

ME Forms

Free forms, diaries and charts for the management of ME/CFS.

(Myalgic Encephalomyelitis/Chronic Fatigue Syndrome)



INTRODUCTION

I am "90% expert" in the ME/CFS that I have, and my hope is that you can become your own expert. I have improved my quality of life by pacing and sticking to a well-balanced routine.

I have built this website for others with ME/CFS, or Health Professionals treating people with ME/CFS, to help manage 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, recording and regularly reviewing your own routine. This user-friendly system can help you manage your time and, more importantly your energy.

The 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. They can be downloaded as a Word document, a PDF file or a JPEG which you can edit and print.

If you have found this free website useful, you may wish to make a donation to ME Research UK.

HOW TO USE THE FORMS

There are 8 different forms/charts/diaries. Click on one of the above buttons to take you to the relevant page. They can be used in the order above (A-H), or individually, to help you build up an overall picture of your current activity. You can then plan a newly balanced routine with properly managed activity, pacing and resting. On each page there are examples of completed forms together with blank templates for you to download. Some pages have several completed examples or several variations of the blank templates. Decide which template best suits you, then download it (for free). Some forms have extra notes at the bottom for with further explanation.

A Activity Categories

The Activity Categories Form helps you to think about the different types of activity you do and whether each task uses a High, Medium or Low amount of energy. Categorising activity in this way will help you to understand how you spend your energy. You can also use this form with the Daily Record of Activity, Weekly Record of Activity, Daily Routine Planner, Weekly Routine Planner and Daily Diary Grid. There are further explanatory notes on the form itself. There are 2 examples and 1 blank template of this form.

B Daily Record of Activity

A form on which you can record in detail what you are currently doing during the day, how long you do it for and whether it is High, Medium or Low energy use. You could use this form for a couple of days if your daily routine does not vary much, or for longer if your days vary over a week or two. Build up a picture of how you spend your energy and consider the strengths and weaknesses of your current lifestyle in relation to your management of the ME/CFS. You can then use this completed form to help you design a more balanced routine on the Daily/Weekly Planner. If your daily routine does not need to be recorded in detail you may wish to use the Weekly Record of Activity Form instead to build up a picture of your current activity. There are 2 completed examples and 2 blank templates of this form.

C Weekly Record of Activity

Not as detailed as the Daily Record of Activity but the same objective. Keeping a note of what you do and when you do it can help you see your energy spend over a week and assess the strengths and weaknesses of your current lifestyle. You can use this completed form to help you design a more balanced routine on the Daily/Weekly Routine Planner. There is 1 completed example and 1 blank template of this form.

D Daily Routine Planner

You can plan to carry out High, Medium and Low activities in the most useful way throughout the day. If you have completed the Activity Categories form and Daily/Weekly Record of Activity they can also help you to consider a more balanced routine. One example shows how you can use sticky notes to plan the days rest and activity periods, but not necessarily the detail of what you will actually be doing. The routine can then be adjusted when you feel ready to increase activity (or decrease in the case of a relapse!). If you use sticky notes you can move them around accordingly. There are 2 examples and 3 blank templates of this form.

E Weekly Routine Planner

You can plan when to carry out High, Medium and Low activities in the most beneficial way throughout the week. Perhaps you have a High activity which you could do on two different days in the week, several days apart? If you have completed the Activity Categories form and the Daily/Weekly Record of Activity they can help you plan a more balanced routine. The routine can then be adjusted when you feel ready to increase activity (or decrease in the case of a relapse). There is 1 completed example and 1 template of this form.

F Symptom Rating Chart

Use this form to help you work out a rating or scoring system based on how severe or mild the ME symptoms are each day. If you look at the form you will see I suggest a score of 1-9, 9 being the most well. It is not necessary to consider a 9 as how you were before you developed ME. You can use your own interpretation of illness and wellness that is appropriate to you on good and bad days. Symptom Rating Chart helps you to look at the ME/CFS more objectively. You may wish to record a daily rate/score on the Daily Diary Grid. There is 1 example and 2 templates of this form.

