

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



Introduction

I have had ME since 1998 and I have built this website for others with ME, or Health Professionals treating people with ME, to provide assistance with managing the illness. There are Forms, Charts and Diary Templates which can help you to manage your time and, more importantly, your energy. This is not a cure, simply paper-based tools to help you increase your understanding of how the ME impacts on you, which in turn can help you gain, or increase your management of the illness and (hopefully) make improvements too.

ME Forms provides you with various examples and blank templates of each form, to help you design, plan and record your own routine. The idea is to help you document something that works specifically for you and that you can refer back to and amend or update at anytime. All the blank templates can be downloaded onto a computer as a Word document, a PDF file or a JPEG and can be freely edited by you.

I have used the forms for several years - have they helped me? Yes. Will they help you? I hope so. For example, the Daily Diary Grid sheet takes a few seconds to complete at the end of each day. It provides a snapshot of the amount of rest/activity/sleep for that day which can be very useful to look back as you build up information over several weeks or months. I provide completed examples of all the forms.

I now feel as though I am a "90% expert" in the ME that I suffer from and my hope is that you can become your own expert.

Some of you may find this type of record-keeping is not for you. Not a problem. Maybe you just want to use one or two forms, or maybe you already do something similar. Indeed, if you use something yourself which you think others may benefit from, please use the Contact page to tell me about it and I could add it to this website.

This website is free to all users. If you have found it useful, you may wish to make a donation to meresearch.org.uk.

How to Use the Forms

There are 8 different forms/charts/diaries. They can all be used individually and some can be used in conjunction with other forms to help you build up an overall picture/plan. Clicking on one of the above buttons will take you to the relevant page. On each page there are examples of completed forms together with blank templates for you to download. Some pages have several examples of the same form and/or several variations of the blank templates. Have a look through and decide which template best suits you, then download it (for free) on to your computer. Some forms have extra notes at the bottom for 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. You can build up a picture of how you spend your energy and consider the strengths and weaknesses of your current lifestyle in relation of your management of the ME. 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 will 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 how 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 will 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 your experience of illness and wellness that is appropriate to you on good and bad days. As you (hopefully) improve you can adjust the rating system to fit with your current level of health. You may wish to record the 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 at the end of each day to record essential 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 focusing on increasing, for example using a computer. 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 and to varying degrees. Labelling these symptoms or each cluster of symptoms may give you greater understanding and objectivity of this confusing illness. 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 one 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.

About me

My name is Sue and I live in the south-east of England. I can currently drive to the local supermarket and on another day meet a friend for coffee and cake, both in the same week. Most of my days are 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 with my body supported by several pillows. I have not settled for this daily/weekly routine - I plan (hope) to be able to do more.

Back in February 1998 I had a great job in IT and I played netball, squash and enjoyed cycling. Then on the 12th of that month I woke up feeling as though all the muscles in my arms, legs and torso were no longer functioning. Yes there was pain too, or should I say extreme discomfort, but the two main sensations were a weakness and heaviness that was overwhelming. My glands were swollen, my throat sore and every time I moved my head I felt as though someone was kicking it. I had 6 weeks off work and then struggled back part-time, relapsed, returned to work, relapsed... (I had a very understanding employer). I finally had to stop working, or rather my body finally stopped working, in 1999.

I remained chairbound/housebound for the next few years, then suffered from an additional mild chronic illness which impacted on the ME catastrophically. I became bedbound. 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 still sticking to a strict routine, making increases and adjustments when I felt ready - which could be days, weeks or even months later.

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 feedback about ME Forms. Also, please contact me if you have suggestions about this website or wish me to create another version of an existing form. Perhaps you have your own form, chart or diary which you think others may benefit from that you could send to me or describe and I could add it to this website.

Unfortunately 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 I have suffered from since 1998. I hope this website helps you to become your own expert.

| Please use the | form below t | o get in touc | h or email me | direct at info | @meforms.org. |
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| Message: * | | |

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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) |
| Reading a book (up to 1 hour) | Reading a book (more than 1hour) | Walking informal |
| Phone conversations | Sitting in upright chair (up to 30 mins) | Sitting in upright chair (more than 30 mins) |
| 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

EXAMPLE EXAMPLE EXAMPLE EXAMPLE EXAMPLE EXAMPLE EXAMPLE

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 |
| Talking up to 15 mins | Talking 15-30 minutes | Talking more than 30 minutes (hi-cog) |
| Reading a book up to 15 mins | Reading a book 15 to 30 mins | Reading a book more than 30 mins (hi-cog) |
| | 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 |
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ACTIVITY CATEGORIES

| LOW ENERGY USE | MEDIUM ENERGY USE | HIGH ENERGY USE | | |
|----------------|-------------------|-----------------|--|--|
| Low High | Low High | Low High | | |
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- 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.

