

# ME FORMS

## Free Forms, Diaries and Charts for the Management of ME/CFS

(Myalgic Encephalomyelitis /Chronic Fatigue Syndrome)

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# ME Forms Website Home Page

## **Become Your Own Expert**

I am "90% expert" in the ME/CFS that affects me and I hope you can become your own expert.

I have improved my quality of life by pacing and sticking to a well-balanced routine, using the tools on this website.

## **A Practical System**

I have built this website for others with ME/CFS, or health professionals treating people with the illness. The blank forms, charts and diaries (with completed examples) are designed to help you improve your understanding and management of ME/CFS by planning and regularly reviewing your own routine. This user-friendly system can help you manage your time and, more importantly, your energy.

## **Using the Forms**

The 8 forms, charts and diaries can be used in the above order, from A-H, or, just pick the ones that you will find most useful.

I have provided completed examples of all the forms in PDF format. Blank versions, for you to edit and complete, are in both PDF and WORD format.

You can also [download a PDF of all forms and text](#) if you think this might be an easier way to view the information.

The forms, charts and diaries on this website continue to help me with my management of the illness - I hope they will help you too.

## Instructions/Guidelines for Each Form

### A – ACTIVITY CATEGORIES

The Activity Categories form helps you consider ALL the different activity you do and whether it uses a **High, Medium** or **Low** amount of energy.

Categorising activity in this way will enable you to understand how you spend your energy and help when planning a balanced routine. There are further explanatory notes on the form itself.

There are 2 completed examples (one showing a lower level of activity and the other with higher levels of activity) and 1 blank template of this form. Blank forms are available in Word or PDF format. Example forms are available in PDF format only.

### B - DAILY RECORD OF ACTIVITY

Use this form to record your current daily activity, in detail - what you are doing, how long you do it for and whether it is High, Medium or Low energy use? Build up a picture of how you currently spend your time and energy. Do you have the right balance of rest and activity? (If your activity doesn't vary much from day to day you may wish to use the Weekly Record of Activity Form instead.)

Completing the **Daily Record of Activity** will show you the strengths and weaknesses of your current lifestyle. Do you have the right balance of rest and activity? Using this information will help you when considering an improved and more balanced routine, to be entered on the **Daily** or **Weekly Routine Planner**.

There is one completed example and one blank template of this form. Blank forms are available in Word or PDF format. Example forms are available in PDF format only.

### C – WEEKLY RECORD OF ACTIVITY

Use the **Weekly Record of Activity** to record your current activity, particularly if your lifestyle doesn't vary much from day to day (otherwise use the **Daily Record of Activity**) - what you are doing, how long you do it for, is it **High, Medium** or **Low** energy use? Build up a picture of how you currently spend your time and energy.

Completing the **Weekly Record of Activity** will show you the strengths and weaknesses of your current lifestyle. Do you have the right balance of rest and activity? Using this information will help you when considering an

improved and more balanced routine, to be entered on the **Daily** or **Weekly Routine Planner**.

There is 1 completed example and 1 blank template of this form. Blank forms are available in Word or PDF format. Example forms are available in PDF format only.

## **D – DAILY ROUTINE PLANNER**

This form helps you plan a balanced and sustainable daily routine. Use the information you have gathered on the **Daily** or **Weekly Record of Activity** and consider how to improve your current activity and rest regime - then record an improved schedule on the **Daily Routine Planner**. The **Activity Categories** form will also help when thinking how to spread **High, Medium** and **Low** activity throughout the day. (Your routine can be adjusted when you feel ready to increase activity - or decrease in the case of a relapse.)

One example, below, shows how you could use sticky notes to plan the days' rest and activity periods, but not necessarily the detail of what you will be doing. If you use sticky notes you can easily adjust them as necessary.

There are 2 examples and 2 blank templates of this form (one with 20 minute timeslots). Blank forms are available in Word or PDF format. Example forms are available in PDF format only.

## **E – WEEKLY ROUTINE PLANNER**

This form helps you plan a balanced and sustainable weekly routine. Use the information you have gathered on the **Daily** or **Weekly Record of Activity** and consider how to improve your current activity and rest regime; then record an improved schedule on the **Weekly Routine Planner**.

The **Activity Categories** form will also help when thinking how to spread **High, Medium** and **Low** activity throughout the day. Perhaps you have a High activity which you could do on two different days in the week, several days apart? (Your routine can be adjusted when you feel ready to increase activity - or decrease in the case of a relapse.)

There is 1 completed example and 1 blank template of this form. Blank forms are available in Word or PDF format. Example forms are available in PDF format only.

## **F – SYMPTOM SCORE CHART**

Use this form to help work out a score based on how severe, moderate or mild the symptoms are each day.

If you look at the form you will see I suggest a score of 1-9 (with 9 being the most well). It is not necessary to consider a '9' as how you were before you developed ME/CFS. Use your own judgement of illness and wellness, that is appropriate to you, to decide how to score your symptoms. The **Symptom Score Chart** helps consider the illness more objectively. (You may wish to record your score on the **Daily Diary Grid**.)

