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# Chapter 1

# Introduction

## Introducing rest-do days

A rest-do day is a practical approach to living with fatigue. By seeking a balance between resting and doing, I've learned how to *rest* more regularly. On the same day, I'll also be able to *do* the activities that are necessary to life and those that make my *days* worth living. A life worth living involves doing more than existing and surviving. When I rest, often I ask myself what am I resting? It could be any of my capacities: to speak, to move, to think and many more. I can also ask myself what I am taking a break from? Often I am aware of needing to have a rest from worries, noise and busy times.

Rest-do days are a simple and flexible approach to make our daily lives interesting and satisfying. They are not a quick fix, but if you're experiencing fatigue and there is not much prospect of recovery, it can be a relief to imagine doing anything satisfying in the foreseeable future. My rest-do days habit has seen me through many changes and challenges over the past seven years and I am not giving it up. I am so fascinated by the process that I've written this book.





As well as resting more regularly, I attend to the demands of my everyday activities. When I do something like take a sip of a drink, I am making demands on myself – using my senses, energy and many capacities to move and think. The demands vary depending on the activity. Too often activities are assumed to be physical exercise, but we are much more than muscles and bones. In this book any kind of doing is understood as an activity with varied demands.

There are many influences on what we do and why. Activities which we value can offer respite from fatigue, especially if we have control over what to do and how to do it.[1] Your fatigue might be associated with health problems like a heart condition, stroke, autoimmune disease, cancer, depression, long COVID, or difficult times that seem to go on and on. For rest-do days, it does not matter why you are experiencing fatigue.

It is important to let go of the idea that rest is the same as sleep, a time when we are inactive.[2] Often in research, sleep and rest are assumed to be the same thing. In everyday life, seeing rest as a time when we can do less demanding activities is helpful. There are other misunderstandings about fatigue which I've explored in this book. Those misunderstandings can make fatigue baffling for some health professionals. For people already experiencing pain and disruptions to their lives because of serious illness, fatigue can be overwhelming. It is important to appreciate that fatigue is more than feeling tired, affecting many of our body functions and aspects of our lives. It is an enduring concern for many people.

## Box 1.1: How rest-do days came about

I started to pay more attention to my habits of resting and doing when I was first seriously unwell and was still working. It was the summer and when I got home, I found myself sitting without moving until darkness. I became thirsty, hungry and sad. I was managing to work, but other important activities were not happening. I knew I had to pace myself more carefully. Rather than rushing home from work and collapsing, I had to find rests throughout the day.

When I got home from work I wanted to sink into the sofa and do nothing. Not sleep. Just do nothing. But I learned that doing nothing is not restful or restorative because it is quite difficult to do.[3] Even when I was sitting staring into the gloomy room, vague worrying thoughts made me clench my jaw. My rest-do days started when I began to carefully work through small steps of essential activities: getting a drink and something to eat before deciding what to do while I rested. I noticed how I could rest in the car to prepare: for a working day, the journey home and before I went back indoors for the evening. I still rest in the car when I'm out, but I have now been retired for nearly six years.

I realised that I was simplifying my activities, pushing aside concerns about what had happened at work or what might happen next. It was much more important to focus on exactly what I needed now. This approach was rather like my strategy for long-haul flights with my children when we visited my brother abroad. From when they were about six, the rule was to do one thing at a time. We ate our meals and then we watched a film. This strategy paced our activities over the long tiring journey. We kept track of our stuff in the confined space and focused on exactly what would be the most important and satisfying thing to do next. We had to negotiate priorities, especially when my son wanted to spend hours playing video games on one flight. Those long haul journeys with my children could be profoundly restful: eating a meal that had been prepared for me, playing a card game without worrying about the laundry and reading a guidebook without thinking about work.

I imagined my fatigue was restricting my activities like being on a long-haul flight. I found I could adjust my habits of resting and doing. Friends had been coming to stay and I started to enjoy their company more: like flight attendants, they could bring me a drink. I found myself describing to one friend how I was paying much more attention to resting and doing, to give me energy for the activities I had to do. She said it would help to give my approach a name and I came up with rest-do days. They have continued ever since to make their mark on my daily life.

## Sharing rest-do days

I've always enjoyed writing and drawing, and soon rest-do days made an appearance in my conversations and online writing life.[4] People who knew me were interested to know more. While there are many sources aiming to support people to live a better life, they can be reliant on people making more effort to change particular activities. The effort in rest-do days is in paying attention and experimenting to make them work for you, which can apply to any activity. This book takes a different route from the story of triumph over adversity. Rather than seeing myself as being on the winning side in a battle against fatigue, my approach has been to find space to learn why and how it is possible to live with it in the long term.

