



Patient Handbook

# Physiotherapy for Hypermobility Trial (PHyT)

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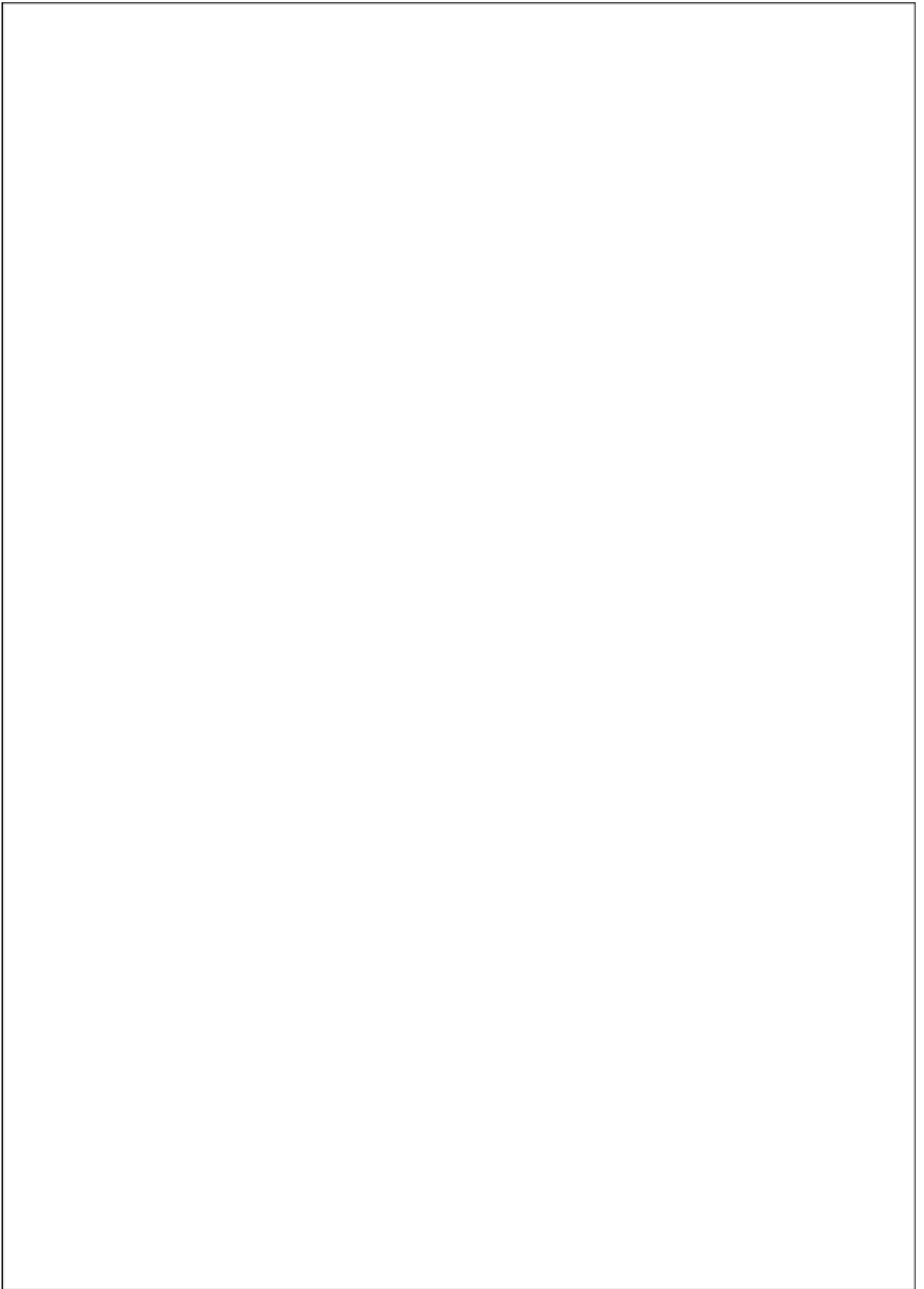
North Bristol NHS Trust  
Royal National Hospital for Rheumatic  
Diseases NHS Foundation Trust

