnaires (see Chapter 6). The Modified Fatigue Impact Scale assesses both fatigue and cognitive symptoms.

The following measuring instruments, which are also included in the first guideline, are suitable for administering to the cognitive symptoms of clients with post-COVID syndrome (and their relatives):

- The Cognitive Complaints-Participation measure (CoCo-P),
- The 'Checklist for cognitive and emotional consequence of Stroke' (CLCE-24).

It is important to explain that there is no brain injury (which is what the measurement instruments were originally designed for) but that the instrument is used to assess cognitive symptoms in post-COVID syndrome.

### Goals of measuring in cognitive complaints

The observation of daily activities and the answering of the questionnaires contribute to giving the client insight into the complaints. The results can be used to establish a good relationship with fatigue. Periodic measuring and recording of information is important for evaluating the treatment. In this way, the possible reduction in experienced cognitive complaints can be recorded and it can contribute to insight into the effect of the occupational therapy treatment on the client's cognitive complaints.

#### 7.2.2 Occupational therapy intervention

Based on the information obtained from observations and measurement instruments, the goals to be worked on and the way in which they will be achieved are determined together with the client (and his/her environment). It is important that the approach and the learning strategy to be applied match the individual possibilities of the client as closely as possible.

#### Psycho-education

Psycho-education, i.e. explaining the possible cause(s) of the cognitive symptoms in post-COVID syndrome, is important for cognitive symptoms. In addition, information about the expectation that the symptoms are temporary in nature and an explanation of the possibilities for influencing this can strengthen the client's control during the treatment process. It is important to explain the overstimulation symptoms and to recognise the signals and situations in which the overstimulation symptoms may occur.

#### Mental energy management

In the previous section on fatigue, it was described that it is important to look for a basic activity level that does not increase the complaints and thus does not exceed the limit of the maximum load capacity. This can create a balance in daily activities. From there, the activity level can be gradually built up again (NVAB, 2021).

Establishing a basic activity level, experience shows, is also the starting point for recovery of cognitive symptoms in post-COVID syndrome.

The interventions are aimed at energy management: increasing mental capacity in daily activities. This involves the learning of internal and/or external strategies or compensation strategies that are individually suited to the client and are primarily intended to save mental energy in daily activities.

Some examples that are especially aimed at the attention:

- Make a plan for an activity in advance
- Applying the PRET strategy
- Consciously focus attention on a task, repeat, take time
- Divide activity into sub-steps
- Self-assessment

Some examples that focus on memory:

- Writing things down, using lists
- Making daily or weekly plans

### **Treatment of sensory sensitivity or overstimulation**

Learning to recognise the situations in which overstimulation occurs is important. The influence of the overstimulation symptoms will be different for each client. The general points of attention and specific occupational therapy interventions as described in Chapter 7 of the first guide can be applied.

#### **Structure**

Mental energy can be built up by increasing the duration, frequency and/or complexity of activities. Use is made of mental activities that fit into the client's daily life. Examples are reading, using the computer, watching TV or preparing a meal. The starting point of the build-up is the level that the client can handle reasonably easily. The build-up takes place in achievable, small steps. This increases the client's confidence in his/her own abilities.

### **7.3 Cooperation with other disciplines**

It is important to consciously use the individual possibilities that a client has and to actively involve those around him. This applies to people in the private sphere as well as at work.

It is also important to coordinate the individual approach and structure with other stakeholders. disciplines.

An adjustment of the approach is necessary when psychosocial stress arises or is present and possibly co-morbidity such as depression, anxiety or Post Traumatic Stress Disorder (PTSD). In such situations, it is important to work together with a psychologist and/or to consult with the referring physician.

## Chapter 8 Psychological complaints and sleeping problems with consequences for the performance of daily activities



The symptoms of post-COVID syndrome often have a strong impact on daily life and can be a trigger for the development of psychological symptoms. In addition, psychological complaints and sleep problems affect the course of the treatment and recovery. It is therefore important to address these complaints in the occupational therapy treatment.

### 8.1 Expected problems in post-COVID syndrome

In the first wave of the pandemic, the focus was on the acute symptoms and hospitalisations. Attention then was only partially focused on the people who experienced COVID-19 at home. It only became clear later that this group could also experience long-term symptoms. Many people were concerned about the erratic course of the disease. Unfamiliarity with the duration of the (often long-lasting) complaints created uncertainty about the future and could therefore facilitate psychological complaints.

#### 8.1.1 Wide variation in outcomes

Quantitative data on the incidence of psychological symptoms in post-COVID syndrome vary widely in the studies available to date. This is partly due to differences in the target group studied (infected at home or in hospital), the time of the study (immediately after infection or after a longer period, in the first wave or a later wave), and there is variation by country and/or the socio-cultural circumstances of the pandemic.

For example, depressive complaints occur in 10% to 68% of the populations studied and anxiety complaints in 5% to 55% of cases. Sleep problems, which increase the risk of depression, occur in 26%-52% of cases.

The severity of acute symptoms is not predictive of the severity of cognitive or psychiatric problems (Vanderlind et al., 2021 ).

#### 8.1.2 Risk factors

There appear to be a number of risk factors for the development of psychological symptoms in post-COVID syndrome, namely:

- Women > men
- Psychiatric history
- Reduced sense of smell
- Experienced stigma related to COVID-19 / lack of understanding
- Infection of a family member
- Social isolation, quarantine, small social network
- Reduced quality of life

It is also known that the degree and intensity of psychological problems can vary from person to person.

People with a small social network appear to be susceptible to feelings of hopelessness and psychological complaints (Berends, Claus, De Waele, Crunelle, Matthys & Vanderbruggen, 2021).