G Daily Diary Grid

This grid is completed once a day to record important daily statistics - hours slept overnight, hours slept and rested during the day, time spent doing High, Medium and Low activity etc. I provide some blank column headings on one template so you can decide what you would like to record eg use a column to record a specific activity that you are currently gradually increasing, for example using a computer. If you increase the activity weekly or monthly this is the place to record it. You can look back over the previous weeks/months to see what you were doing, and how many minutes or hours a day you were doing it for. It is a snapshot of each day to build up a picture of what works and what doesn't. On this form there are also columns for the Symptom Rating Score and to make a few notes. There are 2 examples and 2 blank templates of this form.

H Symptom Categories and Warning Signs

This form will be specific to you. Your symptoms will present themselves in various different ways. Labelling these symptoms or each cluster of symptoms may give you greater understanding and objectivity of this confusing illness. I have specific symptoms that appear if I overstretch my arms or legs - identifying this and labelling it has helped me to prevent it happening (mostly). The section to complete on warning signs can help you to 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. Click on either the Word or PDF link below the form to open the document on your computer. Alternatively, right click on any form and choose "Save picture as..." to save it as a JPEG to your computer. Forms may be edited and printed to suit your needs.

TOP TEN TIPS

- 1 There are no tablets for ME/CFS. The best medicine is good **quality rest** (in a quiet room, supported by pillows or cushions), good **sleep** and a balanced, **manageable routine**.
- 2 If you have a **secondary** medical problem, (even a minor one), try to get it **treated** or managed - it may be having a **negative** impact on the ME/CFS.
- 3 **Pacing** is not just about the time it takes to do an **activity** but also the amount of **energy required**, so make a **realistic plan** and stick to it – don't get carried away.
- 4 Buy a **stopwatch** to limit yourself when doing an activity. When it beeps, STOP.
- 5 **Little things make a difference**, for example (i) adjust a pillow or cushion to make sure you are properly 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?
- 6 **Giving way** to the symptoms is **not** the same as **giving in**, but sometimes it's **necessary**.
- 7 Let the symptoms tell you they are there, don't go looking for them.
- 8 If you **overdo** it – don't give yourself a hard time, (but make sure it was for **something worthwhile**!)
- 9 Exercise or **activity** needs to be based on **recovery** and strengthening - NOT on a keep fit "go for the burn" basis.
- 10 If you're on the phone when your rest time arrives, tell them you'll ring back later.

AND A FEW MORE

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.

When deciding if something is beyond your **current boundaries**, look at what you have been achieving recently. Match the level or slightly increase – **do not make big leaps**.

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

Consider 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 **cope with extra activity** on odd days 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, or **3 minutes activity 3 times a hour**, depending on how severely you are affected?

If you're having a **bad time**, you need to **stabilise** and go back to a **routine** you know works, before changing anything.

Don't wait until you "recover" from ME/CFS to start a new hobby or project – start it now, a little bit at a time, in manageable chunks.

ABOUT ME

Now (2017)

My name is Sue and I live in the south-east of England. I can currently drive myself to the local supermarket to go shopping and on another day meet a friend for coffee and cake, both in the same week. I can attend all medical appointments, dentist, doctor etc. Most of my time is spent at home where I can 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. Resting involves laying down in a quiet room being supported by several pillows. I do not fall asleep when I rest. I have not settled for this daily/weekly routine - I plan (hope) to be able to do more.

Before ME/CFS

I had a great job working in IT for a large company. I was also very sporty and regularly played netball, squash and enjoyed cycling. I loved driving and would often go away for weekends.

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-type illness). 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 chairbound/housebound for the next few years, then suffered from an additional mild chronic illness which impacted on the ME catastrophically. In 2008 I became bedbound for several months. I gradually improved with very careful pacing of activity and sticking very strictly to a 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 still sticking to a strict routine, making increases and adjustments when I felt ready - which could be days, weeks or even months later.