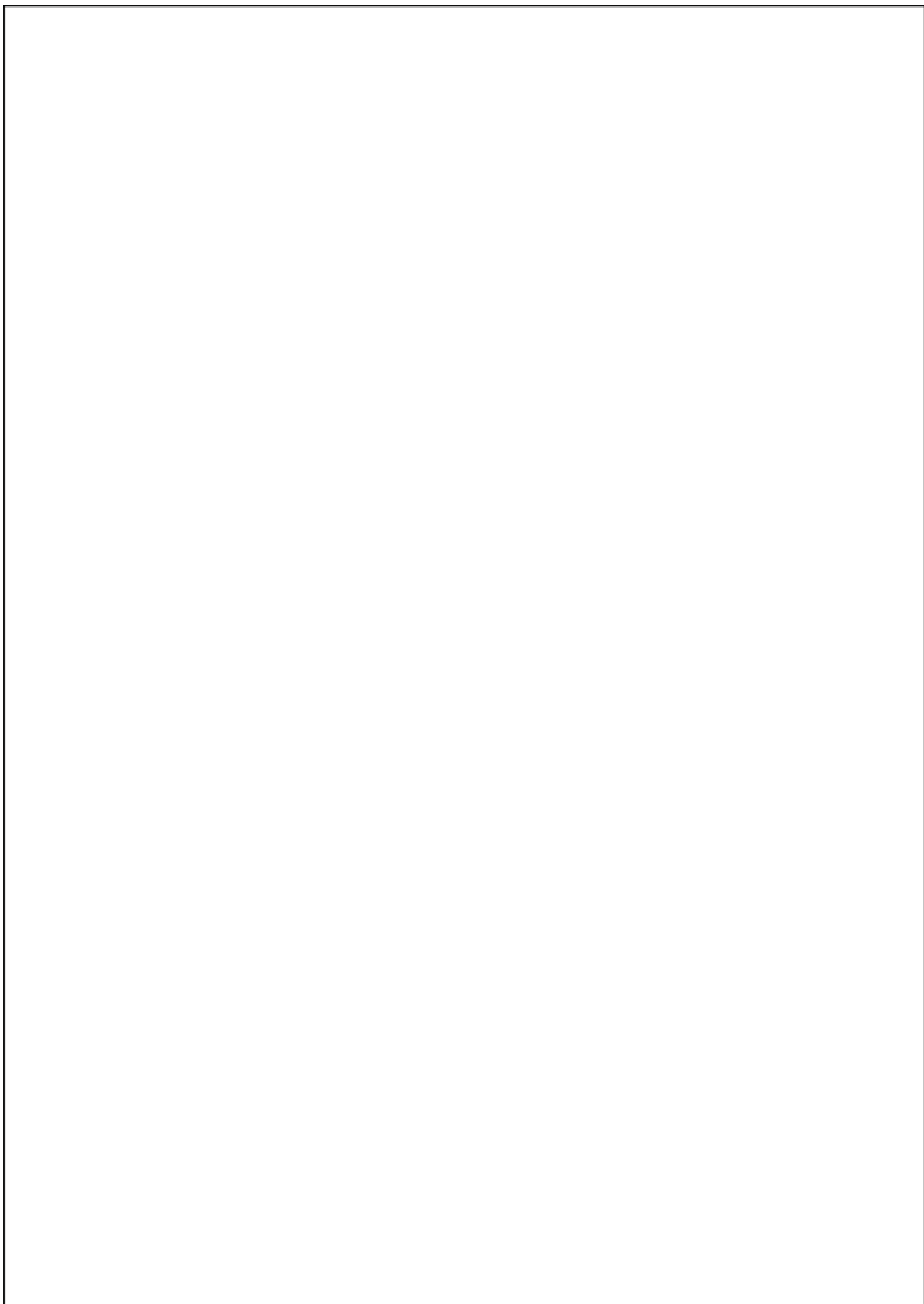
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University of the  
West of England

**better**together





## **INTRODUCTION**

Welcome to the Physiotherapy for Hypermobility Trial (PHyT). Your physiotherapy treatment will be structured as follows:

- Six 30min sessions
- Spaced over four months

Your physiotherapist will discuss with you how best to space these sessions, according to your own needs.