There is 1 completed example and 1 blank template of this form. Blank forms are available in Word or PDF format. Example forms are available in PDF format only.

## **G – DAILY DIARY GRID**

This grid is completed daily to record important statistics, eg hours slept overnight, daytime sleep, rest periods, time spent using **High**, **Medium** and **Low** activity etc.

It is a snapshot of each day to build up a picture of what works and what doesn't. There are also columns for the **Symptom Score** and a comment box.

You could change some column headings temporarily to help you record a specific activity that you are gradually increasing, for example using a mobile phone or cooking. If you increase the activity weekly or monthly this is the place to record it. You can look back over the previous days/weeks/months to see what you were doing, how many minutes or hours a day you were doing it and how it affected you.

Each sheet covers 3 weeks, I am currently on sheet number 456! I have found this to be the most useful form. I look back over the previous weeks/months/years to see how I managed a difficult period, the amount of 'rest' time I had or to see how much I've improved.

There are 2 examples and 1 blank template of this form. Blank forms are available in Word or PDF format. Example forms are available in PDF format only.

## **H – SYMPTOM CATEGORIES AND WARNING SIGNS**

This form will be specific to you. Labelling your symptoms or cluster of symptoms may give you greater understanding and objectivity of this confusing illness. (If I overstretch my arms or legs I have specific symptoms that appear and often make my symptoms worse that day and continue to worsen the next day - identifying and labelling this has raised my awareness of the hazard and helped me to prevent it.)

Think about any warning signs that may occur and record these on the second part of the form. This can help you identify when you need to consider adjusting your activities that day/week.

There is 1 completed example and 1 blank template of this form. Blank forms are available in Word or PDF format. Example forms are available in PDF format only.

## Top Tips

**The best medicine** is good quality rest (in a quiet room, supported by pillows or cushions), good sleep and a balanced, manageable routine.

**A secondary medical problem**, even a minor one, can make things a lot worse, try to get it treated or managed - it may be having a negative impact on the ME/CFS.

**Pacing** is not just about the time it takes to do an activity, but also the high, medium and low amount of energy required.

**Make a realistic plan** and stick to it – don't get carried away.

**Use a stopwatch** to limit yourself when doing an activity. When it beeps, STOP.

**Little things make a difference**, eg (i) adjust a pillow or cushion to make sure you are fully comfortable (ii) don't have the bath or shower too hot – it's exhausting (iii) never stand when you can sit, never sit in an upright chair if an armchair is available. What else would help you?

**Giving way** to the symptoms is sometimes necessary - this is not the same as giving in.

**Let the symptoms** tell you they are there, don't go looking for them.

**If you overdo it** – don't give yourself a hard time, (but make sure it was for something worthwhile!)

**Exercise or activity** needs to be based on recovery and strengthening - NOT on a keep fit "go for the burn" basis.

**If** you're on the phone when your rest time is due, tell them you'll ring back later.

**Resting on a good day** adds credit to the energy bank. Resting on a bad day is getting out of debt from the energy bank.

**Do not make big leaps** when increasing activity or exercise - look at what you have been achieving recently, perhaps try a 10% increase.

**It's easy to get impatient** and think "if doing a little is OK, then doing more won't be a problem" - unfortunately it often is.

**Which times of the day** are best suited to high, medium and low activity? Can some high level activities be broken into smaller segments?

**When your body copes with extra activity**, it is usually because of consistency the majority of the time, which means 'credit' in the energy bank. It doesn't mean you can overdo it every day.

**Try resting more frequently** rather than for longer spells. Break the day up into small chunks. Would 10 mins rest every hour work for you? Perhaps 3 minutes activity 3 times an hour?

**If you're having a bad spell**, you need to stabilise - go back to a routine or a "baseline" of rest/activity you know works for you.

**Don't wait until you "recover"** from ME/CFS to start something new - start it now, a little bit at a time, in manageable chunks.



## About Me

My name is Sue and I live in the south-east of England.

### **Before ME/CFS**

I had a great job working in IT for a large company. I enjoyed sport and regularly played netball, squash and enjoyed cycling.

### **ME/CFS - Day One and What Followed**

(If you are newly diagnosed, don't panic, this is my story, not yours)

On 12 February 1998 I woke up and could barely move due to overwhelming muscle weakness and heaviness, like an invisible elephant sitting on top of me. My glands (everywhere) were swollen, my throat sore and every time I moved my head I felt as though someone was kicking it. Initially, I was diagnosed with a virus (later confirmed by a specialist as glandular fever). I had 6 weeks off work and then struggled back part-time, relapsed, returned to work, relapsed... (I had a very understanding employer). During this time my diagnosis moved to Post Viral Fatigue Syndrome and then some time later, ME/CFS. I finally had to stop working, or rather my body finally stopped working, in late 1999.

I remained chair bound/housebound for the next few years, then suffered from an additional mild chronic illness which impacted on the ME catastrophically. In 2008, I became bed bound for several months. I gradually improved with very careful pacing of activity and sticking very strictly to an hourly/daily/weekly routine until I was finally well enough to attend an appointment with a specialist to deal with my secondary medical condition. Once this was controlled, I began to make further improvements by continuing to stick to a strict routine, making increases and adjustments when my body felt ready - which could be days, weeks or even months later.