Many approaches to improving health and wellbeing separate the body and mind, recommending approaches such as an increase in levels of exercise, improving diet and mindfulness. However, for health problems like chronic fatigue syndrome, strategies such as graded exercise programmes are not recommended.[5] Fatigue affects my body and mind at the same time and, most significantly, what I can do and how I do it. My actions engage my body, mind and the world I share with you, all at once. By attending to my everyday activities and making continuous small changes, at my own pace, rest-do days have meant that I can find ways of living with my fatigue. I want to share them in the hope of helping other people to value their own resting and doing.

As I've been writing, I've thought about how supporting a book and turning its pages can be a demanding activity for a reader experiencing severe fatigue. It is too much for me at times, when I prefer to use my e-reader. Focusing on my activities, rather than my mind or body, has made rest-do days infinitely flexible and interesting. I'm not reliant on my willpower to keep up particular regimes or strategies.



# Introducing myself

Before I became unwell, I was familiar with focusing on activities from my professional life as an occupational therapist and subsequently an academic, teaching and researching occupation. For all of my life, there were impacts on what I did and how I did things from my hearing impairment. From my early adulthood, I started to have problems with osteoarthritis in my knees and hands as well: pain and stiffness, which has steadily extended to many of my joints. Fatigue is now permanently part of my life; this is because since 2016 I have also had vasculitis, an autoimmune disease which causes inflammation, damaging my blood vessels and the body tissues alongside.[6]

## Being unwell

There are various patterns of symptoms for different sorts of vasculitis: mine is called GPA (granulomatosis with polyangiitis) and it affects blood vessels all over the body, including tiny ones in my eyes and lungs. I think of it as an arthritis of the blood vessels, with similar patterns of pain, flare ups and relapses. There is no cure for it and the treatment is to suppress the immune system to limit the inflammation and the damage. Sadly, some people die before they get treatment, because vasculitis is rare and difficult to diagnose.

Throughout the book, there are references to the regular rituximab infusions I have.[7] The infusions do help with the fatigue but they soon wear off, so I enjoy the extra energy as a bonus rather than seeing it as a return to some sort of normal life. To be honest, vasculitis is not a great disease to have but without it I wouldn't have written this book.

There are many causes of fatigue, and it is unlikely your fatigue is due to undiagnosed vasculitis. There are many more common causes. If you are worried about what is causing your fatigue, then I suggest that first you try having a rest-do day, to create some space and time to explore how you are feeling unwell and what, if anything, helps you feel better. More details will help other people to help you. Then seek support and maybe further investigations. I went to my GP and it took several months to sort out what was going wrong. Once I'd got my diagnosis from a rheumatologist, it took me a few more months to discover Vasculitis UK, which has been an invaluable support.[8] If you know your fatigue is related to another disease, it may be well worth exploring relevant charities to see what support and information they offer.

## Being a retired occupational therapist

I first came across people living with fatigue in my work as an occupational therapist. As well as people with chronic fatigue syndrome, there were others with multiple sclerosis, rheumatoid arthritis, dementia and many other health issues. I had to retire early because of my vasculitis and found myself revisiting some of the approaches I'd used in my practice. I was relieved to find that they mostly worked well for me, as long as I was realistic and flexible.

The occupation in occupational therapy is much more than paid work. It is everything that keeps us occupied and occupies our time.[9] As therapists, we focus on activities, skills and tasks, using them as therapeutic media for change, in the same way as a music therapist would use music or a physiotherapist would use movement. With an occupational therapist you could be brushing your hair, digging over some earth or doing some creative writing. In hospitals, there tends to be a focus on self-care activities such as getting dressed and eating, but in the community the scope is much broader.

Occupational therapists recognise the risks of occupation being harmful – for example, when a person is forced to do things in particular ways or limited by unhelpful requirements and restrictions on their occupations.[10] Those risks could occur for many reasons. The places and the resources for our occupations affect how well we can meet our needs. For that reason, occupational therapists might be involved in addressing social issues, such as access to public facilities.

This book may inspire you to find out more about occupational therapy. If you want to find an occupational therapist in the UK, try checking the Royal College of Occupational Therapists' website.[11] You will also find them working in hospitals, social services, prisons, schools and social enterprises. The title of occupational therapist is protected by law in the UK and many other countries. Be sure that the person you have in mind is qualified to do the job, as you would with any professional. To practise as an occupational therapist in the UK, it is necessary to gain a recognised qualification and register with the Health and Care Professions Council.[12]

## Being an academic

The second half of my occupational therapy career involved teaching undergraduate and postgraduate students, not only to gain their qualifications but also to do research. I was able to combine my interests in mental health and occupation in my doctorate and post-doctoral research programme.[13] I also became a co-editor for two editions of a textbook on occupational therapy and mental health. My research and influence on occupational therapy led to a Fellowship of the Royal College of Occupational Therapists.[14] After I retired through ill health, I became an honorary professor at the University of Essex.