### 8.1.3 Depression and anxiety

Anxiety and depression are more common in people who have experienced COVID-19 at home. Many experience the erratic recovery as elusive, which can lead to panic, crying fits, a sense of failure, anger or powerlessness. Overburdening, for example by resuming (too many) activities at home and at work too soon, can play a role in the development of psychological complaints. Financial insecurity as well as a lack of understanding from the environment (at home or at work) can also contribute to worrying, gloomy thoughts or anxiety symptoms.

Meanwhile, more attention has been paid to the complaints associated with post-COVID syndrome, and better information is available. It is conceivable that this will reduce or eliminate a number of triggers that can cause or aggravate psychological symptoms.

Fortunately, many COVID-19 survivors also show tremendous resilience, with those with weak social networks requiring attention (Berends et al., 2021).

## 8.2 Occupational therapy directed at psychological complaints and sleeping problems

### 8.2.1 Clinimetrics

For the occupational therapy treatment of psychological symptoms in post-COVID syndrome, a number of measuring instruments and interventions can be used that are also used for disorders with psychological and somatic components, such as for chronic pain or somatically unexplained physical symptoms (MUPS). These correspond to the clinimetrics for psychological complaints as described in the first guide (Chapter 8).

- Inventory of psychological complaints
- Hospital Anxiety and Depression Scale (HADS)
- Primary Care Post Traumatic Stress Disorder Screen for DSM 5 (PC-PTSD-5)
- The Occupational Performance Questionnaire (QOP)
- Canadian Occupational Performance Measure (COPM)

With regard to sleep problems, reference is also made to the clinimetrics for sleep problems in chapter 8 of the first guide:

- Activity monitor
- Questionnaires and sleep diary

### 8.2.2 Occupational therapy intervention

#### **Advice and self-management**

In addition to the interventions from the first set of guidelines, generic advice and (self-management) strategies are available that can support clients in dealing adequately with stress and stress reduction. These can be supportive in the treatment to improve functioning in daily activities. Some examples are:

- Relaxation, such as mindfulness, yoga and relaxation exercises
- Stimulating the vagus nerve by, for example, humming or singing
- Going into nature
- Ensure a healthy lifestyle (healthy diet, moderate exercise (e.g. walking), healthy sleep)
- Strengthening resilience (through laughter, social engagement)
- Tackling limiting beliefs
- Develop a new narrative and make new choices
- Seeking emotional or practical support for safety and/or social connection

(Peters et al. 2021) .

There are several websites available with generic advice and self-management strategies. Some of them are included in this guide as additional information.

### 8.3 Cooperation with other disciplines

In case of psychological complaints or sleeping problems, it is advisable to cooperate with, for example, POH-GGZ (in the Netherlands), primary care psychologists or sleep coaches.

If the symptoms hamper the progress of the occupational therapy treatment, it may be advisable to first have a referral made to a colleague or other health professional with specific expertise in the treatment of psychological symptoms and/or sleeping problems. In consultation with the client, the occupational therapy treatment can be stopped temporarily and resumed as soon as there is an opportunity to work on the goals within the occupational therapy treatment.



## Chapter 9 Work resumption

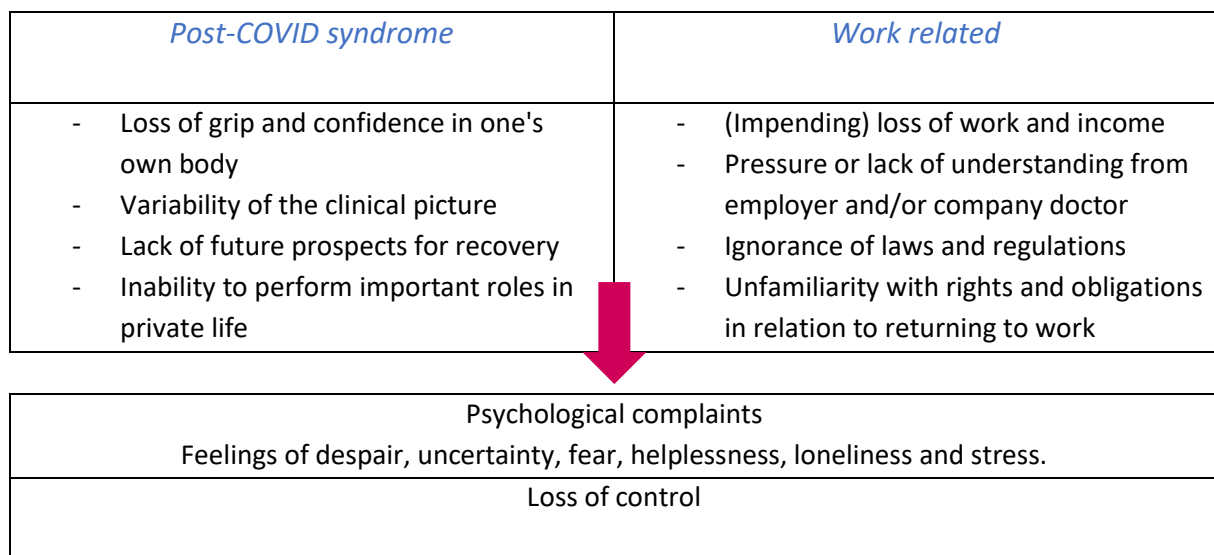


### 9.1 Work problems and post-COVID syndrome

It is now clear that the many and varied symptoms, the slow and erratic recovery, lack of familiarity with the clinical picture, treatment and prognosis can lead to major problems in getting back to work (Centrum Werk en Gezondheid 2021). It is also recognised in practice that clients who have already resumed work to a large extent may develop symptoms again after a few months, thus reducing their functional capacity and reporting to work. On the other hand, there is a group in which recovery starts so slowly that almost any form of reintegration leads to overburdening and a decline in functioning.