### **Gettings things sorted in 2009**

After seeing a specialist to help with a medical condition I suspected was impacting on the ME/CFS (although not related) I was gradually able to improve my lifestyle. I was extremely strict with myself in creating and sticking to a routine of careful pacing and activity. After a while I was able to drive short distances (something I hadn't done for years).

### **My Daily Routine in 2018**

I can drive myself to the local supermarket to go shopping and on another day meet a friend for coffee and cake (some people eat carrot cake when they could have chocolate!), both in the same week. Most of my time is spent at home where I use my laptop (and try my hand at building websites!), chat, watch TV and do some pottering about. Some weeks I can do a bit more, some weeks I need to do less. My current routine includes four rests spaced throughout the day, 3 for 20 minutes and one for 10 minutes. I have not settled for this daily/weekly routine - I plan (hope) to be able to do more.

### **Improved routine in 2024**

I can do more than in 2018! My resting timetable is now two 20-minute rests a day. (I did have a severe relapse in 2020, but gradually worked my way back up to where I am now.) I try not to go more than 5 hours without a formal rest period during the day, as I do notice the difference if I let this slip. I also make sure I have complete rest days every week. I still have a few weeks or a couple of months every now and then when this level of activity cannot be maintained, and I become mostly housebound for a while, but with careful planning, I do improve.

### **Treatments Tried Since 1998**

Some of these may, or may not, work for you - this is my experience only.

**Graded Exercise** - I tried this for years (following constant medical advice) and suffered relapse after relapse. I started by walking for 1 minute every other day and tried to build it up over the weeks and months, sometimes only increasing by 15 seconds a week. At one point I could walk for 30 minutes for several consecutive days, but could do nothing else, and then relapsed anyway. Every combination I tried ended in a relapse. It was only when I stopped Graded Exercise in 2008 and focused more on pacing, that I began to improve.

**Pacing** - made a big difference, along with categorising High, Medium and Low levels of activity, and implementing a manageable routine.

**Dietician** – Received some very helpful advice in 2020 – it may have contributed to my recovery from a relapse.

**Consultants** – 2 different Neurologists (2008, 2020) – both helped me tremendously.

**Homeopathy** - No difference, except the effort of getting to the appointments made me worse.

**Nutritional Supplements** - (through a qualified Nutritionist) - No obvious improvements. When I eventually stopped them, I didn't feel any worse. I still take fish oil as advised by a Neurologist.

**Tai Chi** - Enjoyable, but no benefit. Had to stop after a few weeks as it became too much for me.

**Cranial Osteopathy** - Exhausting, no improvement.

**Physiotherapy** - Exhausting, any benefits were cancelled out by the effort of going to the appointment.

**Vitamin B Injections/Tablets** - they may have helped, certainly didn't harm.

**Acupuncture (at Home)** - I tried this for 5 years and then looked back over my Daily Diary Grid and realised that any gains I'd made during that time were probably not due to the treatment. I s

## Contact

### How to get in touch

I am very happy to receive **any feedback or suggestions** about this website, [meforms.org](http://meforms.org).

Please note, I cannot help with advice on your individual circumstances or activity programme. All the knowledge or advice I can give is on this website or on the individual forms.

Please get in touch using the email address below - I'd love to hear from you.

Email: [meforms@hotmail.com](mailto:meforms@hotmail.com)

## ACTIVITY CATEGORIES

LOW ENERGY USE		MEDIUM ENERGY USE		HIGH ENERGY USE	
Low	High	Low	High	Low	High
Lying in Bed with radio on		Watching TV		Using the stairs	
Sitting up in Bed		Sitting on the sofa		Sitting in upright chair	
<i>Talking up to 15 mins</i>		<i>Talking 15-30 minutes</i>		<i>Talking more than 30 minutes (hi-cog)</i>	
<i>Reading a book up to 15 mins</i>		<i>Reading a book 15 to 30 mins</i>		<i>Reading a book more than 30 mins (hi-cog)</i>	
		Flicking through newspapers/magazines		Getting ready for bed	
		Cutting toenails		Getting dressed	
		Using computer		Standing (up to 2 minutes)	
				Travelling in a car	
				Walking	
				Stretching Exercises	
				Washing Hair	
				Bath/Shower	
				Towel drying after bath	

- Hi-cog = high cognitive requirement
- Italics = activity in more than one column. Some activities in the Low column become Medium if done for more than a few minutes, which can also be applicable for Medium/High activities.
- By placing the activity to the left, right or centre of each Energy Use Column you can identify different levels within each category.
- Break an activity down into individual components eg a doctors' appointment can be walking to the car, travelling in a car and sitting in an upright chair.
- As you improve, some activities in the High column move left to the Medium column and Medium move to Low. Enter new activities in the High column.
- **Remember PACING eg cut toenails over several hours, or even days**

