

THE PRAGMATIC REHABILITATION INITIAL PRESENTATION

PHYSIOLOGICAL EXPLANATION OF SYMPTOMS FOR CFS PATIENTS

Research began in muscle disease clinics.

Researchers were looking for signs of : **Persistent virus**
Disease
Damage
Chemical imbalance

The good news is that they did not find any evidence of any of these.

However, they did find that in patients with CFS there are fewer powerhouses in the muscles.

These powerhouses are called mitochondria, which you don't need to remember.

What would be useful for you to understand is that these powerhouses are the tiny parts of the cell that produce energy.

There is **reduced energy metabolism** in muscles.

It's as though muscles have a slightly flat battery.

It's difficult for CFS patients to be as physically active for as long.

This is a very physical condition.

But, it is reversible.

Researchers went on to discover that in patients with CFS there is:

Reduced muscle strength
Low blood pressure on standing associated with
Reduced muscle tone. This can cause dizziness.

Let me explain

1. Muscles act as **pumps**, helping to **squeeze** blood back to the heart and on to the brain.
2. When we are sitting or standing, blood pools in the lower limbs because of gravity.
3. In CFS, with reduced muscle strength and reduced muscle tone, *less blood* is squeezed back to the heart and less goes onto the brain.

It's like a plumbing problem.

Less blood to the brain causes symptoms such as: **Dizziness**
Fatigue
Light headedness
Lines, dots, floaters

Some patients also complain of **palpitations**.

Because of the complaints of palpitations researchers began to investigate the cardiovascular system.

Again, the good news is that **no abnormalities were found**.

However, they did find evidence the cardiovascular system had become severely **deconditioned or unfit**.

Let me explain this.

The heart is a muscle pump

In people who are healthy and active:

1. The muscle wall of the heart is **thick**.
2. With each contraction **plenty** of blood is pumped around the body.
3. Because the heart is efficient it beats **slowly**.
4. And so it tires **less easily**.

If active people reduce activity a deconditioning effect occurs :

1. The muscle walls of the heart reduce in **thickness**.
2. The output of the heart is reduced: with each contraction **less blood** is squeezed around the body.
3. To **compensate** for this the heart beats **faster** to get more blood round the body.
4. And so it tires **more easily**.

In CFS we know that activity levels are reduced and this deconditioning effect has been found:

There is evidence of

- **Reduced thickness of heart wall muscle**
- **Cardiac output is reduced**
- **Increased heart rate at rest.**
- **Lungs are less efficient in taking up oxygen.**

This deconditioning or unfitness causes intense and unpleasant symptoms on activity such as:

Palpitations

Breathlessness on exercise

Excessive sweating

Nausea and fatigue.

However this research does not explain the complaints of **unrefreshing sleep**.

This is the next area researchers turned to.

Two groups of people were taken into sleep labs, a group of healthy volunteers and a group of patients with CFS.

In the healthy volunteers researchers found

The first third of the night is all about physical restoration.

This period of sleep is known as **Non Rapid Eye Movement sleep (NREM)**

During this period of sleep we restore physically from the wear and tear of the day's activity.

This period of sleep is divided into 4 stages.

Stage 1 is light sleep, drowsing. If you heard a noise or your name called you would be roused.

Stages 2 and 3 are slightly deeper.

Stage 4 is **very deep sleep**.

Deep sleep is very important.

1. It is the part of sleep that makes us wake feeling **refreshed**.
2. Our muscles start to **relax** and
3. **Growth hormone** is produced which does just what it suggests: repairs body tissue after the wear and tear of the day.

The next part of the sleep pattern is called **Rapid Eye Movement sleep. (REM)**

This is all about psychological restoration.

Things like information processing and emotional issues are dealt with.

However, in patients with CFS researchers found this pattern is **fragmented or broken**.

1. There is significantly **less** deep sleep.
This means no matter how long patients stay in bed they wake feeling unrefreshed.
2. There is **more** Stage 1 sleep, so sleep can be more restless.
3. There are more **shifts** between the stages of sleep.
4. There is more **movement** of muscle.
This predisposes patients to have **muscle ache and pain in the day**.

