



THE UK
SEPSIS
TRUST

RECOVERY & WELLBEING DIARY

INTRODUCTION

Welcome to The UK Sepsis Trust's (UKST) Recovery and Wellbeing Diary! It has been created to help enhance your journey following sepsis and serious infection (including COVID-19).

Every aspect of your life influences your state of wellbeing. Researchers investigating happiness have found there are key factors that can enhance an individual's state of mind. These include activity, diet, sleep, connection and having a sense of purpose. During recovery from a serious illness these can often be affected in profound ways.

Everyone's recovery is unique and isn't always dictated by the seriousness of their illness or length of hospital stay. Recovery following critical illness is rarely straightforward and can be frustrating at times. Progress often waxes and wanes, and you may well experience relapses. This is normal, and whilst it can be upsetting, please try to remember that you're not alone.

“When I first came home from hospital even the simplest of tasks felt nearly impossible. I'm doing so much better now. Keeping a diary has really helped me see how far I have come.”

We're hoping this diary will help you to:

- Clearly understand and document your current behaviour patterns
- Identify existing positive trends that you can take in your recovery
- Notice any unhelpful patterns that you may need to address and raise with your GP
- Help you plan and prioritise future activities

We've included ideas, suggestions and templates to inspire you, and sufficient blank templates to last a month. The topics we cover are: **Activity & Fatigue, Pain, Sleep, Nutrition, Memory & Cognition, and Mental Health.**

To get started, identify the areas that you feel might benefit from being monitored. The diary can work in isolation or alongside any other records you might keep.

Remember to look back and read through your entries every week, as it's a great way to track your strengths, weaknesses, struggles and successes!

Please note that this isn't a substitute to any guidance you might receive from your GP or other health professionals, and we'd encourage you to maintain close ties with them on your journey back to health.

ACTIVITY & FATIGUE

Activity doesn't just mean exercise! Anything we do counts as an activity and requires energy. It could be a physical task like showering, walking or making a cup of tea – a cognitive task such as reading a book, listening to a podcast or talking on the phone – or an emotional task, like speaking about your experiences with a loved one or a healthcare professional. Once you start getting an insight into your tolerance for different activities, you can plan and prioritise your time more effectively. Don't be surprised if, in the early days of your recovery, your tolerance is significantly reduced – this is normal and to be expected.

Fatigue can be difficult to describe. People often refer to it as complete physical and mental exhaustion that isn't relieved by sleep or rest periods. This is common following any illness and will often resolve itself as your health improves. For some people fatigue can continue for several weeks, months, or even longer, making recovery more challenging.

“It took longer than expected to get back on my feet, but each day I did a little bit more. Being patient paid off in the long run and the diary helped me see I was making progress and kept me going.”

The signs and symptoms will vary from person to person, but some of the most frequently cited include:

- Being very weak and excessively tired nearly all of the time
- Muscle and/or joint pain
- Feeling dizzy, faint, and/or sweating
- Breathlessness
- Not being able to remember things

It's important to know the baseline from which you're starting. Some people feel able to exercise during recovery and this can sometimes have a positive effect on their wellbeing. For others engaging in physical activity can improve energy levels but this needs to be carefully managed. The key is to pace yourself – using the diary can help you to do this.

You could use the diary to:

- ✓ Monitor your daily activities and rest periods. These could be of high or low intensity and encompass activities such as washing and household chores, to periods of exercise (see activity planner).
- ✓ Be creative! Devise your own fatigue scales or symbols to denote when your fatigue is at low/medium/high levels.
- ✓ Break your day and week up into small chunks to help with planning and prioritising activities

PAIN

Pain and discomfort are common during recovery. In particular joint, muscle, and nerve pain. Everyone's ability to tolerate pain varies and will be affected by previous experiences with pain related to other medical issues or long-term problems. Including a pain section in your diary can help you regain some control over your health, your life and pain management.

Something you can do to help monitor this is to use a pain scale and body map (see appendix) to score your overall pain out of 10. Use the body map provided to shade in the problem areas.

In time, some people might be able to gradually increase low impact activities to their daily routine. If this is possible, record progress in your diary for a week or two and then use a new body map to score it again. This can help identify improvements, which in turn will aid your psychological recovery.

You could use the diary to:

- ✓ Identify any pain patterns. You might find that you have pain flare ups following meals, during certain types of weather, or after a particular activity.
- ✓ Understand what works for you, and which therapies alleviate your pain
- ✓ Improve communication with your GP and/or other health professionals. Having information to draw upon makes it easier to answer questions about your pain and participate fully in your care plan.

SLEEP

Sleep is essential to both our physical and mental health. Following serious illness, many people report changes in sleep pattern which are sometimes quite significant. Prioritising sleep is important as it can enhance our immune system, cognitive function and help our body to heal more quickly.