The aim is to increase your ability to manage your joint hypermobility in the long term. Treatment will include education, advice and physical activity and the sessions will be adapted to you so that you can get the best out of them. Each session will have an education and advice 'theme' and you will be asked to do some preparation in advance. Each session will also include specific exercises and advice about being physically active doing something that you enjoy.

You will have already received booklets with advice about joint hypermobility from Arthritis Research UK and the Hypermobility Syndrome Association. This patient booklet is designed to support your physiotherapy treatment and tries not to repeat too much information that you have already.

**This booklet is yours to keep.**

**Please bring it with you to all sessions.**

**Use it as your personal record and re-use it in the future.**

## **PROGRAMME**

The six sessions are structured as follows:

- Aims, benefits of physical activity, posture, movement quality, pain relief.
- Medication, sleep hygiene, goal setting, exercise, physical activity.
- Pacing of activity, exercise, physical activity.
- Dealing with set-backs, exercise, physical activity.
- Taking control, exercise, physical activity.
- Long term management, staying active.

**Your physiotherapist may change the order of topics and concentrate on some in more detail than others, depending on your needs.**

**Video can sometimes help you to remember how to do specific exercises or movements. If you want a visual reminder, please ask your physiotherapist to record the movements using your own mobile device.**



## **AIMS, BENEFITS OF PHYSICAL ACTIVITY, POSTURE, MOVEMENT QUALITY, PAIN RELIEF**

### **AIMS**

Your physiotherapy sessions aim to:

- Help you to understand your condition, the effect that it has on your day to day life, and how you can manage it better.
- Help you to understand the benefits of physical activity for joint hypermobility and reduce any fears that you might have about being active.
- Help you to improve the control that you have over how your body moves.
- Equip you with the skills to set personal goals in relation to physical activity, work towards these goals and to deal with set-backs.

### **EXERCISE FOR JOINT HYPERMOBILITY**

Some of the benefits of exercise for joint hypermobility that have been reported in the literature (Palmer et al 2013a) include improvements in:

- Balance
- Fatigue
- Mental health
- Muscle strength
- Pain
- Physical function (including walking distance)
- Proprioception (the sense of where your limbs are in space)
- Quality of life
- Sleep

It is therefore likely that being more physically active will significantly improve your condition and that is why it is a primary focus of your physiotherapy treatment.

From our experience, people with joint hypermobility do not injure themselves when they become more active so any changes in your condition are likely to be positive.

### **Difficulties with doing exercise**

Some of the reasons why you may not want to exercise include:

- Lack of time
- Being unsure what exercises are best
- Fear of aggravating symptoms
- Fear of causing damage

Your physiotherapy treatment will help to address these so that you have greater confidence and skills in managing your condition through being more physically active.

## **EXERCISE RECOMMENDATIONS**

It is important to recognise that each person is very different in terms of their starting point and their ability to change their activity levels. It is recommended that you do:

- Some functional or recreational activity (e.g. walking or gardening) that you enjoy, perhaps with other people.
- Physical activity that can be part of your daily routine.
- Some specific exercises for your joint hypermobility.

General health recommendations are that adults should aim for the following levels of activity, but for many people with joint hypermobility, this should be a long-term aim:

### **In the long term aim for:**

#### **How hard?**

- Moderate intensity.
- You should feel warm and slightly out of breath.
- You should still be able to hold a conversation.
- You may feel some discomfort but it should not be getting worse.

#### **How long?**

- 30 minutes per day.
- It doesn't have to be in one session.
- It can be broken down into manageable chunks of time throughout the day.

#### **How often?**

- Most days of the week.
- Ideally it should be built into your daily routine.

Remember that you are likely to benefit from any increase in physical activity, so take small steps towards these general recommendations and try to make it fun (e.g. playing with your children or being active with friends and family).