So what's going on?

There's evidence to suggest that the **body clock in the brain** has lost control of the body's physical rhythms.

It might be helpful to imagine the body clock like the **conductor** of an orchestra. Just as the conductor cues the players to play at the right time to produce a harmonious sound, **the body clock switches on/off the body's rhythms at the right time.**

These body rhythms include **sleep, eating** and **fatigue** and even things like going to the **loo** at the same time every day.

When the BC is disturbed it loses control of the body rhythms which become out of synch. This causes symptoms. There is evidence that the following rhythms are disrupted.

1. **The sleep/wake rhythm.** You have shown us from your questionnaire that you have a problem with your sleep/wake pattern. And research shows sleep disorder.
2. **The fatigue/alert rhythm is also affected.** We have a fatigue & alertness rhythm. In the middle of the night I'm at maximum fatigue. If you woke me then and asked me short term memory questions such as 'what did you do yesterday/tomorrow?', or put the lights on and asked me to do exercises I'd find it very difficult to cope. In the day, I'm alert. However in CFS, the fatigue rhythm shifts into the day causing abnormal **daytime fatigue**. This causes a **reduced attention capacity** and problems with **information processing**. If several people are speaking all at once to a patient it's difficult to take it all in and the patient may develop a **glazed look** on their face.

Because of the shift of this rhythm patients may tend to be more alert in the night.

Another body rhythm that is disturbed in CFS is the production of the hormone **CORTISOL**.

The body clock has had us partially shut down for the night.

1. Cortisol is an important steroid hormone. **Cortisol's job is to prime us for the day..**
2. It switches on our metabolism in the morning and helps us cope with the **physical and mental** activities of the day.
3. There's evidence to show that there is a **mild deficiency of cortisol** in some patients with CFS.
4. **With reduced cortisol it's harder to be as physically and mentally active.**
5. **This may explain why patients adopt a low risk taking /more sedentary lifestyle**
4. The deficiency of cortisol is not corrected by giving steroids, but restored by **regular activity and regular sleep.**

THE FIRST SOURCE OF ABNORMAL FATIGUE IN CFS COMES FROM

- **DISTURBED SLEEP &**
- **FATIGUE RHYTHMS**

AND WITH THE OTHER RHYTHMS AFFECTED, IT IS DIFFICULT TO MAINTAIN NORMAL DAILY ROUTINE ACTIVITIES

- 1) Because the body rhythms are out of synch it's hard to be as **physically active**.
- 2) Patients tend to prioritise essential tasks: work, home etc.,
Demanding physical activities going lower down the list.
- 3) With reduced activity the **muscles, heart and circulatory systems** become **deconditioned** or unfit.

This explains the deconditioning of the muscle, heart and lungs and symptoms that has been found in CFS patients we described at the start.

This deconditioning is 2nd SOURCE OF FATIGUE in CFS (DRAW ARROW) and causes other intense symptoms: dizziness, palpitations, excessive sweating, and nausea.

Also, muscles unaccustomed to regular exercise are predisposed to muscle ache, pain, stiffness and swelling 24 to 48 hrs afterwards. This is called **Delayed Onset Muscle Soreness (DOMS)**.

I haven't got a problem with my body clock. (Put hand over 'body clock')
However, if I hadn't been exercising regularly and then did a workout I would experience this DOMS: I would have muscle aches, stiffness and maybe feel fluey 24-48 hours afterwards.

It's the same for CFS patients.

If the CFS patient does anything over and above their usual activities they will experience DOMS and the symptoms of deconditioning in addition to the abnormal fatigue from the body clock.

This leads to the final piece of the jigsaw.

Increased Nervous system arousal & Adrenaline

The nervous system is made up of nerve cells that carry information to and from all parts of the body to make the body work

It is divided into

- The brain and spinal column
- The nerves that conduct impulse to and from organs, muscles and tissues.

Any physical and mental exertion switches on the nervous system and production of adrenaline, a powerful hormone.