## ACTIVITY CATEGORIES

LOW ENERGY USE		MEDIUM ENERGY USE		HIGH ENERGY USE	
Low	High	Low	High	Low	High
Sitting on sofa with radio on		Using the stairs		Walking formal (Graded Exercise)	
<i>Reading a book (up to 1 hour)</i>		<i>Reading a book (more than 1hour)</i>		Walking informal	
Phone conversations		<i>Sitting in upright chair (up to 30 mins)</i>		<i>Sitting in upright chair (more than 30 mins)</i>	
Crosswords		Getting ready for bed		Visitors (active)	
Reading newspapers/magazines		Getting dressed		Travelling in a car	
Paperwork/admin		Blow-drying hair		Standing (more than 3 minutes)	
Catalogue shopping		Towel drying after bath		Driving	
Visitors (sedentary)		Washing Hair		Heavy housework eg vacuuming	
Watching TV		Washing-up		Changing bed linen (duvet/sheet)	
Using computer		Putting washing in machine		Light Gardening	
		Putting washing on clothes dryer		Shopping (hi physical activity + hi cog)	
		Putting clothes in airing cupboard			
		Putting clean clothes in wardrobe			
		Light housework – dusting (up to 3 mins)			
		Washing fruit & veg			
		Meal preparation			
		Emptying bins			
		Standing (up to 3 minutes)			
		Travelling in a car			
		Stretching Exercises			
		Bath/Shower			
		Changing bed linen (pillow cases - sitting)			

- Hi-cog = high cognitive requirement, eg when shopping
- Italics = activity in more than one column. Some activities in the Low column become Medium if done for more than a few minutes, which can also be applicable for Medium/High activities.
- By placing the activity to the left, right or centre of each Energy Use Column you can identify different levels within each category.
- Break an activity down into individual components eg a doctors' appointment can be walking to the car, travelling in a car and sitting in an upright chair.
- As you improve, some activities in the High column move left to the Medium column and Medium move to Low. Enter new activities in the High column.
- **Remember PACING eg change bed linen over several hours, or even days**

## ACTIVITY CATEGORIES

LOW ENERGY USE		MEDIUM ENERGY USE		HIGH ENERGY USE	
Low	High	Low	High	Low	High

- Some activities in the Low column can become Medium if done for more than a few minutes, which can also be applicable for Medium/High activities.
- By placing the activity to the left, right or centre of each Energy Use Column you can identify different levels within each category.
- Break an activity down into individual components eg a doctors' appointment can be walking to the car, travelling in a car and sitting in an upright chair.
- As you improve, some activities in the High column move left to the Medium column and Medium move to Low. Enter new activities in the High column.

### Daily Record of Activity (with activity categories)

Date: Wed 16 June

Time	Minutes/ Hours	High/ Medium/ Low Activity	Activity Description
8.30am	8 hours	-	Overnight sleep
9.00am	10 min	Medium	Get up / Get breakfast
9.10am	50 min	Low	Eat breakfast / Watch TV
10.00am	30 min	High	Shower
10.30am	45 min		Rest
11.15am	15mins	Medium	Get dressed
11.30am	3 hours	Low	Watch TV / On phone
2.30pm	15 min	Medium	Get Lunch
2.45pm	3¼ hours	Low	Eat Lunch / Watch TV / On phone
6.00pm	2¾ hours		Sleep
8.45pm	15 mins	Medium	Get food
9.00pm	3½ hours	Low	Eat / Watch TV
12.30am	15 mins	Medium	Get ready for bed
12.45 am	-	-	Go to bed
<b>TOTALS</b>	<b>Sleep: 10¾ hrs Rest: 45 mins Low: 10hr35min Medium: 1hr10min High: 30 min</b>		

High, Medium or Low Activity = High, Medium or Low Energy Use

This example shows a day without any routine or careful planning, with long periods of activity and only one REST time.



**Daily Record of Activity** (with activity categories)

Date:

Time	Minutes/ Hours	High/ Medium/ Low Activity	Activity Description
<b>TOTALS</b>	<b>Sleep:</b>	<b>Rest:</b>	<b>Low:</b>
	<b>Medium:</b>	<b>High:</b>	