#### Influencing factors

The combination of disease-specific factors of post-COVID syndrome with reintegration and work-related factors can create a very stressful situation and associated psychological symptoms. The combination of factors can impede recovery and thus also reintegration and maintain absenteeism as shown here schematically.



#### Understanding own possibilities

Some of the clients who want to go back to work seem to overestimate their own capabilities. This applies to both their physical and mental capabilities to resume their work tasks. They are often people who are used to coping with a lot and have a busy life, both at work and privately. They often have difficulty recognising body signals and assessing their new situation and possibilities.

#### End of first year of illness

For the mandatory process steps in the first year of illness, included in the Wet Verbetering Poortwachter (WVP), please refer to the first guideline.

In post-COVID syndrome, it is common for the first year of illness to have already passed before a client can start reintegration.

## Track 2

After the first year of illness, the WVP requires the implementation of a possible 'track 2 trajectory'. This 'track 2 trajectory' implies that a search must be made for other suitable work than the original, own function, and moreover with another employer. This can be very confrontational for the client who wants to reintegrate into his own job but has not shown sufficient ability to do so. However, entering into this path cannot always be avoided.

It is sometimes possible to focus on return to work in the second year as well. This depends on the possibilities in the work situation, the willingness of the employer and on personal factors.

It is recommended that clients contact C-support to explore the possibilities in their personal situation.

## Return to work

If a track 2 project is started, usually a reintegration coach will be involved by the employer. This coach fulfils a guiding role in the search for a suitable workplace. However, this possibility does not apply when returning to own work.

Independent entrepreneurs are responsible for their own reintegration and are often looking for guidance in returning to work. Occupational therapy can play an important role in these situations.

## 9.2 Occupational therapy aimed at returning to work

It is desirable that clients take responsibility and initiative in their own reintegration process. Occupational therapy is aimed at helping the client to assume this role.

### 9.2.1 Clinimetrics

The measuring instruments included in the first guide are all suitable for use with clients with post-COVID syndrome.

Suitable to be taken if return to work is one of the treatment goals:

- Utrecht Scale for the Evaluation of Rehabilitation-Participation (USER-P)
- Questionnaire Work Limitations
- PRPP@Work

It is also important to get a good estimate of the personal characteristics through observation: does someone tend to underestimate or overestimate his capabilities. The intervention and instruction (stimulation or inhibition) will be adapted to this.

### 9.2.2 Occupational therapy intervention

#### Combined approach

Occupational therapy for clients with post-COVID syndrome is aimed at restoring control and developing self-management to enable an appropriate and sustainable return to work. An important feature of occupational therapy treatment is that interventions are aimed at both work and daily activities in the home. It is precisely this combined approach towards a work-life balance that contributes to the success of reintegration.

#### Work as a tool

In the first instance, resumption of work is a means of building up the client's overall capacity. Any form of work should therefore serve the recovery and not the other way around.

General points of interest are:

- Pay attention to a good work-life balance
- Make sure that there is enough time and energy left to work on physical and mental recovery
- Ensure that the client is given sufficient time to recover in his work situation
- Offer a realistic picture of the reintegration period. It may take several months or longer before the client can perform (his own) work again.

### **Made-to-measure**

Because of the variation and the often long-lasting nature of the symptoms, as outlined above, combined with the individual's characteristics, customised treatment is important.

The therapist's guidance and role should be tailored to the client's problems and needs (Centrum Werk en Gezondheid, 2021).

### **Influence on own actions**

Education about the clinical picture and the symptoms are important conditions for giving the client insight into his/her own possibilities in work. An important characteristic of occupational therapy treatment is allowing the client to experience in activities what influence he or she can exert to influence the symptoms. With this insight, workload and workload capacity can become more balanced. This is the basis for gradually building up the activity level.

### **Education about laws and regulations**

Knowing the frame of reference of laws and regulations and, just as essential, knowledge about the role the client can play in the reintegration process, can reduce fear and uncertainty and lead to a certain degree of control. As an occupational therapist, it is important to be alert to time-related actions and to prepare the client for them (e.g. filling in a functional capacity list, reporting better in time).

### **Work resumption plan**

A resumption of work plan provides support in building up work capacity and can be helpful in communicating with the employer or company doctor. It thus supports the reintegration of the client with post-COVID syndrome. The occupational therapist draws up this plan together with the client. The points of attention and components of the resumption of work plan as included in chapter 9 of the first guide are suitable for this.

### **Building up in work**

The methods, skills and therapeutic principles that occupational therapists use to help a client build up his activity level in the work situation are similar to those that can be used for daily activities in the home. Increasing the load in a measured way and at an appropriate pace can restore the load capacity both in work and in daily activities, although this is sometimes slow.

### **Points to consider when building up your work**

In the initial period, the level of functioning of the client is the starting point. Gradually, the requirements and wishes of the position and the employer are worked on during reintegration. Resumption of work is then seen as the goal of the occupational therapy treatment.

In addition to the general principles for building up the activity level from chapter 3, it is important for an adequate build-up in work to distinguish between a number of specific work-related elements that are further explained after the list:

- The work tasks
- Division into 'activity blocks'
- Recovery activities
- Working hours
- Workplace
- Workload

### **Work tasks**

- Start with tasks that are appropriate for the client's current level of workload
- Choose tasks where the PRET strategy (Pause, Find Quiet Environment, One Thing at a Time, Adjust Pace) can be applied
- The client experiences the task as meaningful and/or has affinity with it
- The intensity of the tasks is low
- Some output can be delivered in a short time
- The tasks must be performed without time pressure
- Partial tasks of own job are desired but not necessary
- Adapt tasks if necessary (e.g. reading from paper instead of screen)

The tasks are built up together with the client in terms of complexity, intensity and duration. The build-up of tasks is aimed at the client's own function.