The nervous system and adrenaline **prepares us for action to** improve performance & alertness. This is called the fight or flight response.

It's important to understand that the **brain doesn't care** if the effort is physical or mental. It automatically activates the nervous system & produces adrenaline.

There are many reasons why there is increased nervous system activity and more adrenaline in CFS:

Abnormal Daytime Fatigue

Deconditioning.

Frustration with limited lifestyle.

Distress at the scepticism of others, being disbelieved by doctors, family, friends.

Fear of symptoms.

Helplessness associated with lack of medical explanation.

Worry about the future.

Nervous system arousal & adrenaline prepare the body for action by:

1. **Increasing heart rate.**

Causing symptoms such as : **palpitations**
pounding
tightness

You may remember I mentioned patients that CFS patients have a higher heart rate.

Increased nervous system arousal puts the heart rate up even higher.

So the heart tires even more quickly at times of physical and mental exertion leaving patients feeling drained.

2. **Increasing blood pressure**

This ensures adequate blood supply to vital organs

This contrasts with times of low blood pressure on standing in CFS

3. Increasing breathing rate.

We should breathe from the diaphragm, the big dome shaped muscle that pushes the lungs up and down like a pump.

With increased mental or physical activity we need more oxygen.

To get this we breathe faster from the top of the lungs.

We overbreathe

1. During this time we overuse the muscles of the **chest wall**. This can cause **pain and discomfort**.

2. We also overuse the **neck muscles**. These are **delicate** and are not designed for prolonged overuse heaving up and down the heavy rib cage. This causes :

- **Neck stiffness or pain.**

Neck muscles are attached to the skull & shoulder blades. Increased use of these muscles pulls on their attachments to the **skull** and **shoulder blades**.

This **can cause headaches** that **last for several days** and **may not respond to analgesia**.

Overuse of neck and shoulder muscles can cause localised stiffness

3. Adrenaline reduces the amount of *saliva* produced which causes a drier mouth. The combination of a drier mouth and breathing faster dries up the back of the throat this

Sensitises the throat

Makes swallowing more difficult

Patients may feel the sensation of a lump in the throat.

And because they've overused their neck muscles their throat may feel sore too.

4. When we breathe faster, we take in more oxygen and give out more **carbon dioxide**.

This means there is less carbon dioxide in the bloodstream which affects the blood supply to the brain.

This causes **unpleasant symptoms** :

You may first notice visual disturbance, looking through frosted glass.

Light headedness, dizziness.

Pins and needles, numbness, tingling.

Feeling unsteady on your feet.

Balance problems/Feeling the ground is coming up to meet you.

Slurring words, feeling clumsy.

A spaced out feeling, you're there but you're not there.

Increased sensitivity to light and noise.

4. Increases muscle tension.

This is part of the **fight or flight** response. The nervous system and adrenaline prepares us for action by tensing the muscles. If the tension in the muscles isn't released with physical activity it can cause

Aches and pain;

Muscle twitching, shakiness, tremor

Feelings of weakness

The longer the nervous system is aroused by the exertion the longer the muscles are tensed for and the more the discomfort.

It's important also to remember that the muscles in CFS are already at a disadvantage because of

- sleep disorder and
- reduced muscle strength.

5. Redistribution of blood around the body.

- Adrenaline takes blood from **non-essential organs** & sends it to **heart and muscles**.

The skin: the blood vessels are shut down in the skin giving the appearance of **pallor**. Family members may sometimes notice the colour draining from the patient's face.

Extremities become cold

Sometimes however, patients may notice **flushing** and **temperature change as blood is shunted around the body**.

- The passage of food through the bowels depends on the blood supply. When the blood is directed away to the heart and muscles the passage of food is slowed down. This may cause, **constipation, distension, gripe pains**. 60% of patients complain of IBS type symptoms.

In addition - To prepare us for action adrenaline wants to empty the **stomach, bowels and bladder** so we can **run faster**.

The stomach : Adrenaline affects **motility** and **acid production**.

Increased levels of exertion e.g., exams, may cause **butterflies**. The stomach **contracts**, there may be a **loss of appetite** and even **nausea**.