Treatments tried since 1998 - some of these may work for you, this is my experience only

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 - no obvious benefit.

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

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. At one point I could walk for 30 minutes for several days, but could do nothing else, but then

relapsed anyway. Every combination I tried ended in a relapse. It was only when I stopped in 2008 and focused more and more on pacing, that I began to improve.

Since 2008 the most beneficial "treatment" for me, has been pacing and careful planning. 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.

CONTACT

I am very happy to receive any feedback/suggestions about ME Forms. 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. My 'expertise' relates only to the ME/CFS I've had since 1998 - I hope this website helps you to become your own expert.

Please use the form below to get in touch or email me direct at info@meforms.org.

Name: *

Email: *

Subject: *

Message: *

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 1 hour)</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
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

[illegible]

- 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
TOTALS	Sleep: 10¾ hrs Rest: 45 mins Low: 10hr35min Medium: 1hr10min High: 30 min		

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:

[illegible]

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 ^{am}	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 ^{am}	Wash/Dress	4:15 ^{pm}	Eat / TV
8:10	TV	10am	Shower	10:30	Bed (Sleep)	1:30	Eat	11am	Eat	11:00 ^{am}	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 ^{pm}	Lunch	12pm	Bed (Doze)	5pm	Bed	12pm	Bed	1:15	Bed (Sleep)		
1:30	Bed	1:40 ^{pm}	TV/Phone	1:30 ^{pm}	Lunch	6pm	Eat	2pm	Read	2:15	TV		
4:30	Read in Bed	6pm	Rest/Sleep	1:45 ^{pm}	Watch TV	6:15pm	TV	4pm	Bath	6:15	Sleep		
5:30	Dinner	9pm	Eat / TV	5:30 ^{pm}	Rest	10pm	Go to Bed	5pm	Bed (Sleep)	7:30	Eat		
6pm	Watch TV	1am	Go to Bed	6pm	Phone/TV			6:30 ^{pm}	Eat	7:45 ^{pm}	TV		
12pm	Go to Bed			7pm	Eat			6:45 ^{pm}	Phone	9pm	Go to Bed		
				7:10 ^{pm}	TV			7:45 ^{pm}	TV				
				10pm	Go to Bed			8pm	Dozed				
								10pm	Bed, but couldn't				
									Sleep till				
									1am.				

WEEKLY RECORD OF ACTIVITY

[illegible]

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	LUNCH	6.15 pm	
8.00 am	GET UP	1.15 am		6.30 pm	
8.15 am		1.30 pm		6.45 pm	
8.30 am	BREAKFAST	1.45 pm		7.00 pm	TEA
8.45 am		2.00 pm		7.15 pm	
9.00 am		2.15 pm		7.30 pm	
9.15 am	SHOWER	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	CHOCOLATE!	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	BED
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	*
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			6.15 pm		
8.00 am			1.15 pm			6.30 pm		
8.15 am			1.30 pm			6.45 pm		
8.30 am			1.45 pm			7.00 pm		
8.45 am			2.00 pm			7.15 pm		
9.00 am			2.15 pm			7.30 pm		
9.15 am			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			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		
11.45 am			5.00 pm			10.15 pm		
12.00 pm			5.15 pm			10.30 pm		

* 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

DAILY ROUTINE PLANNER (with activity categories)

[illegible]

* 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		L	Read book	L	Read book	L	Read book	L		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)

[illegible]

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

SYMPTOM RATING CHART

RATING No	RATING 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).
2	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.
5	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.
8	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 Rating Number for each day can be entered onto the Daily Diary Grid to help monitor your progress.

We will 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 Rating Descriptions and Activity Recommendations.

(Alternative Rating Nos could be: 1 (Severe) 2 (Bad) 3 (Mild) and add a + or – sign against the rating as appropriate for that day. This would still represent 9 different, but meaningful levels.)