Everyone's sleep requirement is different, so using a diary can help you understand how much time you spend asleep and identify anything that interferes with your cycle. This could include flashbacks, anxieties or worries, eating too late, being over-stimulated or being in pain. Factors that can impact sleep are:

- Temperature and darkness of bedroom
- Routine in the lead up to sleep and wake up time
- Spending too much time on electronic devices just before going to sleep
- Caffeine, alcohol and nicotine use

You could use the diary to:

- ✓ Track what time you're going to bed and waking up
- ✓ Record the total number of hours slept (see activity planner)
- ✓ Record when your sleep is interrupted or disturbed, as well as strategies to help you get back to sleep again
- ✓ Document the timings of caffeine, alcohol, nicotine or any other stimulant you may be having

NUTRITION

Some of your nutritional and hydration reserves may well have been depleted while you were unwell. These need to be restored over time as they are essential to everyday health and wellbeing, playing a huge factor in recovery. This should not be underestimated.

Generally, a well-balanced, nutritious diet, is the best way for most people to maintain and enhance health. Plenty of fresh or frozen vegetables, a little fruit, and ‘good’ oils such as olive oil alongside sensible portions of protein and carbohydrates, such as found in Mediterranean diets, are relatively easy to access and palatable to most people. Some people struggle to regain their appetite, so smaller, more regular, meals may suit.

The balance between water and electrolytes (‘salts’ such as sodium, potassium, magnesium) is also crucial to how all our systems function – including our nerves and muscles.

“It took some time to develop a regular, healthy eating and drinking pattern. I certainly found it helpful to eat a bit less, but more often! Keeping a diary reminded me of what I’d done because I couldn’t remember.”

A healthy, well-balanced diet can help you to:

- Have more energy
- Limit further weight loss
- Help re-build muscle
- Enhance your immune system

If you have any specific nutritional concerns, or ongoing medical conditions which can affect appetite or nutritional absorption then these should be discussed with your GP and/or Dietician.

You could use the diary to:

- ✓ Document what, how much and when you are eating and drinking (see food chart)
- ✓ Identify meal/drink times which work for you

MEMORY & COGNITIVE FUNCTION

Something that many people report following sepsis and serious illness is a change in cognitive (brain) function. This can often present as changes in short term memory, poor attention and concentration. If this occurs, it's understandably worrying, but it's also worth remembering that it's relatively common.

It's often a result of some changes in the neurological pathways during and after sepsis. Sepsis can affect the cells in the brain (due to inflammation), change the way blood is distributed, and prevent the 'engines' of the cells (mitochondria) from working as well. All this can contribute to the 'brain fog' people often report during recovery.

Things usually improve over time, but most find it may take a little longer than expected. It may help to speak to your GP about possible referral to a specialist Occupational Therapist or neuropsychological assessment. This can help identify what cognitive problems you may be experiencing and provide you with the best ways to manage these.

For many people it can be about acknowledging the new status quo (which often isn't easy), developing coping mechanisms, and trying to retrain the brain to get back to normal capacity (where it used to be).

You could use the diary to:

- ✓ Plan and prioritise your daily activities. Often people find things are worse when they are tired or stressed. So identify good or bad patterns and plan your day around that.
- ✓ Write lists to help you remember
- ✓ Allocate and prioritise time for things that can help with your memory, e.g.
 - Physical activity
 - Meditation
 - Brain training games/apps (see useful links page)
 - Doing things you enjoy
 - Rest periods

“I was rather surprised at how forgetful and confused I was when I first got home. Everything seemed to take much longer and was more difficult than before. It took time for me to re-learn things and I had to be patient as progress was so slow.”

MENTAL HEALTH

Your mental health is just as important as your physical health, and may require a substantial amount of attention and recovery time. People often feel confused, distressed, shocked and at times traumatised by their experiences. There is nothing to be ashamed or embarrassed about. Recovering from serious illness can be a traumatic and challenging experience, so it's important to try to be as open and honest about how you're feeling mentally so people can understand and support you.

Some helpful activities to consider trying are mindfulness, meditation and relaxation exercises (see useful links page).

“Before I got ill I was a pretty positive, sunny sort of person. But after being so sick I developed dark thoughts which I found hard to shake off. Concentrating each day on the good things that I enjoyed really helped – and logging these in the diary was useful.”

Writing down thoughts and feelings can sometimes help understand and monitor patterns, so you may wish to include a section for this in your diary. If you're finding it difficult to speak face to face, you could share some of the things you've written down with someone close to you, to help them understand how you're feeling.