Higher levels cause the stomach to contract more vigorously.

Food is pushed up into the food pipe that can cause acid reflux. (Patients often use antacids)

There may also be pain behind the sternum.

There may even be vomiting if the person is under extreme levels of exertion.

The bowels and bladder empty, causing diarrhoea and urinary urgency.

At times of great stress people go to the loo more.

6. Arouser

Finally, adrenaline helps to keep us alert: it is an arouser and it interferes with sleep.

(Draw arrow and write) Nervous system arousal IS THE 3rd SOURCE OF FATIGUE AND MUSCLE ACHE AND PAIN.

These **3 sources** of fatigue make up **Chronic Fatigue Syndrome**.

So let's put this altogether.
Your bottom line problem is :

(Point to notes to draw all points together)

The body clock has **lost control** of body rhythms.

A **sleep disorder** develops.

With Daytime fatigue.

And with these **other rhythms** affected.

It's hard to be as **physically active**.

Which over time leads to **deconditioning of the** heart, lungs and muscles.

Daytime fatigue and deconditioning, frustration and striving to get back into life arouses the nervous system and produces **adrenaline** which hits the patient's **weak spots** (heart, muscles).

These are the problems.

So now let's look at **how this happens**.

Why/how has the BC lost control of physical rhythms?

The body clock is reset every 24 hours by cues or signals.

It's like you or me tuning into our favourite radio station, we look for its signal.

The body clock is the same, it looks for the following cues/signals and if it finds them it **resets itself and controls the body rhythms.**

1. Bed time.

Going down into **deep sleep** is very important cue for the body clock.

The amount of deep sleep depends on the amount of aerobic exercise.

The more regular exercise, the more deep sleep.

Athletes have more deep sleep on the days they have an aerobic workout.

2. Waking time. Getting up time.

That's important too that it's regular

The longer that we are awake for

the greater the urge to sleep

and the deeper the sleep.

So it's best to avoid sleeping in the day.

Let me explain that.

If I'm active in the morning & feel sleepy after lunch, and go to sleep, I'll have the deep sleep I earned from the morning activity.

Consequently my night time sleep will be minus that deep sleep I had in the day and so will be less deep and more restless.

3. Social routines.

Going to work or college.

4. Regular meals times.

ACTIVITY AND REST PATTERNS.

These are really important that's why I am printing them in big letters!

In CFS something has **interfered** with these regular cues which have become disrupted.
The body clock can't reset itself and loses control of body rhythms,
This causes symptoms of overwhelming fatigue, concentration problems, muscle aches etc..

- Although this may not be the case for you, an easy way to understand how **quickly** the body clock loses control is to consider jet travel:
 - 1) After a 6 hour flight in an easterly direction it takes 8 days for **cortisol** levels to return to normal.
 - 2) During this time people feel **symptoms** (poor sleep and daytime tiredness),
 - 3) After adopting the **social routine** of the new destination people resynchronise their rhythms.

And there's **no mystery!**

CFS is like having very *severe jetlag* with body rhythms out of synch accompanied by severe deconditioning.

- **Shiftwork also** interferes with body rhythms. After just 5 days on night duty, nurses had a **cortisol** deficiency that **mimicked** that seen in CFS.

In CFS there are generally other triggers involved.

70% of patients go down with what we call a **physical trigger**.

Infection, virus, illness, hospitalisation, trauma, operation.

These events affect sleep patterns and activity.

Lets look at how an infection can trigger CFS.

When a virus enters the body antibodies attack it.

As they break down the viral cell wall chemicals are made that make us sleepy.

This can be good because it has a **restorative** function.

However.

- Sleeping in the day makes night time sleep of poorer quality.
- Also being unwell or hospitalised means we may well have a disrupted night sleep.
- We may wake early. We may wake late.
- We don't always feel like going into work.
- We may lose our appetite.
- We don't feel as energetic.
- We may rest more.

So these cues are changed from the usual routine.

They become **irregular** and are **weaker**

The body clock can't reset.