In this unpaid role, I have kept in touch when I can and supported ex-colleagues. I can also access the library resources and I have found it very satisfying to investigate research on fatigue, exploring links with rest-do days.

## Introducing the book

I've designed this book to appeal to people in different ways. Sometimes writing this book has reminded me of preparing teaching materials. I used to enjoy creating teaching materials that were visually engaging, so I was easily persuaded to illustrate this book. In conversations I've had about rest-do days, people have varied in their attentiveness and reasons for wanting to know more, or less. It has been interesting to talk with people who are seeking out information and advice for themselves or others. I've also been bearing in mind that health professionals often recommend self-help books to the people they work with.

The next chapter, '*Getting started*', is an initial guide to having a rest-do day which I suggest you begin with, whatever your reasons for reading this book. In that chapter, I've retraced my first steps to find out if regular rests could help me. From the start I was wondering about the principles and practice of balancing activity and rest, so there are some initial ideas about why rest-do days might be helpful.

The next five chapter titles all start with the word '*Being*'. I think titles are important. Short titles help us to save energy because we can remember them more easily. By using the word '*being*' at the beginning of Chapters 3 to 7, I have suggested that we are focusing on the present situation, choosing different ways of being. Some of these ways may appeal more to you than others. I've found they all appeal to me at different times.

Chapter 3 is about being supported for our rest-do days. We can make connections for support through our links with our inner resources, other people and the world around us. Because I have been immersed in occupational therapy all of my adult life, I have explored action as my main way of connecting with my supports. For example, if I decided to rest by going outside I could grasp a walking stick or hand rail. I could chat with a neighbour. I could lean on a wall, watching and listening to birds, traffic and other people around me.

When I started writing this book, I knew that being informed helped me to understand the effects of fatigue. In Chapter 4, fatigue is described and defined, exploring its various dimensions and considering how it is dealt with. In self-help books, readers are often encouraged to change their habits with willpower, which is not reliably sustainable. By that, I mean it can be difficult to keep going. I wrote Chapter 5, '*Being organised*', to focus on the many ways we can organise our habits. Rest, as a habit, can be rewarding. There is time and space to daydream or work out what we could do next and how we are going to do it.

Of course, it is not always possible to be organised. Chapter 6 is about being realistic. Fatigue can challenge every aspect of our lives. Some days I rest much more than others, often when I am worried or recovering from busy times. Sensory overload, stress and unrealistic expectations can make it difficult to balance resting and doing. I've explored some of the strategies from my occupational therapy practice which I have found to be helpful.

Whether resting or doing, being inspired can feel good. Chapter 7 covers ideas about inspiration and rest-do days, moving through an imaginary House of Occupation. In Chapter 8, the '*Afterword*', I've shared my final thoughts about rest-do days: finding escape from fatigue, self-help and how to apply the principles in practice.

In each chapter, I've aimed for a balance between interesting ideas, practical strategies, stories and discussions. There are questions and small tasks, with some worksheets, for you to try out if you want. There are sections called Knowing more, with more details about some of the ideas. I've also included Worksheets to encourage you to think about how the ideas in the book might be most useful for you. The first of these is at the end of this chapter.

I've used numbers in the text to reference many sources, ranging from academic books to research papers and online sources of information for any audience. The list of references for each chapter are at the end of the book.

## Some thoughts before we get started

Rest-do days are not a cure for fatigue. As I've already said, I assume my fatigue will never completely go away, but I know I can feel satisfied with what I do in my everyday life. If you've made the effort to start reading this book, then it's likely you could be feeling dissatisfied and concerned about your energy levels. To speak with anyone about your fatigue takes effort in itself, so this book could help you.

Rest-do days are simple in theory, but as you start to work them out for yourself, many possibilities arise. As an approach, they can be configured to any personal circumstances, without simplifying the complexities of life. By including all our everyday activities, rest-do days are a flexible and central part of life.[15] They offer us choices about how to respond to personal, social, political and economic influences on what we should do and why.[16] Any activity can be beneficial or harmful to health, depending on how much a person does it, how much choice they have and the situation they're in. Books can be an important and helpful way of supporting a person's recovery or adjustment to their health problems or life difficulties, at a pace they are in control of. Take your time, there is no rush.



## Worksheet 1: Prepare for rest-do days

At any starting point it's good to pause, to take in where you are, where you have come from and what lies ahead. The questions in this worksheet are designed to help you do that.

**What prompted me to start reading this book?**

**What interests me about rest-do days now?**

**How could the contents of this book apply to me and my situation?**