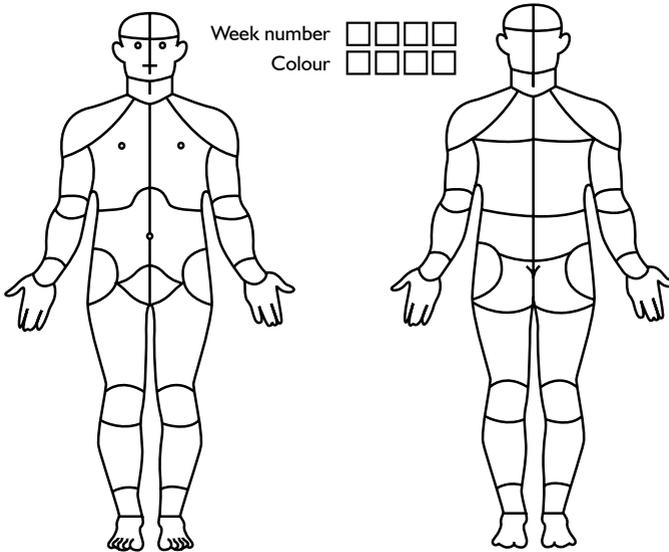
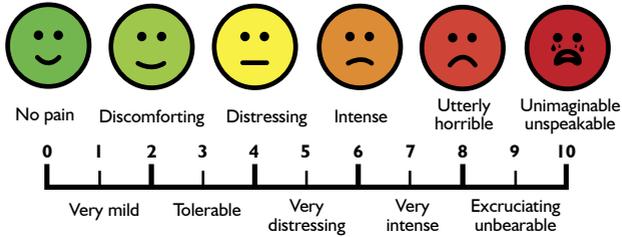
Quite often, people need additional support in their recovery, and if you feel like this would help, a good place to start is to talk it through with your GP. He or she will be able to refer you to different services or suggest various treatments.

You could use the diary to:

- ✓ Write down your thoughts and feelings (see wellbeing diary template)
- ✓ Identify activities which help improve your mood
- ✓ Log the impact of new approaches such as mindfulness or meditation
- ✓ Highlight all that is positive around you by including a gratitude section (see appendix and wellbeing diary template)
- ✓ Identify any patterns and connections with other aspects of your health

APPENDIX

PAIN SCALE & BODY MAP



GRATITUDE PROMPTS

- What positive quality do I admire about myself?
- What positive qualities of a role model do I value?
- What is one thing I am looking forward to today?
- What one thing (within my control) would make today great?
- What is one thing I appreciate about my health?
- What obstacle have I overcome that I appreciate about myself?

USEFUL LINKS

WEBSITES & PHONE NUMBERS

The UK Sepsis Trust

sepsistrust.org/get-support/
0808 800 0029

NHS – Every Mind Matters

www.nhs.uk/oneyou/every-mind-matters/

British Association for Counselling and Psychotherapy (BACP)

www.bacp.co.uk/

British Dietetic Association

<https://www.bda.uk.com/food-health/food-facts/nutrients-food-facts.html>

Samaritans

www.samaritans.org/how-we-can-help-you/contact-us
116 123

Mind

www.mind.org.uk/information-support/

USEFUL APPS

The following apps can be found in both Apple and Google app stores, and are either free to use or have a free trial period. To find the app, simply type the title of the app into the search bar.

Mental Health

Catch It
Feeling Good: positive mindset
My Possible Self
Stress and Anxiety Companion
Worry Tree
Thrive

Cognition

My Cognition - Home

Mindfulness and meditation

Calm
Headspace
ibreathe

Gratitude and Journalising

Gratitude: Diary, vision board
Daylio Journal
Reflectly

GENTLE EXERCISE LINKS

www.nhs.uk/live-well/exercise/sitting-exercises/
www.nhs.uk/live-well/exercise/strength-exercises/
www.nhs.uk/live-well/exercise/flexibility-exercises/
www.nhs.uk/live-well/exercise/balance-exercises/



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Using a diary to monitor symptoms and track progress can be a valuable tool in someone's recovery journey. We hope this resource will help people to understand and further enhance their recovery following sepsis and critical illness.

– Oliver Jones, UKST lead support nurse

Visit us at sepsistrust.org

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WELLBEING DIARY

WEEK NUMBER _____



MONDAY



TUESDAY



WEDNESDAY



THURSDAY



FRIDAY



SATURDAY



SUNDAY



WELLBEING DIARY

WEEK NUMBER _____



This weeks mantra

I am grateful for

One thing I want to achieve

Have I had enough...

Sleep



Sunshine/daylight



Social interaction



Water



Relaxation time



Me time...

Listen

Read

Watch

Do

ACTIVITY PLANNER WEEK NUMBER _____



Use this document and plan your activities and rest. Remember everything we do requires energy!

Date	Midnight to midday (morning)											Midday to midnight (afternoon/evening)												
	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
__/__/__																								
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								

Key:

A1 - Activity type 1 - requires more energy
A2 - Activity type 2 - requires less energy

R - Rest time - ideally without devices etc
S - Sleep

F - Periods of excessive fatigue

FOOD CHART WEEK NUMBER _____



Document if you are having any vitamins or added food supplements in the notes section below.

	MON	TUE	WED	THU	FRI	SAT	SUN
DATE							
BREAKFAST							
LUNCH							
DINNER							
SNACKS							
WATER	○ ○ ○ ○ ○ ○ ○ ○						
NOTES							