It loses control of body rhythms causing symptoms in addition to the symptoms of the trigger.

However, we know lots of people who get ill and don't get CFS.
So why do some people go into CFS?

One important factor is :

ACTIVITY LEVELS BEFORE CFS.

It's people who are active, on the go, with **many commitments** who get CFS.

Deconditioning happens very quickly.

- **Within 24 hours of bed rest an active person begins to decondition.**
Lying flat causes a **headward shift** of body fluids, the heart fills quicker and in response there is a reduction in the volume of blood plasma.
Reduced blood volume causes low blood pressure on standing with less blood going to the brain.
This causes problems with balance, feeling **light headed** and **dizziness**.

Even with **chair rest** deconditioning happens very quickly.

After 4 days chair rest healthy volunteers had **low blood pressure** on standing and **increased heart rate**. **Causing dizziness and palpitations.**

After 8 days they had a **reduced exercise capacity**.

CFS patients are not **couch potatoes**.

They are active and, **importantly,**

- **Deconditioning happens to a greater extent in those who were active compared with those who are already sedentary.**

Another important factor is :

PERSONALITY STYLE

Patients who get CFS tend to be **doers, achievers, conscientious, good listeners, have many commitments and don't like being ill.**

These sort of people may be under **pressure** from **others: work/family commitments or themselves** to **return** to previous commitments **too soon.**

If they return before :

1. Recovering from illness.
2. Resynchronising body rhythms.
3. Regaining full fitness.

they will be **symptomatic.**

To cope with the challenge of work / previous commitments there will be increased nervous system arousal and **adrenaline.**

This causes more symptoms: **dizziness,**
fatigue,
muscle ache.

But because they are **conscientious** and **copers** they may continue to **struggle** into work/college.

They may come in from work & crash out – this uses up deep sleep so **night time sleep will be more restless and less refreshing.**

Also sleeping before bed time or in the day will cause **further disturbance of body rhythms.**

If patients feel symptomatic they may **prioritise** activities with demanding physical activities going lower down the list.

For example: They may **park closer** to the supermarket.

They'll take the **lift** rather than walk up the stairs.

At the **weekend** they may rest in order to recover and restore for the next week.

So without realising, reducing activities causes **further deconditioning.**

On a **good day** attempting activities at pre-sickness levels will be too much for their reduced physical capacity (because they've started **deconditioning**).

It will cause intense symptoms that are only relieved by **rest.**

Rest causes further deconditioning

It becomes a vicious circle.

A pattern of **boom and bust** develops.

It's important you're aware not every patient goes down with a physical trigger.
For some it's a history of **PERSISTENT STRESSES (30%)**

The patients who get CFS are **copers**, they often have many **commitments** on the go.
With each extra commitment taken on more adrenaline is made.
They make **even more adrenaline** when there are extra pressures from **work, family or personal relationships etc.**

Over time increased adrenaline (as we've seen on the previous sheet) causes symptoms including:

Fatigue
Dizziness
Muscle ache

For some getting into bed of a night may give them their first **space** to think about their problems.
Mental effort causes adrenaline to be produced.
Adrenaline is an arouser and it **pushes away** the deep sleep cue.
So their sleep becomes restless and **they wake feeling tired and unrefreshed.**

Over time a similar pattern develops with disrupted sleep and reduced activity and patients spiral into the same vicious circle.

Although we know that there is no disease in CFS we know that there is severe deconditioning of the body with the following physical changes:

- Muscle & CV deconditioning
- A sleep disorder
- Increased nervous system arousal and adrenaline production

We know that:

- **graded aerobic exercise reverses these problems.**

The exercise needs to be **aerobic** to give the necessary level of stimulation to the heart, lungs and muscles to reverse the deconditioning in those organs and systems.

However, because there is severe physical deconditioning we know graded exercise is very hard to do.

Consequently, we start exercise at a level well below current ability.

The exercises are performed at home with the patient in charge of their own programme.

Frequent doses of aerobic exercise performed at a very low level spread over the day are **most effective** in reversing the deconditioning.