EXAMPLE EXAMPLE EXAMPLE EXAMPLE

Date: Wed 16 June

Daily Record of Activity (with activity categories)

| 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 |
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| TOTALS | Sleep: 103/4 | hrs Rest : 45 n | nins 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.

| Dail | y Record | of | Activity | (with activity | categories) |
|------|----------|----|----------|----------------|-------------|
|------|----------|----|----------|----------------|-------------|

Date:

| Time | Minutes/ Hours | High/ Medium/ Low Activity | Activity Descri | ption | |
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| TOTALS | Sleep: | Rest: | Low: | Medium: | High: |

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

WEEKLY RECORD OF ACTIVITY

| TIME | MONDAY | TIME | TUESDAY | TIME | WEDNESDAY | TIME | THURSDAY | TIME | FRIDAY | TIME | SATURDAY | TIME | SUNDAY |
|------|-------------|--------|------------|-------|-------------|---------|-----------|--------|-------------|---------|--------------|--------|----------|
| 7am | Get up | gan | Get up | 8am | Wake up | 7pm | Wake up | 8am | Get up | 9.30 | Get up | 8am | Wate op. |
| 7-10 | WatchTV | 9-10 | Break fast | 10 am | Get Up | 12pm | Get up | 8-10am | Break fast | 9.30 | Eat | Apm | Get up. |
| 8am | Break fast | 9,15 | Watch TV | 10.15 | Breakfast | 12·10pm | Read | 8.20pm | TV | 10:30cm | Wash / Dress | 4.15,0 | Eat ITV |
| 8.10 | TV | 10am | Shower | 10-30 | Bed (Sleep) | 1.30 | Eat | llan | Eat | 11.00 | Go Shopping | 8pm | Bed. |
| Man | Bed (Sleep) | 10-30 | Phone/TV | 11-30 | Bath | 1.45 | Read | 11.15 | TV | lpm | , , | 8 | |
| Ipm | Shower | 1.30pm | Lunch | 12pm | Bed (Doze) | 5pm | Bed | 12pm | Bed | 1.15 | Bed (Sleep) | | |
| 1-30 | Bed | 1-40pm | TV/Phone | 1.30 | n Lunch | 6pm | Eat | 2pm | Read | 2.5 | TV | | |
| 4.30 | | | | | Watch TV | 615pm | TV | Hpm | Bath | 6-15 | Sleep | | |
| | | | Eat/TV | | | | Go to Bed | 5pm | Bed (Sleep) | 7.30 | Eat | | |
| 6pm | Watch TV | lam | Go to Bed | 6pm | Phone / TV | | | 630pm | Eat | 7-45pm | TV | | |
| 12pm | Go to Bed | | | 7pm | Eat | | | 6.45pm | Phone | apm | Go to Bed | | |
| - | | | | 7.10p | TV | | | 7.45pm | TV | | | | |
| | | | | 10pm | Go to Bed | | | Spr | Dozed | | | | |
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THIS EXAMPLE SHOWS A WEEK WITH NO ROUTINE/PLANNING.

WEEKLY RECORD OF ACTIVITY

| TIME | MONDAY | TIME | TUESDAY | TIME | WEDNESDAY | TIME | THURSDAY | TIME | FRIDAY | TIME | SATURDAY | TIME | SUNDAY |
|------|--------|------|---------|------|-----------|------|----------|------|--------|------|----------|------|--------|
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|----------|------------------------------------|-----|---------|--------------------------------|-------------|----------|----------|---------------|
| 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 | Г |
| 8.00 am | Get up/ Get breakfast | М | 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 | Н | 4.00 pm | Computer | Г | | | |
| 9.20 am | REST | | 4.20 pm | Computer | L | | | |
| 9.40 am | REST | | 4.40 pm | REST | | | | |
| 10.00 am | Get dressed/ | Н | 5.00 pm | Pottering about/ Tidying up | М | | | |
| 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 | М | | | |
| 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 | М | 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.