### **Division into 'activity blocks'**

Clients with post-COVID syndrome often appear to have difficulty stopping work on time. Body signals such as fatigue are often noticed too late, which means that more energy is used than desirable. As a result, recovery time is often (too) long.

Based on expert-based evidence, the use of fixed time units and a fixed frequency for work tasks appears to be more effective in order to stay within the limit of strain and to build up adequately. It is important to combine cognitive, physical and recovery (rest) activities. Ideally, these activities should alternate in a fixed order and have the same time unit. This creates a block structure that can give structure and direction to the build-up programme.

The client's load capacity determines the duration of a block of activities; the client stops before complaints arise. A careful distribution over the day and time is necessary. By changing the proportions between physical, cognitive and recovery activities in a block of activities and reducing the duration of a recovery activity, the intensity of the work increases.

### Recovery activities

A commonly used strategy to recover from exertion after an activity when the load is reduced is to perform a physical activity after a cognitively strenuous task. This can ensure cognitive recovery after the activity. The reverse is also true: performing a cognitive task after a physical activity.

The recovery time is the starting point. This means the recovery time that someone needs to be able to carry out the minimum daily activities at home again after work. As an indication, recovery time may not exceed working hours. Always discuss with the client what is acceptable for him. It is important to keep the limit together with the client and to watch for signs of exhaustion.

### Workplace

The workplace and working conditions are important factors for work resumption and in which different considerations can be made:

- Working physically or online
- Travelling or working from home
- Influencing environmental stimuli

The workplace and working conditions can also be built up during the reintegration process.

### Workload

Work pressure increases the intensity of work. Caution is needed in the build-up because the risk of Post-Exertional Malaise (PEM) appears to be high.

The workload that is normal/appropriate for the client's job is worked towards.

## 9.3 Cooperation with other disciplines

The starting point is that communication on returning to work should as far as possible take place through the client himself. If this is not sufficient, the occupational therapist can seek contact with the employer and/or the company doctor for cooperation. The role of the company doctor is to check the resumption of work plan against the client's medical possibilities and the law. The employer is responsible for the practical implementation of the resumption of work plan.

Post-COVID syndrome is a new and complex syndrome. There is still little evidence and the parties involved are often still searching for the most appropriate approach. It has proved useful to discuss this and to look for best practices together.

If there are limitations or problems that impede return to work that are beyond the scope of occupational therapy, cooperation with other professionals is desirable.

It is desirable that the client takes responsibility and initiative in the reintegration process. The occupational therapist can advise and support the client in this role.

## 9.4 Funding

When resumption of work is a means to realise the balance between load and load capacity in the client's daily activities, funding from paramedic COVID-19 recovery care is opportune. As soon as resumption of work becomes the objective, the financial responsibility for the programme lies with the employer. It is then realistic that the employer takes care of the costs of the guidance by the occupational therapist.

If the entitlement for remedial care is no longer possible or insufficient, the advice is to approach an employer or the client himself (self-employed) for financial reimbursement of the occupational therapy. The treatment options offered by occupational therapy for post-COVID syndrome have proven in practice to be very valuable in enabling clients to resume their work.

## Chapter 10 Group treatment for clients with post-COVID syndrome



Group treatment is still little used in occupational therapy. However, there are important advantages to group treatment. Moreover, the large influx of clients requires new, innovative ideas to design occupational therapy treatment efficiently. A group programme as presented in this chapter can serve as an example for occupational therapy practice.

### 10.1 Introduction

In group treatment, the recognition and acknowledgement of the issues at stake and the possibility for clients to learn from each other are important additions to a treatment process that are not addressed in an individual course of treatment.

A multidisciplinary group programme called 'Energiek' has been in existence for several years. This programme consists of occupational therapy and physiotherapy group interventions and is aimed at building fitness and energy management and implementing this in daily life at home and at work. This programme has been proven effective in people with a muscular disease and severe fatigue (Veenhuizen et al, 2015). This programme also seems suitable for group intervention in post-COVID syndrome. This is why a number of occupational therapists have started offering a programme based on the 'Energiek' programme.

### 10.2 Post-COVID Syndrome Clients

Since the summer of 2020, a referral flow of clients with post-COVID syndrome to occupational therapy has started, especially in primary care. The influx is still growing and increasingly the demand exceeds the supply. There are waiting lists for occupational therapy. Several occupational therapy practices in the Netherlands are investigating the possibilities of starting group interventions, which is partly motivated by the large supply and/or demand from clients.

### 10.3 Group treatment aimed at daily functioning at home and at work

Based on the group programme 'Energiek' and using the knowledge and experience gained in the individual post-COVID syndrome treatment processes, a monodisciplinary group programme has been set up. The programme takes place in small groups and focuses on energy management and its implementation in daily life at home and at work.

#### 10.3.1 Structure of the programme

The programme starts with an individual intake. On the basis of the intake, it is assessed whether the client can participate in the group programme. The group programme consists of 6 sessions and is concluded with an individual evaluation. The group size is 3 to 6 persons maximum. Each session lasts 1 - 1.5 hours and depends on the size of the group and the capacity of the group members.

The first 3 sessions are weekly and focus on education and gaining insight into one's own situation. The last 3 sessions take place every other week. The implementation of what has been learned in daily activities is central.

The outline programme is included as an appendix to this guide.