The daily routine of the programme needs to be rest followed by activity / exercise followed by rest. The rest between activity / exercise allows the power houses to recharge with energy ready for the next session and reduces nervous system activity.

The following suggested exercises are generally started at the levels described: after I've outlined the exercises I will describe when to increase, hold steady or reduce exercises. We advise that patients wear trainers for exercises and avoid those exercises that aggravate orthopaedic problems.

1. We always advise an EXERCISE BIKE: this is **partly weight bearing**.

There are two bike sessions a day. We ask patients not to load the bike with tension at the start of treatment.

For 1st week: Increase by 2 or 3 revs per day – each patient decides when to increase depending on how they feel – so as a rough guide patients may at the end of the first week reach 20 pedals

A.M	5 revs	7 revs	10 revs	12	15	17	20
P.M	5 revs	7 revs	10 revs	12	15	17	20

For 2nd week: Increase by 5 revs per day.

A.M	25	30	35	40	45	50	55
P.M	25	30	35	40	45	50	55

For 3rd week: At 60 revs* time the session (roughly, this usually takes one minute). From this level we ask patients to start timing each session and increase by 5 seconds per session

A.M	60revs*	1.10	1.20	1.30	1.40	1.50	2.00
P.M	1.05	1.15	1.25	1.35	1.45	1.55	2.05

The regular stimulus of the bike on the muscles will produce more power houses so the timed increases can become greater.

By the 4th week it may be possible to increase by 7 seconds per session

And the 5th week increase by 10 seconds per session

THE AIM IS To build up to two 15-minute sessions daily that are then consolidated into one 30 minute session (by increasing one session by a minute a day as the other session is correspondingly reduced). Tension can be added when patients are doing 20 to 25 minutes.

AS WELL AS THE PARTLY WEIGHT BEARING BIKE THE NEXT AEROBIC ACTIVITY IS EITHER A

- 2. MARCH or DANCE or JOG.** Because these are fully weight bearing they are far more demanding on the deconditioned body compared with the bike. Consequently, we expect the time spent marching to be half the time spent on the bike: when a patient has built up to a minute on the bike 30 seconds marching would be a comparable amount.

There are two fully weight bearing sessions a day starting at 5 seconds. These are increased by 2 or 3 seconds per day

A.M	5 secs	7 secs	10 secs	12	15	17	20
P.M	5 secs	7 secs	10 secs	12	15	17	20

THE AIM IN TIME: is to build up to two 10-minute sessions daily that are then developed into one enjoyable exercise sessions of your choice for about 20 to 30 minutes eg. Aerobic video, pool work, brisk walk / jog, gym.

- 3. WE WOULD ALSO RECOMMEND PATIENTS TO DO 3 STAIR SESSIONS PACED OVER THE DAY**

WE STRESS THAT THESE ARE NOT FLIGHTS OF STAIRS!

This activity is an instant CV work out that is very effective in reconditioning the heart and body.

We suggest that patients start with climbing one stair in the am, one at lunchtime and one in the pm. When possible increase by one step – gradual increase determined by the patient will allow the body to absorb the exercise without jeopardising progress.

1	2	3	4	5	6	7	8
1	2	3	4	5	6	7	8
1	2	3	4	5	6	7	8

4. ANOTHER BENEFICIAL EXERCISE WE ADVISE IS STANDING.

Standing is hard work it requires a fit heart – in good health we take the ability to stand for granted; because of reduced muscle tone blood pools in the calf muscles causing a low blood pressure on standing resulting in dizziness.

THREE TIMES A DAY :Increase by 5 seconds per day

10secs	15secs	20secs	25secs	30secs	35secs	40secs	45secs
10	15	20	25	30	35	40	45
10	15	20	25	30	35	40	45

A DAILY TIMED WALK : FROM SITTING IN A CHAIR

Increase by 5 seconds out and 5 seconds back

<u>OUT</u>	10secs	15secs	20secs	25secs	30secs	35secs	40secs
<u>BACK</u>	10secs	15secs	20secs	25secs	30secs	35secs	40secs

Knowing when to increase or hold steady

After each activity rest and monitor symptoms prompted by the exercise.