High, Medium or Low Activity = High, Medium or Low Energy Use

EXAMPLE

EXAMPLE

EXAMPLE

EXAMPLE

EXAMPLE

EXAMPLE

## WEEKLY RECORD OF ACTIVITY

TIME	MONDAY	TIME	TUESDAY	TIME	WEDNESDAY	TIME	THURSDAY	TIME	FRIDAY	TIME	SATURDAY	TIME	SUNDAY
7am	Get up	9am	Get up	8am	Wake up	7pm	Wake up	8am	Get up	9:30 <sup>am</sup>	Get up	8am	Wake up.
7:10	Watch TV	9:10	Breakfast	10am	Get Up	12pm	Get up	8:10am	Breakfast	9:30	Eat	4pm	Get up.
8am	Breakfast	9:15	Watch TV	10:15	Breakfast	12:10pm	Read	8:20pm	TV	10:30 <sup>am</sup>	Wash/Dress	4:15 <sup>pm</sup>	Eat / TV
8:10	TV	10am	Shower	10:30	Bed (sleep)	1:30	Eat	11am	Eat	11:00 <sup>am</sup>	Go Shopping	8pm	Bed.
11am	Bed (Sleep)	10:30	Phone/TV	11:30	Bath	1:45	Read	11:15	TV	1pm	Home		
1pm	Shower	1:30 <sup>pm</sup>	Lunch	12pm	Bed (Doze)	5pm	Bed	12pm	Bed	1:15	Bed (Sleep)		
1:30	Bed	1:40 <sup>pm</sup>	TV/Phone	1:30 <sup>pm</sup>	Lunch	6pm	Eat	2pm	Read	2:15	TV		
4:30	Read in Bed	6pm	Rest/Sleep	1:45 <sup>pm</sup>	Watch TV	6:15 <sup>pm</sup>	TV	4pm	Bath	6:15	Sleep		
5:30	Dinner	9pm	Eat / TV	5:30 <sup>pm</sup>	Rest	10pm	Go to Bed	5pm	Bed (Sleep)	7:30	Eat		
6pm	Watch TV	1am	Go to Bed	6pm	Phone/TV			6:30 <sup>pm</sup>	Eat	7:45 <sup>pm</sup>	TV		
12pm	Go to Bed			7pm	Eat			6:45 <sup>pm</sup>	Phone	9pm	Go to Bed		
				7:10 <sup>pm</sup>	TV			7:45 <sup>pm</sup>	TV				
				10pm	Go to Bed			8pm	Dozed				
								10pm	Bed, but couldn't				
									Sleep till				
									1am.				

### WEEKLY RECORD OF ACTIVITY

TIME	MONDAY	TIME	TUESDAY	TIME	WEDNESDAY	TIME	THURSDAY	TIME	FRIDAY	TIME	SATURDAY	TIME	SUNDAY

**DAILY ROUTINE PLANNER** (with activity categories)

Time	Activity	*	Time	Activity	*	Time	Activity	*
7.00 am	Bed		2.00 pm	Watch TV	L	9.00 pm	Watch TV	L
7.20 am	Bed		2.20 pm	Watch TV	L	9.20 pm	Watch TV	L
7.40 am	Bed		2.40 pm	REST		9.40 pm	Watch TV	L
8.00 am	Get up/ Get breakfast	M	3.00 pm	Read	L	10.00 pm	Bed	
8.20 am	Watch TV	L	3.20 pm	Read	L			
8.40 am	Watch TV	L	3.40 pm	Read	L			
9.00 am	Shower/Bath	H	4.00 pm	Computer	L			
9.20 am	REST		4.20 pm	Computer	L			
9.40 am	REST		4.40 pm	REST				
10.00 am	Get dressed/	H	5.00 pm	Pottering about/ Tidying up	M			
10.20 am	Sit up, on bed/ Listen to radio	L	5.20 pm	Listen to radio	L			
10.40 am	Sit up, on bed/ Listen to radio	L	5.40 pm	Listen to radio	L			
11.00 am	Sit up, on bed/ Listen to radio	L	6.00 pm	Listen to radio	L			
11.20 am	REST		6.20 pm	Make/Eat Tea	M / L			
11.40 am	Chat on phone	L	6.40 pm	REST				
12.00 pm	Chat on phone	L	7.00 pm	Washing up	M			
12.20 pm	Read	L	7.20 pm	Watch TV	L			
12.40 pm	REST		7.40 pm	Watch TV	L			
1.00 pm	Prepare Lunch	M	8.00 pm	Watch TV	L			
1.20 pm	Eat lunch/ Watch TV	L	8.20 pm	Watch TV	L			
1.40 pm	Watch TV	L	8.40 pm	REST				

\* H = High Activity (energy use) M = Medium Activity L = Low Activity

This example shows a carefully planned timetable with rests and different levels of activity spread throughout the day. Grey shaded areas highlight REST times spread throughout the day.

EXAMPLE

EXAMPLE

EXAMPLE

EXAMPLE

**ACTIVITY**

**RESTING**

**DAILY TASKS**

**DAILY ROUTINE PLANNER**

7.00 am		12.15 pm		5.30 pm	
7.15 am		12.30 pm		5.45 pm	
7.30 am		12.45 pm		6.00 pm	
7.45 am		1.00 pm	<b>LUNCH</b>	6.15 pm	
8.00 am	<b>GET UP</b>	1.15 am		6.30 pm	
8.15 am		1.30 pm		6.45 pm	
8.30 am	<b>BREAKFAST</b>	1.45 pm		7.00 pm	<b>TEA</b>
8.45 am		2.00 pm		7.15 pm	
9.00 am		2.15 pm		7.30 pm	
9.15 am	<b>SHOWER</b>	2.30 pm		7.45 pm	
9.30 am		2.45 pm		8.00 pm	
9.45 am		3.00 pm		8.15 pm	
10.00 am		3.15 pm		8.30 pm	
10.15 am		3.30 pm		8.45 pm	
10.30 am		3.45 pm		9.00 pm	
10.45 am		4.00 pm	<b>CHOCOLATE!</b>	9.15 pm	
11.00 am		4.15 pm		9.30 pm	
11.15 am		4.30 pm		9.45 pm	
11.30 am		4.45 pm		10.00 pm	<b>BED</b>
11.45 am		5.00 pm		10.15 pm	
12.00 pm		5.15 pm		10.30 pm	