### 10.3.2 Clinimetrics

The following measuring instruments have been selected in this group programme and are administered at the start and at the end of the group treatment as an evaluation:

- COPM (for the group targets)
- Utrecht Scale for the Evaluation of Rehabilitation-Participation (USER-P)
- Patient Reported Outcome for Occupational Therapy (PRO-ergo)
- Modified Fatigue Impact Scale (MFIS)  
and/or
- The Individual Stress Checklist (CIS20R)

The explanation of the measuring instruments is included in the first guideline.

### 10.3.3 Occupational therapy interventions

A selection has been made for the group programme from the interventions presented in this and the previous guideline. This selection of instruments and methods is based on occupational therapists' practical experience with individual clients with post-COVID syndrome. An example of the programme with the selected interventions is included as an appendix.

For occupational therapists with little or no experience of group treatment, it is important to consider the characteristics of group treatment, such as group dynamics, the role of the occupational therapist and the role of the participants towards each other.

### 10.3.4 Experiences

Experiences with the present occupational therapy group treatment for clients with post-COVID syndrome are positive. After completion of the group treatment some of the clients indicate that they no longer need the support of an occupational therapist. The instruction, explanation and exercises have given them enough handles to continue working independently on their recovery in daily activities. Some of the participants still need a follow-up individual occupational therapy programme, for example because of specific complaints or individual goals that were not achieved in the group sessions. The positive experiences are a recommendation for occupational therapy group intervention in post-COVID syndrome.



## Realisation of guideline 'Occupational Therapy for clients with post-COVID syndrome'.

The guideline 'Occupational Therapy for Clients with post-COVID Syndrome' has been developed with the cooperation of the members of the COVID-19 expert working group. This working group, consisting of active members of various consultation groups of Ergotherapie Nederland, has been active since the beginning of the COVID-19 pandemic. For chapter 2, rehabilitation specialist Paulien Goosens was approached, because of her specific knowledge.

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### Additional Information

#### Chapter 6

Value cards (waardekaarten) <https://info.ergotherapie.nl/cursus/cursus-waardekaarten>

ACT in Action value list - ACT course & training

#### Chapter 8

- [www.actionforhappiness.org](http://www.actionforhappiness.org) Great Dreams: Ten keys to happier living
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- <https://centrumwerkgezondheid.nl/>
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## Appendix 1 A methodical treatment process for clients with post-COVID syndrome

### The Canadian Practice Process Framework (CPPF)

The Canadian Practice Process Framework (CPPF) is a practice process model. It is a generic tool for occupational therapists to guide their work with clients. It supports the therapist to work in an evidence-based, client-centred and activity-oriented way. The process model provides insight into the eight steps of the occupational therapy treatment process (Polatajko, Craik, Davis, & Townsend, 2007). The process model can give novice occupational therapists and occupational therapists with little experience in treating the target group guidance on how to structure the treatment. For the treatment of clients with post-COVID syndrome, the COVID-19 working group of Ergotherapie Nederland has made a first attempt to fill in the eight process steps as a support for the treatment practice.

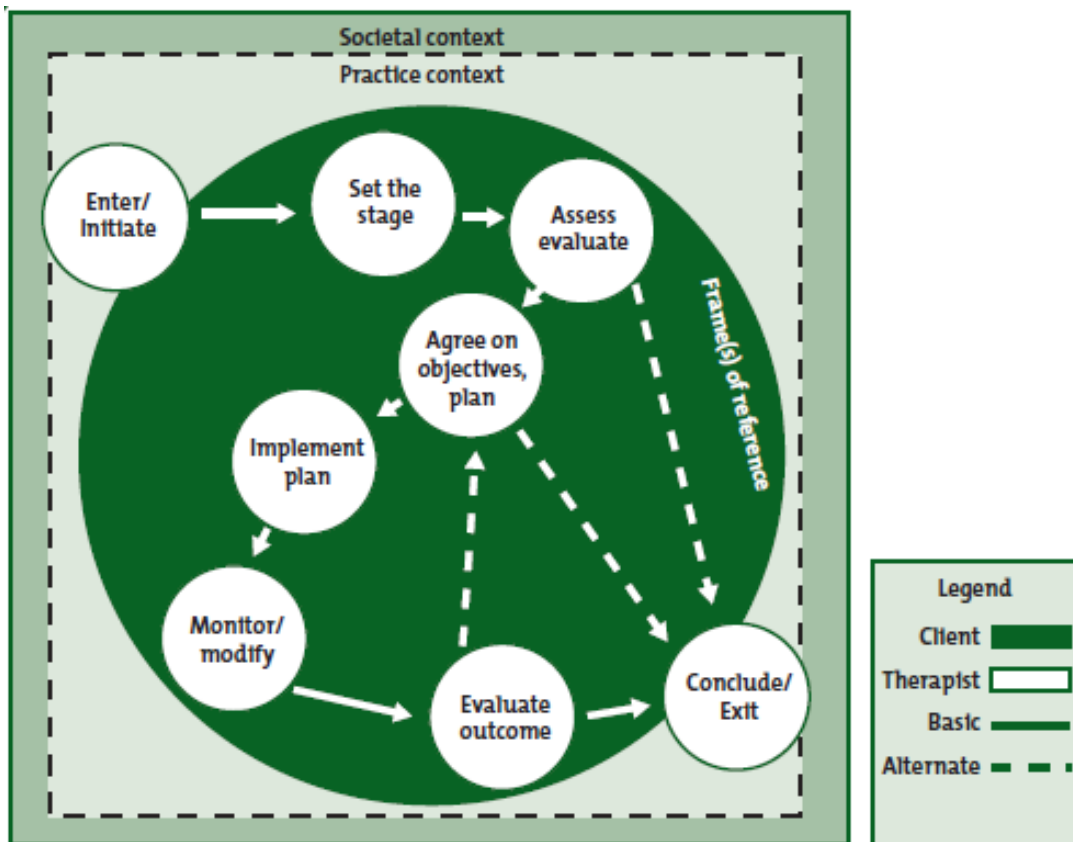


Figure 1 Canadian Practice Process Framework (Polatajko, Craik, Davis, & Townsend, 2007).