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 | 2 |
| 12.00 pm | | 5.15 pm | | 10.30 pm | , , |

| 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 am | | | 6.30 pm | | |
| 8.15 am | | | 1.30 pm | | | 6.45 pm | | |
| 8.30 am | | | 1.45 pm | | | 7.00 pm | | |
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| 9.00 am | | | 2.15 pm | | | 7.30 pm | | |
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| 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

| 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 | | |
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| 9.00 am | | | 4.00 pm | | | 11.00 pm | | |
| 9.20 am | | | 4.20 pm | | | 11.20 pm | | |
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| 1.40 pm | | | 8.40 pm | | | | | |

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

| Time | Activity | * | Time | Activity | * | Time | Activity | * |
|------|----------|---|------|----------|---|------|----------|---|
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^{*} H = High Activity (energy use) M = Medium Activity L = Low Activity

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WEEKLY ROUTINE PLANNER (with activity categories)

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

| TIME | MONDAY | * | TUESDAY | * | WEDNESDAY | * | THURSDAY | * | FRIDAY | * | SATURDAY | * | SUNDAY | * |
|------|--------|---|---------|---|-----------|---|----------|---|--------|---|----------|---|--------|---|
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^{*} H = High Activity (energy use) M = Medium Activity L = Low Activity

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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 | | | |
| 2 | Severe symptoms all day. | activity level should be extremely carefully managed OR if following a relapse, activity to be drastically | | | |
| 3 | Severe symptoms with some lessening of symptoms (more Severe than Bad). | reduced or even STOPPED completely short term (a couple of days). | | | |
| 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 | | | |
| 5 | Bad symptoms all day. | to decrease activity levels (activity been at "just about manage it level", rather than "sustainable level") | | | |
| 6 | Bad symptoms at times with some lessening of symptoms to Mild, <u>OR</u> Mild symptoms all day. | OR may be due to a specific occasion which required extra activity OR unwell with a head cold for example. | | | |
| 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 | | | |
| 8 | Just about symptom free all day. | of activity is sustainable. | | | |
| 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 |
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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

| | | | | | | | | 0.1 |
|----------------|-------------------------------|---------------------|------------|--------------------|------------------|--------------------|-------------------|--|
| Date | Overnight Sleep/ In Bed | Daytime Sleep | Resting | Medium Activity | High Activity | Trips Out | Symptom Rating | Comments/Symptom Description |
| Mon 4 Apr | 石岩 | / | 2 El | 12 hrs | 10 mins | _ | 7 | Otish. Some mild symptoms first thing in the morning. |
| Tues 5 Apr | 74 | / | Zzho | 12 hrs | _ | _ | 7 | |
| Wed 6 Apr | 72/934 | _ | 23 hrs | 12 hrs | _ | Dentist 134 hrs | 7 | Long time at dentist. Fest myaggic in the evening |
| Thur 7 Apr | 8/10 | 1 hr Junchtime | 3 hrs | 14 hrs | , | _ | 5 | Myalgia II all day, especially throat + glands. |
| Fni 8 Apr | 8/934 | 45min Lunchtime | 3 hrs | 14 hrs | _ | _ | 5 | Bad all day. |
| Sat 9 Apr | 734 | _ | 23 hrs | 12 hrs | _ | - | 6 | Symptoms not as bad as yesterday, but bad enough! |
| San 10 Apr | 72/92 | / | 234 hrs | 12 hrs | _ | | 6 | More symptoms in morning, less in afternoon, Okish in evening |
| Mon 11 Apr | 734/1 | / | 2½ hrs | 12 hrs | 5min | 1 | 7 | only 5 mins of High activity instend of 10, because of Dentist. |
| Tues 12 Apr | 792 | _ | Ziz hrs | 1/2 hrs | _ | _ | 7 | Fingers - crossed have recovered from this to Dentist. |
| Wed 13 Apr | 72/92 | / | 2½ hrs | 12 hrs | - | - | 7 | Okish all day- |
| Thur 14 Apr | 7/9= | Drowsy agternoon | Zi hrs | là his | _ | - | 6 | Not so well today - no teason? Joints achey especially |
| Fri 15 Apr | 734/934 | / | Zi hrs | 1 hrs | _ | - | 7 | Dropped medium activity by 15 mins today because of senterday |
| Sat 16 Apr | 634/94 | _ | 21 hrs | 12 hrs | _ | - | 7 | Watched a lot of TV today! Bud night last night. |
| Sun 17 Air | 72/92 | / | 22 hrs | la hrs | _ | Section . | 7 | Otish. Thinking about increasing medium activity soon. |
| Mon 18 Apr | 7/92 | / | 2½ his | 12 hrs | 10 min | - | 7 | Very weak + Shaky on waking, but cleared after 2 hours, on then Okish. |
| Tue 19 Apr | 74/9/2 | / | 2½ hrs | 12 hrs | _ | _ | 7 | Bored. Bored. |
| Wed 20 Apr | 7/9/2 | _ | 2; his | 13 hrs | , | 1 | 7 | Increased medium activity by 15 mins. Felt ox in evening |
| Thu 21 Apr | 74/92 | | 2 hr | 134 hrs | _ | _ | 7 | Sty feel ox from extra medium activity |
| In: 22 Apr | 734/93 | _ | 21 his | 13 hrs | | - | 7 | Ottish all day. |
| Sut 23 Apr | 794 | / | 22 hs | 13 hrs | _ | _ | 7 | Lots of people here this morning. But all OK. |
| Sur 24 Apr | 72/92 |) Diama 0 11 0 | 22 his | 13/4 hrs | | _ | 7 | Seem to be fire with extra medium activity. Yay! |
| metorms. | org – Daily I | Diary Grid C | ompleted E | XAMPLE | | | | 9 , 0 |