## DAILY ROUTINE PLANNER (with activity categories)

Time	Activity	*	Time	Activity	*	Time	Activity	*

\* H = High Activity (energy use)    M = Medium Activity    L = Low Activity

## DAILY ROUTINE PLANNER (with activity categories)

Time	Activity	*	Time	Activity	*	Time	Activity	*
7.00 am			2.00 pm			9.00 pm		
7.20 am			2.20 pm			9.20 pm		
7.40 am			2.40 pm			9.40 pm		
8.00 am			3.00 pm			10.00 pm		
8.20 am			3.20 pm			10.20 pm		
8.40 am			3.40 pm			10.40 pm		
9.00 am			4.00 pm			11.00 pm		
9.20 am			4.20 pm			11.20 pm		
9.40 am			4.40 pm			11.40 am		
10.00 am			5.00 pm			12.00 am		
10.20 am			5.20 pm					
10.40 am			5.40 pm					
11.00 am			6.00 pm					
11.20 am			6.20 pm					
11.40 am			6.40 pm					
12.00 pm			7.00 pm					
12.20 pm			7.20 pm					
12.40 pm			7.40 pm					
1.00 pm			8.00 pm					
1.20 pm			8.20 pm					
1.40 pm			8.40 pm					

\* H = High Activity (energy use)    M = Medium Activity    L = Low Activity

### WEEKLY ROUTINE PLANNER (with activity categories)

TIME	MONDAY	*	TUESDAY	*	WEDNESDAY	*	THURSDAY	*	FRIDAY	*	SATURDAY	*	SUNDAY	*
8.00-8.15am	Get up/ Get breakfast	M	Get up/ Get breakfast	M	Get up/ Get breakfast	M	Get up/ Get breakfast	M	Get up/ Get breakfast	M	Get up/ Get breakfast	M	Get up/ Get breakfast	M
8.15-9.30 am	Watch TV	L	Watch TV	L	Watch TV	L	Watch TV	L	Watch TV	L	Watch TV	L	Watch TV	L
9.30-10am	Shower	H	Bath	H	Shower	H	Bath	H	Shower	H	Bath	H	Bath	H
10-11am	Rest		Rest		Rest		Rest		Rest		Rest		Rest	
11-12.30pm	Anything whilst sitting on sofa	L	Go shopping	H	Anything whilst sitting on sofa	L	Anything whilst sitting on sofa	L	Anything whilst sitting on sofa	L	Light Housework	H	Anything whilst sitting on sofa	L
12.30-1pm	Rest		Rest		Rest		Rest		Rest		Rest		Rest	
1.00 -1.15pm	Prepare Lunch	M	Prepare Lunch	M	Prepare Lunch	M	Prepare Lunch	M	Prepare Lunch	M	Prepare Lunch	M	Prepare Lunch	M
1.15-2.30pm	Eat Lunch/TV	L	Eat Lunch/TV	L	Eat Lunch/TV	L	Eat Lunch/TV	L	Eat Lunch/TV	L	Eat Lunch/TV	L	Eat Lunch/TV	L
2.30-3pm	Rest		Rest		Rest		Rest		Rest		Rest		Rest	
3-3.05pm	Stretching Exercises	H	Read Book	L	Stretching Exercises	H	Stretching Exercises	H	Stretching Exercises	H	Read Book	L	Stretching Exercises	H
3.05-4.30pm	Read book	L		Read book	L	Read book	L	Read book	L	Read book		L	Read book	L
4.30-5pm	Rest		Rest		Rest		Rest		Rest		Rest		Rest	
5-6.15pm	Anything whilst sitting on sofa	L	Anything whilst sitting on sofa	L	Anything whilst sitting on sofa	L	Anything whilst sitting on sofa	L	Anything whilst sitting on sofa	L	Anything whilst sitting on sofa	L	Anything whilst sitting on sofa	L
6.15- 6.30pm	Prepare tea	M	Prepare tea	M	Prepare tea	M	Prepare tea	M	Prepare tea	M	Ring for Pizza	L	Prepare tea	M
6.30-7pm	Rest		Rest		Rest		Rest		Rest		Rest		Rest	
7-8.40pm	Eat tea/TV	L	Eat tea/TV	L	Eat tea/TV	L	Eat tea/TV	L	Eat tea/TV	L	Pizza Night!	L	Eat tea/TV	L
8.40-9pm	Rest		Rest		Rest		Rest		Rest		Rest		Rest	
9-10.30pm	TV/Bed	L	TV/Bed	L	TV/Bed	L	TV/Bed	L	TV/Bed	L	TV/Bed	L	TV/Bed	L

\* H = High Activity (energy use) M = Medium Activity L = Low Activity. This example shows activity and rest has been spread evenly throughout each day and over the week. Grey shaded areas highlight high energy level activities spread throughout the week.