### Using the roadmap

The step-by-step plan below can be used as a guide in the occupational therapy treatment process from the moment the client has a referral for occupational therapy. It chronologically shows the steps in the occupational therapy treatment process in post-COVID syndrome. The information needed to design the treatment is included in both guidelines: 'Occupational therapy for COVID-19 clients in the (early) recovery phase' and 'Occupational therapy for clients with post-COVID syndrome'. The step-by-step plan should always be used together with both guidelines.

Steps	CPPF	Description	Global description of implementation
Step 0	Waiting list	Offer self-help tips	Self-help tips* are meant to bridge the waiting period (Ergotherapie Nederland, 2021)
Step 1	Enter/ Initiate	Assessing indication for occupational therapy. Telephone contact client. Consultation rules recovery care	Assessment based on referral data, client demand and rules for paramedical recovery care COVID-19. Provide initial information about occupational therapy treatment Send questionnaires* if possible: <ul style="list-style-type: none"> <li>- PRO-ergo questionnaire</li> <li>- Domain-specific questionnaire (e.g. CoCo-P client and neighbour)</li> </ul> If possible, have it filled in before the first treatment. If necessary, the occupational therapist will request information from other medical or paramedical professionals.
Step 2	Set the stage	Engaging with the client	<b>Intake</b> Appointment at the client's practice, department or home <ul style="list-style-type: none"> <li>- Introducing the client</li> <li>- Clarifying the question</li> <li>- The therapist indicates his options regarding the client's question.</li> <li>- If necessary, provide additional information about occupational therapy options and the maximum entitlement to occupational therapy recovery care.</li> <li>- An exchange of common expectations takes place</li> </ul> <b>Measuring instruments:</b> <ul style="list-style-type: none"> <li>- COPM</li> <li>- Pro-ergo</li> <li>- A domain-specific measuring instrument</li> </ul> Have a time list filled in for next appointment (Evenhuis & Eyssen, 2012)



Steps	CPPF	Description	Global description of implementation
Step 3	Assess/ evaluate	Identifying personal, environmental and action-oriented problems: Analysing and interpreting the treatment question on the basis of observations and assessments, with the aim of determining the content model, theoretical framework and treatment strategies.	<p><b>Observation</b>            Observing meaningful activity(ies), paying attention to all areas in which the client reports symptoms (e.g. breathing technique, physical characteristics, pace and dosage, cognitive strategies used, environmental factors)            Use</p> <ul style="list-style-type: none"> <li>- PRPP or AMPS (if possible)</li> <li>- Free observation of daily activities (also at the workplace if possible/ relevant)</li> </ul> <p><b>Research / Assessment</b>            Activity level</p> <ul style="list-style-type: none"> <li>- Time logs, activity scales, activity monitor.</li> </ul> <p>Domain-specific additional examination or assessment aimed at:</p> <ul style="list-style-type: none"> <li>- Fatigue</li> <li>- Energy balance in activities</li> <li>- Over-stimulation</li> <li>- Cognitive complaints</li> <li>- Psychological complaints</li> <li>- Work resumption</li> <li>- Burden of relatives</li> </ul> <p>Identifying strengths and resources</p> <ul style="list-style-type: none"> <li>- enquiries</li> <li>- PEO-fit (Fit-chart)</li> </ul> <p>(Le Granse, van Hartingsveldt &amp; Kinébanian, 2017)</p>

Step 4	Agree on objectives and plan	Formulation of treatment goals, treatment plan and treatment strategy	<p><b>Treatment goals</b></p> <p>Based on the results of the examinations, treatment goals are drawn up together with the client. If possible or desired, involve the patient's next of kin. As long as little is known about the course of post-COVID syndrome, treatment goals are aimed at recovery, even though this may be erratic and take a long time.</p> <p>Goals are aimed at:</p> <ul style="list-style-type: none"> <li>- Recognising and learning to deal with the long-term complaints,</li> <li>- Building up the activity level and</li> <li>- Being able to function again as desired in daily activities and roles.</li> </ul>
<b>Steps</b>	<b>CPPF</b>	<b>Description</b>	<b>Global description of implementation</b>
			<p>Describe the goals SMART</p> <p><b>Treatment plan</b></p> <p>This is drawn up together with the client based on prioritisation of goals. The treatment and the result to be achieved are influenced by the severity of the complaints, the current load capacity and the impression of the adaptive capacity of the client (such as the general health and nutritional status, age, coping style and co-morbidity). Choices are made in terms of frame of reference, treatment strategies, context, resources needed and therapeutic attitude.</p> <p><b>Treatment strategies</b></p> <p>Treatment strategies are determined taking into account the degree of impairment experienced, the client's needs, coping strategies and resilience. Due to the erratic and unpredictable course of the symptoms, education about post-COVID syndrome (explanatory model) is often necessary on a situation-specific basis.</p> <p>Possible treatment strategies are:</p> <ul style="list-style-type: none"> <li>- Self-change (recovery, development, coping, health promotion)</li> <li>- Making changes in daily functioning (compensating, adapting, simplifying)</li> <li>- Changes in the environment (adaptation of physical environment, information and instruction of relatives)</li> <li>- Change through (new) interaction between person, activity, context.</li> </ul>