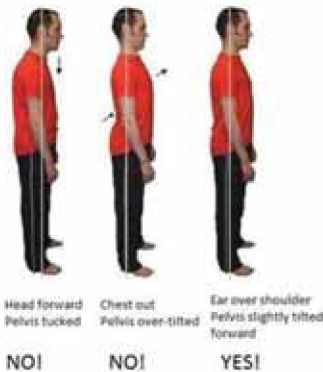
## **POSTURE**

It is important that you try to maintain a good posture. This helps to ensure that you are not overstretching your joints. Better posture may also reduce fatigue as you use less muscle activity. This is especially important if you are in one position for a long time (e.g. working at a desk or watching TV).

It is also important to change position regularly so, if you are sitting for long periods or doing a repetitive task, get up and move around from time to time or go and do something else and come back to it.

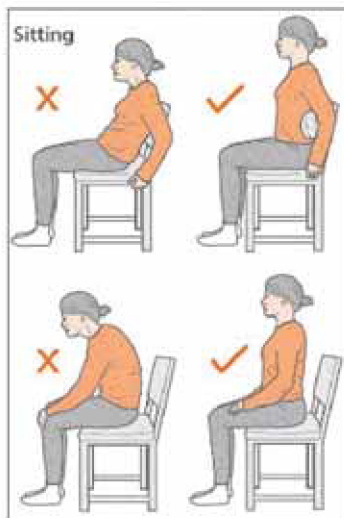
If you use a computer a lot, the Health & Safety Executive have a good checklist which you can use to assess your work environment (<http://www.hse.gov.uk/pubns/priced/vdu-workstation.pdf>).

The diagrams below show good posture and your physiotherapist will spend some time with you looking at and discussing your posture. You will be reminded about the position of your shoulders as well as your spine.



### Standing Posture

The aim should be to have a gentle curve in your low back, with the head in line with the body.



### Sitting Posture

Again, the aim should be to have a gentle curve in your low back. Sometimes the use of a support in the low back can help.



### Lying Posture

The use of pillows can often help to reduce pressure on the low back and hips. When lying on your back place a pillow under all of your leg and ankle, not just the knee.

### MOVEMENT QUALITY

People with joint hypermobility often have problems sensing where their joints are in space (known as 'proprioception'). They may also lack strength or tone in the muscles that control movement of the joints. This can affect the way that

people with joint hypermobility move, and they often use 'trick' movements to get by. This can lead to increased stress and strain on the muscles and joints and therefore it is important to learn how to move more efficiently. This is one of the hardest parts of managing joint hypermobility as the way that you move may seem normal to you and changing it is extremely difficult.

A large part of your physiotherapy treatment will involve exercises to improve the way that you move. It is important to remember that the **quality of movement** is the most important thing, not how many exercises you do or how fast you can do them. As you learn to move more efficiently you will be able to progress the exercises and your more general activity.

Your physiotherapist will work closely with you to look at how you move and will help you to change things if necessary. This will include the way that you walk, how you reach for things and any other tasks that may be a specific problem for you.

### **PAIN RELIEF**

The use of ice, heat or Transcutaneous Electrical Nerve Stimulation (TENS) can be useful to settle pain.

**TENS** is a small device which sends a tingling sensation through small pads around the painful area. TENS is available from most physiotherapy departments and high street chemists. It may be used during light activities.

Use **ice** if joints are hot and swollen:

- Bag of frozen peas wrapped in a damp tea Towel.
- 10-20 minutes.

Use **heat** if joints are stiff and aching

- Hot water bottle (wrapped in a dry tea towel) or wheat pack.
- 20-30 minutes.

**WARNING**  
Heat & ice can  
burn

Check your skin – a slight  
redness is normal but it  
should not become very  
red and inflamed

### **EXERCISE**

Your physiotherapist will introduce a few specific home exercises based upon what they observed in your initial physiotherapy assessment (see later section on 'Home Exercises').

### **BEFORE THE NEXT SESSION**

- Complete the reflection form.
- Read the information about medication, sleep hygiene and setting goals (next session).
- Think about the personal goals that you would like to achieve:
  - Over the next 4 months.
  - In the long term.