### WEEKLY ROUTINE PLANNER (with activity categories)

TIME	MONDAY	*	TUESDAY	*	WEDNESDAY	*	THURSDAY	*	FRIDAY	*	SATURDAY	*	SUNDAY	*

\* H = High Activity (energy use) M = Medium Activity L = Low Activity

## SYMPTOM SCORE CHART

SCORE	SCORE DESCRIPTION	ACTIVITY RECOMMENDATION
1	It can't get any worse than this.	1,2,3 scores probably result from severe onset and activity level should be extremely carefully managed <u>OR</u> if following a relapse, activity to be drastically reduced or even STOPPED completely short term (a couple of days).
<b>2</b>	Severe symptoms all day.	
3	Severe symptoms with some lessening of symptoms (more Severe than Bad).	
4	Bad symptoms all day with some worsening to Severe symptoms (more Bad than Severe).	4,5,6 scores probably mean been overdoing it and need to decrease activity levels (activity been at "just about manage it level", rather than "sustainable level") <u>OR</u> may be due to a specific occasion which required extra activity <u>OR</u> unwell with a head cold for example.
<b>5</b>	Bad symptoms all day.	
6	Bad symptoms at times with some lessening of symptoms to Mild, <u>OR</u> Mild symptoms all day.	
7	Mainly symptom free. Symptoms that are Bad last only for a short time eg an hour or so on waking or in the evening, <u>OR</u> Mild and last slightly longer. Recovery from symptoms during same day may be noticeable.	7,8,9 scores are probably an indication that current level of activity is sustainable.
<b>8</b>	Just about symptom free all day.	
9	Symptom free all day and feel energised.	

The chart is not meant to be used to judge HOW MUCH you do, but rather how well you are at your current activity levels. The Symptom Score for each day can be entered onto the Daily Diary Grid to help monitor your progress.

We all have different interpretations as to what is a Severe, Bad or Mild day, and what this means in terms of Activity Recommendation. You could use the blank chart to fill in your own Score Descriptions and Activity Recommendations.

Alternatively you could use: 1 (Severe) 2 (Bad) 3 (Mild) and use + or – instead of numbers to make nine distinctive levels, as above.

It's important to be aware of daily variations. When recorded, scores can show reactions to lifestyle changes, activity, medications etc. Don't let it all blur into one.

# SYMPTOM SCORE CHART

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## Daily Diary Grid

Sheet No:

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Date	Overnight Sleep/ In Bed	Daytime Sleep	Resting	Medium Activity	High Activity	Trips Out	Symptom Score	Comments/Symptom Description
Mon 4 Apr	7 <sup>1</sup> / <sub>9 1/2</sub>	—	2 1/2 hrs	1 1/2 hrs	10 mins	—	7	Okish. Some mild symptoms first thing in the morning.
Tues 5 Apr	7 <sup>1</sup> / <sub>9 1/2</sub>	—	2 1/2 hrs	1 1/2 hrs	—	—	7	———— " —————
Wed 6 Apr	7 <sup>1</sup> / <sub>9 3/4</sub>	—	2 <sup>3</sup> / <sub>4</sub> hrs	1 1/2 hrs	—	Dentist 1 3/4 hrs	7	Long time at dentist. Felt myalgic in the evening
Thur 7 Apr	8 10	1 hr lunchtime	3 hrs	1 1/4 hrs	—	—	5	Myalgia II all day, especially throat + glands.
Fri 8 Apr	8 9 3/4	45 min lunchtime	3 hrs	1 1/4 hrs	—	—	5	Bad all day.
Sat 9 Apr	7 <sup>3</sup> / <sub>9 1/2</sub>	—	2 3/4 hrs	1 1/2 hrs	—	—	6	Symptoms not as bad as yesterday, but bad enough!
Sun 10 Apr	7 <sup>1</sup> / <sub>9 1/2</sub>	—	2 3/4 hrs	1 1/2 hrs	—	—	6	More symptoms in morning, less in afternoon, Okish in evening
Mon 11 Apr	7 <sup>3</sup> / <sub>9 1/2</sub>	—	2 1/2 hrs	1 1/2 hrs	5 min	—	7	Only 5 mins of High activity instead of 10, because of Dentist.
Tues 12 Apr	7 9 1/2	—	2 1/2 hrs	1 1/2 hrs	—	—	7	Fingers-crossed have recovered from tip to Dentist.
Wed 13 Apr	7 <sup>1</sup> / <sub>9 1/2</sub>	—	2 1/2 hrs	1 1/2 hrs	—	—	7	Okish all day.
Thur 14 Apr	7 <sup>1</sup> / <sub>9 1/2</sub>	Drowsy afternoon	2 1/2 hrs	1 1/2 hrs	—	—	6	Not so well today - no reason? Joints achey especially
Fri 15 Apr	7 <sup>1</sup> / <sub>9 3/4</sub>	—	2 1/2 hrs	1 1/4 hrs	—	—	7	Dropped medium activity by 15 mins today because of yesterday
Sat 16 Apr	6 <sup>3</sup> / <sub>9 1/4</sub>	—	2 1/2 hrs	1 1/2 hrs	—	—	7	Watched a lot of TV today! Bad night last night.
Sun 17 Apr	7 <sup>1</sup> / <sub>9 1/2</sub>	—	2 1/2 hrs	1 1/2 hrs	—	—	7	Okish - Thinking about increasing medium activity soon.
Mon 18 Apr	7 9 1/2	—	2 1/2 hrs	1 1/2 hrs	10 min	—	7	Very weak + Shaky on waking, but cleared after 2 hours, then Okish.
Tue 19 Apr	7 <sup>1</sup> / <sub>9 1/2</sub>	—	2 1/2 hrs	1 1/2 hrs	—	—	7	Bored. Bored. Bored.
Wed 20 Apr	7 9 1/2	—	2 1/2 hrs	1 3/4 hrs	—	—	7	Increased medium activity by 15 mins. Felt ok in evening
Thu 21 Apr	7 <sup>1</sup> / <sub>9 1/2</sub>	—	2 1/2 hrs	1 3/4 hrs	—	—	7	Still feel ok from extra medium activity
Fri 22 Apr	7 <sup>3</sup> / <sub>9 3/4</sub>	—	2 1/2 hrs	1 3/4 hrs	—	—	7	Okish all day.
Sat 23 Apr	7 9 1/4	—	2 1/2 hrs	1 3/4 hrs	—	—	7	Lots of people here this morning. But all ok.
Sun 24 Apr	7 <sup>1</sup> / <sub>9 1/2</sub>	—	2 1/2 hrs	1 3/4 hrs	—	—	7	Seem to be fine with extra medium activity. Yay!