			<ul style="list-style-type: none"> <li>- Changes in action patterns (in activities and roles)</li> <li>- Adjustment of expectations by the client (if necessary supported by the occupational therapist)</li> </ul> <p>(Townsend et al, 2013; Le Granse, van Hartingsveldt &amp; Kinébanian, 2017)</p> <p>Attention will also be paid to strategies aimed at self-governance and self-management in relation to</p> <ul style="list-style-type: none"> <li>- the persistence of success factors (that which has worked)</li> <li>- factors that make it easier to sustain behaviour (consolidation)</li> <li>- Points to consider when dealing with relapse (including relapse triggers),</li> <li>- learn to independently continue and build on the plan of action set in motion.</li> </ul>
<b>Steps</b>	<b>CPPF</b>	<b>Description</b>	<b>Global description of implementation</b>
Step 5	Implement the plan	Implementing the treatment plan	For the implementation of the treatment plan, Chapter 3 should be consulted first. It discusses the characteristics of the course of treatment and the possibilities of accrual. Then there are references to the domain-specific chapters of the manual where detailed intervention options are provided.
Step 6	Monitor and modify	Evaluating and adjusting treatment goals and treatment plan	The results are evaluated at intervals. Recommended measuring moments are after 3, 6 and 12 months, whereby if possible the (measuring) instruments are used as they were at the start of the treatment. If necessary, (parts of) the treatment plan are adjusted together with the client. -
Step 7	Evaluate outcome	Evaluating treatment outcomes	Joint evaluation, taking the measuring instruments and comparing with the first measurement. <ul style="list-style-type: none"> <li>- PRO-Ergo</li> <li>- COPM</li> <li>- Domain-specific measuring instrument</li> </ul>

			<p>The intervention ends when the goals have been achieved and the client has no new needs. If there are new demands for help, the treatment is continued and the goals and treatment plan are determined again. If the goals have not been achieved, the occupational therapist and the client discuss a follow-up whereby, with mutual consent, termination of the occupational therapy and referral to another professional are possible.</p>
Step 8	Conclude /exit	The joint termination of treatment	<p>Concluding conversation</p> <ul style="list-style-type: none"> <li>- Indications for treatment in case of functional decline.</li> <li>- Follow-up appointment after 3 - 6 months if possible</li> <li>- (Evenhuis &amp; Eyssen)</li> <li>- Final report to referrer, cc client.</li> <li>- Aftercare, in consultation with referrer referral if necessary</li> </ul>

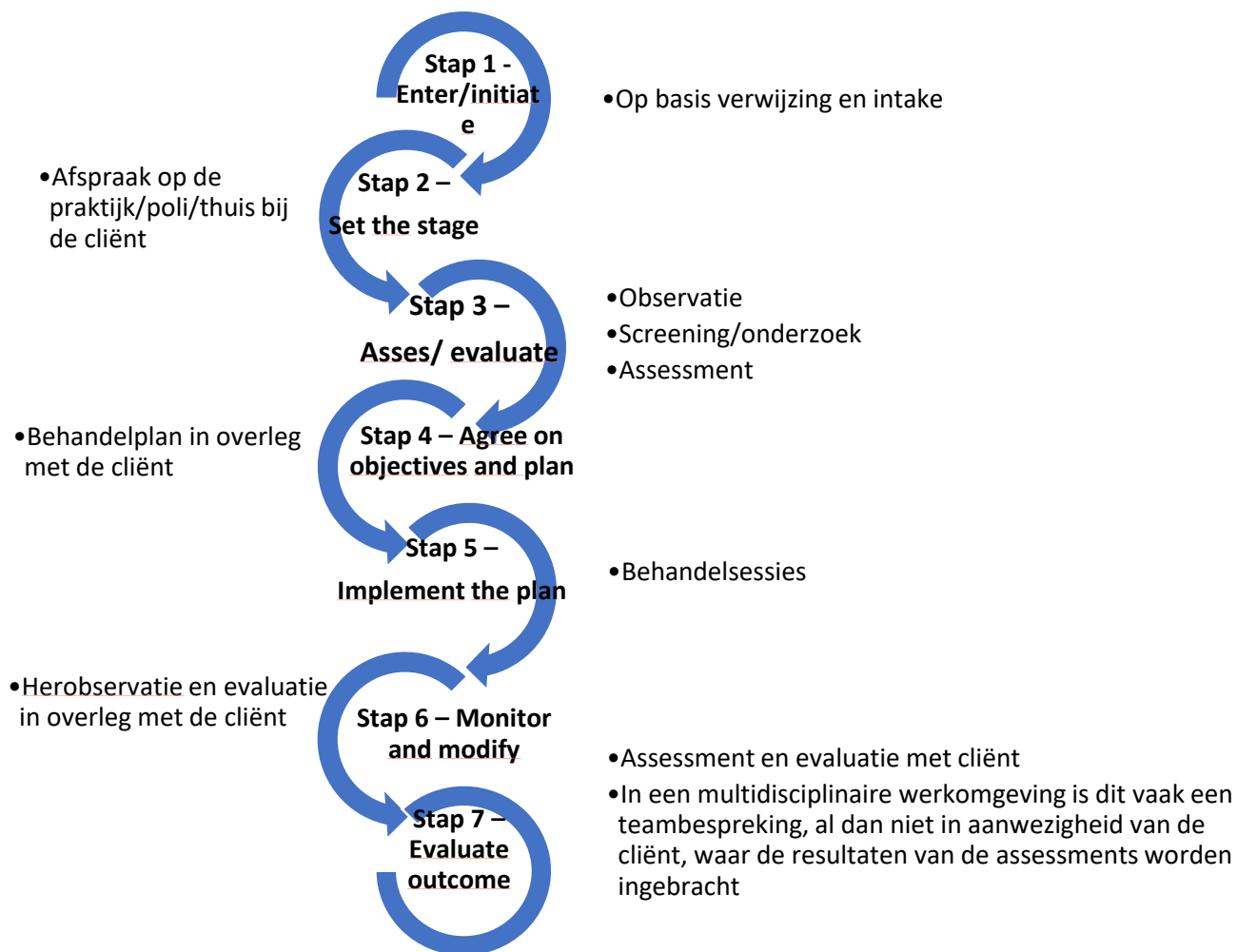


Figure 2 The steps of the Canadian Practice Process Framework (CPPF).