Eg. Breathlessness, palpitations, jelly-like wobbly legs, sweating, dizziness.

If symptoms are mopped up within 10 to 15 minutes, and you feel able to get up and potter around, increase the activity next time.

If symptoms take longer than 10 - 15 minutes to be mopped up, hold steady next time.

You may need to hold an activity steady for several days, that's ok.

Each exercise needs to be monitored in this way and some can be increased more often than others eg. The bike is partly weight bearing and this may increase more frequently than the march/dance which is fully weight bearing. We expect the time for the bike to be roughly half the time spent marching/dancing (1 minute bike : 30 seconds marching/dancing)

Prioritise graded aerobic exercise into your day, postpone or delegate other demands as much as possible. For recovery you need to be focused and single minded on your exercise programme. Recovery depends on what you do. You have the choice to exercise.

You have less energy, meter it out across the day. Take frequent short rests. Saving your energy as much as possible for your for graded exercise will stimulate the production of powerhouses and increase stamina.

Rest sitting upright position. Interrupt rests every half hour by getting up and pottering around.

Read the patient manual. Recovery depends on

1. Your ability to gradually build up exercise.
2. Your understanding of what predisposes and perpetuates CFS.

Prioritize at the start of each day. Spread activities over the whole day.
Stop before you hit the brick wall.

At a time you are most vulnerable to sleeping in the day, save an activity. This will rouse you and help you to avoid sleeping in the daytime.

On bad days try to do a little rather than nothing at all.

Give strong messages to family and friends, your programme is your priority.

Your yardstick is always 'how much more can I do now than at the start of the programme?'

Focus on your achievements now. Symptoms and limitations are temporary.

There is no disease - you have a right to full health.

This is a good news diagnosis.

Carefully built up exercise can reverse the condition. Go for 100% recovery.

Those patients who do too much activity for their reduced level of stamina need to regulate their daily routine activities before starting treatment.

Once the treatment is started a pattern of regular activity with rest before and after builds up the heart, muscles and lungs allowing recovery.

FINALLY A RECAP AT THE END OF THE GRADED EXERCISE PRESENTATION

- Emphasise the importance of rest before and after exercise.
- Emphasise the importance of spreading aerobic exercise across the day.

PACING

- Emphasise the need to spread household chores / shopping etc over the day.
- Avoid loading one part of the day with too much activity.
This will lead to overwhelming fatigue later.
There is then a greater chance of needing a sleep in the afternoon.
- Even if you don't start exercising but just spread your present commitments over the day/week there will be an improvement.
That way you will have more energy and be able to do more.

AIMS OF EXERCISE

- 4 lots of 15 minute aerobic sessions – discuss patient's choice
Gradually building to 2 half hour sessions.

Eg Bike 1st session : 16 min 17 min 18min
 2nd session: 14min 13min 12min Gradually losing the 2nd session.
 Leading to one daily session of 30 minutes.

- With extra time made from joining sessions together use it to do household chores.
- See the house as a gym.
- Build up slowly.
- Eg. Hoovering, do a couple of strips of the carpet in one room.
 Leave it and go into another room to rest.
 Return to do another short spell of hoovering later.

SLEEP

- Explore sleep pattern.
 If they sleep during the day there are two options.
 - ❖ Stop daytime sleep.
 Using exercise at the time of maximum fatigue
 Using distraction techniques Eg. Puzzles, pottering around the house, go outside, sit in the fresh air and daylight.
 Being overactive in the morning means you're more likely to want to sleep in the afternoon.
 Spread activities over the whole day.

SOCIAL, FAMILY AND PRESSURES.

The programme is now your job.
 It is every day across the whole day.
 Be aware of mixed messages.
 Give clear messages to family and friends, this is now your priority.

ROUSING REASSURANCE

From the moment you walk out of this room your recovery is beginning.

Every exercise is strengthening your body.

Exercises need to be paced.

To do too much will drain your powerhouses.

Stop before you hit the brickwall.

There is no disease.

Go for 100% recovery.