# DAILY DIARY GRID - SUGGESTED COLUMN HEADINGS

This Grid helps to build up a record of information you can use to assess your routine and monitor the changes you've made over days/weeks/months. The column headings can be general, eg Low, Medium and High Activity or could be for specific activities that you do daily or gradually want to increase.

## Daily Diary Grid

Sheet No:

Date	Overnight Sleep/ In Bed	Daytime Sleep	Resting	Low Activity	Medium Activity	High Activity	Symptom Score	Comments/Symptom Description

## Daily Diary Grid

Sheet No:

Date	Overnight Sleep/ In Bed	Daytime Sleep	Resting	Sitting Up	Reading	Using Mobile Phone	Symptom Score	Comments/Symptom Description

## Daily Diary Grid

Sheet No:

Date	Overnight Sleep/ In Bed	Daytime Sleep	Resting	Reading	TV	Walking	Symptom Score	Comments/Symptom Description

## Daily Diary Grid

Sheet No:

Date	Overnight Sleep/ In Bed	Daytime Sleep	Resting	Reading	TV	Stretch Exercises	Symptom Score	Comments/Symptom Description

## Daily Diary Grid

Sheet No:

Date	Overnight Sleep/ In Bed	Daytime Sleep	Resting	Medium Activity	High Activity	Trips Out	Symptom Score	Comments/Symptom Description

Daily Diary Grid

Sheet No:

Date							Symptom Score	Comments/Symptom Description

## Symptom Categories & Warning Signs

This is a list of various symptom clusters that are specific to me. Some of the descriptions may appear to overlap but each category does feel physically different and sometimes has an identifiable trigger.

Category	Symptom Description
<b>Fatiguey</b>	Weak, weary, drowsy, feel cold, sore throat, heavy eyes, slightly raised temperature, sensitive skin, headache. Increased appetite. <i>Generally get this after too much activity.</i>
<b>Myalgia</b>	Tight/heavy across the shoulders, muscle ache and weakness in arms, legs & stomach (and all over?), joint pain (knees, elbows and fingers), sore throat, swollen glands, drowsy. <i>Closest to the initial onset of the ME and can reappear with a head cold or virus</i>
<b>Heavy Stuff</b>	Whole body feels heavy and weighed down as though walking around wrapped in an exceptionally heavy cloak. Feel drowsy
<b>Stretchy Leg Myalgia</b> (and sometimes arms too)	Occurs after bending down and stretching muscles in back of legs. Gradual weakness/myalgia spreads up from back of legs throughout the body and increases in severity over the following few hours. Can take several days to recover. <i>(Stopped doing stretching exercises because of this one!)</i>
<b>Done Too Much Activity But OKish</b>	Muscles feel overused especially in arms and legs, but ME/CFS symptoms do not appear. <i>This one's the rarest, but OK!!!</i> It's important to recognise normal tiredness too.

The following are warning signs that can precede some of the above. Taking quick action can sometimes prevent any worsening of symptoms into one of the above categories.

My Warning Signs	Action to be Taken
Overnight sleep longer than 8 hours	Slow down – might need to go back to bed, but do not sleep past 11.30 am otherwise overnight sleep difficult later on.
Impossible to stay awake during the day (usually the afternoon)	Sleep immediately. Decrease activity (add in an extra rest day?)
Increased appetite	Eat enough to feel comfortable. Review timetable and recent activity.

# Symptom Categories & Warning Signs

Category	Symptom Description

Warning signs	Action to be Taken