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.

Sheet No:

| Daily Di | ary Griu | | | | | | | Sileet No. |
|-----------|-------------------------------|------------------|---------|--------------------|--------------------|----------------------|-------------------|------------------------------|
| Date | Overnight Sleep/ In Bed | Daytime Sleep | Resting | Sitting Up | Reading | Moving Around | Symptom Rating | Comments/Symptom Description |
| | | | | | | | | |
| | | | | | | | | |
| Daily Dia | ary Grid | | | | | | | Sheet No: |
| Date | Overnight Sleep/ In Bed | Daytime Sleep | Resting | Reading | TV | Walking | Symptom Rating | Comments/Symptom Description |
| | | | | | | | | |
| | | | | | | | | |
| Daily Dia | ary Grid | | | | | | | Sheet No: |
| Date | Overnight Sleep/ In Bed | Daytime Sleep | Resting | Low Activity | Medium Activity | At Work | Symptom Rating | Comments/Symptom Description |
| | | | | | | | | |
| | | | | | | | | |
| Daily Dia | ary Grid | | | | | | | Sheet No: |
| Date | Overnight Sleep/ In Bed | Daytime Sleep | Resting | Reading | TV | Stretch Exercises | Symptom Rating | Comments/Symptom Description |
| | | | | | | | | |
| | | | | | | | | |
| Daily Di | ary Grid | | | | | | | Sheet No: |
| Date | Overnight Sleep/ In Bed | Daytime Sleep | Resting | Medium Activity | High Activity | Trips Out | Symptom Rating | Comments/Symptom Description |
| | | | | | | | | |
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Daily Diary Grid

| - | Overnight | | | | Г | | |
|------|-------------------------------|------------------|---------|--|---|-------------------|------------------------------|
| Date | Overnight Sleep/ In Bed | Daytime Sleep | Resting | | | Symptom Rating | Comments/Symptom Description |
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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. Closest to the initial onset of the ME and reappears with a |
| | head cold or virus. |
| 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. |
| | Generally get this after too much activity. |
| 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. Appears |
| | during a prolonged bad spell. |
| 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</i> |
| | tolerate, eg a new medication. Not due to activity. |
| Myalgia Pain | Deep ache/burning pain. Almost takes breathe away, makes eyes water, |
| | clammy hands. This one can get very bad. |
| Heavy Stuff | Whole body feels heavy and weighed down as though walking around |
| | wrapped in an exceptionally heavy cloak. Sometimes wake up with this |
| | when it can last for about 2 hours and then change to another category. |
| Deeply Weak and Shaky | Through to the bones, all over body. Sometimes wake up with this when it |
| | can last for about 2 hours and then change to another category. |
| 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</i> |
| | one of the other categories. |
| Stretchy Leg Myalgia | Occurs after bending down and stretching muscles in back of legs. Gradual |
| (and sometimes arms | weakness/myalgia spreads up from back of legs throughout the body and |
| too) | increases in severity over the following few hours. Takes several days to |
| | recover. (Stopped doing stretching exercises because of this one!) |
| Done Too Much Activity | Muscles feel overused especially in arms and legs, but symptoms do not |
| But OKish | progress. This one's the rarest, but OK! |

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 | |
|---------------|---------------------|--------------------|
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