SYMPTOM RATING CHART

RATING No	RATING DESCRIPTION	ACTIVITY RECOMMENDATION
1	It can't get any worse than this.	
2	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).	
5	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.	
8	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 Rating Number can be entered onto the Daily Diary Grid to help monitor your progress.

We will all have different interpretations as to what is a Severe, Bad or Mild day, and what this means in terms of Activity Recommendation. Use this chart to fill in your own Activity Recommendations.

SYMPTOM RATING CHART

RATING No	RATING DESCRIPTION	ACTIVITY RECOMMENDATION

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 Rating Number for each day can be entered onto the Daily Diary Grid to help monitor your progress.

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

Daily Diary Grid

Sheet No:

54

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

DAILY DIARY GRID - SUGGESTED COLUMN HEADINGS

The headings you choose for the 3 blank columns could be three different areas of activity that you hope to gradually increase. If you record it on the Daily Diary Grid, you can go back and see how often and by how much you increased that activity and what effect it had on you.

Daily Diary Grid

Sheet No:

Date	Overnight Sleep/ In Bed	Daytime Sleep	Resting	Sitting Up	Reading	Moving Around	Symptom Rating	Comments/Symptom Description

Daily Diary Grid

Sheet No:

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

Daily Diary Grid

Sheet No:

Date	Overnight Sleep/ In Bed	Daytime Sleep	Resting	Low Activity	Medium Activity	At Work	Symptom Rating	Comments/Symptom Description

Daily Diary Grid

Sheet No:

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

Daily Diary Grid

Sheet No:

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

Daily Diary Grid

Sheet No:

[illegible]

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
Myalgia 1	Tight/heavy across the shoulders, muscle ache in arms, legs & stomach, weak, feel cold, joint pain (knees, elbows and fingers), sore throat, swollen glands, drowsy. <i>Closest to the initial onset of the ME and reappears with a head cold or virus.</i>
Myalgia 2	Weak, weary, drowsy, feel cold, sore throat, heavy eyes, slightly raised temperature, sensitive skin. Can also develop other symptoms eg headache, numbness in lips and toes; pinpricks and increased appetite. <i>Generally get this after too much activity.</i>
Myalgia Attack	Feels like whole body being squeezed, eyes water, pin pricks, joints and muscles ache, sore throat, headache, drowsy. Lasts from 10 minutes to several hours or even longer. Can come and go in waves. Feel washed out afterwards for hours or days depending on how long it lasts. <i>Appears during a prolonged bad spell.</i>
Bouncing Myalgia	One, two or three different symptom categories come and go or “bounce” throughout the day(s). <i>Usually due to something new that the body cannot tolerate, eg a new medication. Not due to activity.</i>
Myalgia Pain	Deep ache/burning pain. Almost takes breathe away, makes eyes water, clammy hands. <i>This one can get very bad.</i>
Heavy Stuff	Whole body feels heavy and weighed down as though walking around wrapped in an exceptionally heavy cloak. <i>Sometimes wake up with this when it can last for about 2 hours and then change to another category.</i>
Deeply Weak and Shaky	Through to the bones, all over body. <i>Sometimes wake up with this when it can last for about 2 hours and then change to another category.</i>
Spongy Stuff	Legs feel like they do after pins & needles with blood rushing back into limbs. Also feel heavy, tired and often feel cold too. <i>Usually appears with one of the other categories.</i>
Stretchy Leg Myalgia (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. Takes several days to recover. <i>(Stopped doing stretching exercises because of this one!)</i>
Done Too Much Activity But OKish	Muscles feel overused especially in arms and legs, but symptoms do not progress. <i>This one's the rarest, but OK!</i>

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.

Warning signs	Action to be Taken
Feel chilly	Slow down and warm up quickly
Dull ache in lower right leg	Slow down and keep leg warm
Overnight sleep longer than 8 hours	Slow down – might need to go back to bed late morning, but do not sleep past 2 pm otherwise overnight sleep difficult later on.

Symptom Categories & Warning Signs

Category	Symptom Description

Warning signs	Action to be Taken