Translated to the Dutch occupational therapy practice by the consultation group ergotherapy in COPD

## Appendix 2 Example of occupational therapy group treatment for clients with post-COVID syndrome

An individual intake is carried out, in which the USER-P and PRO-ergo are taken beforehand. and the COPM is taken at the end of the intake.

Maximum group size 3-4 persons

Ses-sion	Purpose	Topics	Dura-tion
1	Introduction and theory to energy management	Exchange of complaints and experiences	1 hour
		Explanatory model of post-COVID syndrome	
		Energy management theory (e.g. using NRMP)	
		Metaphor battery: fill in for own situation	
		Homework assignment: fill in the time sheets	
2	Gaining insight into load and load capacity	Timetable scoring	1 hour
		Providing insight into activity level (mental, physical, rest, relaxation)	
		Theory of load-bearing capacity (supercompensation)	
		Energy management	
		Homework assignment: weekly planning	
3	Finding balance in daily life	Evaluation of weekly planning	1 hour
		ELVOSICO, PRET method	
		Explanatory model of post-COVID syndrome	
		Relaxation techniques	
4	Building up activities	Evaluation of weekly planning	1 hour
		Traffic light model (border recognition)	
		Build up in activities (extend-longer-complexer-environment)	
		Theory Cognitive Hierarchy	
		Stimulus processing	

5	Work resumption	Legislation and regulations (Eligibility for Permanent Invalidity Benefit (Restrictions) Act)	1 hour
		Draw up a work-life balance sheet	
6	Evaluation	Conclusion and follow-up	1 hour
		Theory on sleeping and pacing	
		Relapse prevention	
		Evaluation of goals and results	
		Tips and tops for each other	

In the last session, the measuring instruments are again taken and, if necessary, (individual) tests are carried out.

Follow-up appointments are planned.

## Appendix 3 Self-help tips from Ergotherapie Nederland (no translation available yet)



### Ergotherapie zelfhulptips bij het post-COVID-syndroom



U bent verwezen naar de ergotherapeut vanwege aanhoudende klachten na het doormaken van COVID-19, we noemen dat ook wel het post-COVID-syndroom.

Klachten die het meest voorkomen zijn ernstige vermoeidheid en energietekort, concentratie en geheugenproblemen, overprikkeling voor geluiden en beelden en slaapproblemen.

Ook hartkloppingen en benauwdheid komen voor.\*

U staat op de wachtlijst voor behandeling. Wij bieden u enkele tips waarmee wij hopen u ondersteuning te kunnen bieden in de periode voordat uw behandeling van start gaat.

Bespreek deze ook tips ook met de mensen in uw omgeving.



#### Regelmaat

1. Zorg voor een vaste dagroutine, zoals vaste tijden voor opstaan, eten en naar bed gaan. Dat kost minder energie.



#### Activiteiten

2. Wissel lichamelijke activiteiten af (zoals wandelen, de was ophangen) met mentale activiteiten (bijvoorbeeld krant lezen, een gesprek voeren).
3. Zorg voor een rustige omgeving en doe één ding tegelijkertijd. Dus bijvoorbeeld niet strijken én tv kijken.
4. Voer activiteiten in een rustiger tempo uit, dan u gewend bent.
5. Doe op een dag de activiteiten die u goed aan kunt. Verspreid activiteiten over de dag en zorg voor voldoende hersteltijd als u iets heeft gedaan.



#### Opladen

6. Herstellen kost energie. Zorg dat niet alle energie op gaat aan verplichte activiteiten. Kies ook dingen die u leuk vindt en waar u energie van krijgt.



#### Rust

7. Neem rust voordat u moe bent.
8. Neem diverse rustmomenten op een dag.
9. Rusten betekent ook daadwerkelijk rusten. Dus niets doen: geen gsm, geen tv, geen visite.
10. Ontspannings- en ademhalingsoefeningen kunnen helpen. Er zijn verschillende voorbeelden te vinden op internet. Probeer uit wat voor u werkt.



#### Slapen

11. Zorg voor een vaste slaaproutine en vermijd cafeïne na 14.00 uur en digitale schermen na 18.00 uur.

#### \*Toelichting

*De klachten bij het post-COVID-syndroom hebben meestal tot gevolg dat uw normale dagelijkse bezigheden thuis, in het gezin of op het werk veel lastiger zijn geworden of soms zelfs helemaal niet meer lukken.*

*Veel van de klachten zijn een normale reactie van het lichaam op het bestrijden van een virusinfectie zoals COVID-19. We zien echter ook dat het herstel soms erg langzaam gaat, er sprake is van terugval en dat er allerlei bijkomende lichamelijke klachten ontstaan. Het wordt dan moeilijk om grip te krijgen op uw situatie. De inzet van een ergotherapeut kan er voor zorgen dat u weer regie krijgt over uw mogelijkheden thuis en op het werk en daarmee, al gaat het soms langzaam, uw energie toeneemt en u uw dagelijkse activiteiten weer kunt oppakken.*