**REFLECTION**

What were the key learning points from this session?

Do any exercises aggravate my symptoms? Which ones?

How will I change them or what will I do to settle symptoms?



## **MEDICATION, SLEEP HYGIENE, GOAL SETTING**

### **MEDICATION**

Painkillers (analgesics) or non-steroidal anti-inflammatory drugs (NSAIDs) can be helpful to take before physical activity. It's better to take a dose before activity to keep the pain under control rather than waiting until it's very bad.

Paracetamol is normally the first choice, and you can take up to eight tablets per day. You can also purchase a stronger tablet containing paracetamol plus low dose codeine from chemists without a prescription. Your doctor can prescribe a stronger painkiller such as higher strength co-codamol or tramadol, if necessary. Codeine sometimes cause side-effects such as constipation or drowsiness. Your pharmacist will be able to give you further information.

If a joint swells up, an NSAID such as ibuprofen may be better. This can also be purchased from chemists without a prescription. However, NSAIDs should not be taken regularly for many weeks or months. See your doctor if you need regular dosing, and it would be better to take regular painkillers instead. NSAIDs should only be used intermittently.

You can also get sprays, gels or creams to help with the pain, including hand symptoms. These can be NSAIDs (such as an anti-inflammatory gel) or based on chilli peppers (capsaicin cream), which allows them to be applied directly onto the site of pain.. This method may not be quite as effective, but may be an option if the tablets aren't suitable for you.

Sometimes poor sleep is a feature of hypermobility. Sleeping tablets are not the answer, but there are some medications which can help relax people, are not addictive, and can have an added benefit of helping the pain. These include amitriptyline or gabapentin and they should be taken regularly for about 6 weeks before deciding if they are helping. These medications can sometimes cause side effects such as a dry mouth or drowsiness in the morning, but these should wear off after a couple of weeks.

### **SLEEP HYGIENE**

Good sleep hygiene can also help to ensure that you have good quality sleep and are alert during the day. Most people need 7-9 hours of sleep per night. The aim is to establish a regular pattern of sleeping and waking. Other tips include:

- Avoid daytime naps.
- Exercise can help but avoid vigorous exercise 2 hours before bedtime.
- Avoid large meals, caffeine, nicotine, and alcohol close to bedtime.
- Exposure to natural light helps with sleep-wake cycles.
- Establish a regular relaxing bedtime routine.
- Try to avoid emotional conversations before bedtime.
- Try not to dwell on, or bring your problems to bed.
- Associate bed with sleep – TV and radio may not help.

- Ensure your bed and bedroom is comfortable, cool, quiet, relaxing and dark.
- Consider your posture and the use of pillows to get comfortable (see p5).

### **GOAL SETTING**

It is important that you set yourself achievable goals in relation to physical activity. Goals give you direction, help to motivate you, and allow you to monitor your progress.

#### **Where do I start?**

Start with something relatively small (but still challenging) and something that is important to you.

#### **What sort of goal?**

Goals should be important for you and must be challenging but also realistic. A goal of running a marathon may be unrealistic but something like using your car less (and walking or cycling instead) is probably much more realistic and achievable. Or it may simply be that you want to be able to stand for longer at social events or play with your children for longer.

#### **I've set my goal, now what?**

You now need to plan exactly 'When', 'Where' and 'How' to achieve it and this is crucial to your success. Writing an action plan will encourage you to adjust your daily routine, and remind you of the changes you have to make. Sometimes a lot of short-term changes must be made to achieve long-term improvement, but if you persevere you will soon notice the benefits.

#### **What happens when I achieve my goal?**

When you achieve your goal, tell everybody! Your family and friends will want to know about your improvements and continue to encourage you. Reward yourself with a nice meal or a day out. When your goal becomes too easy, revise your action plan by setting new goals to ensure that you maintain the improvement and strive for further success.

#### **What if I can't achieve my targets?**

You may have set your sights too high initially, over-estimated your current ability to make changes, or your plan to achieve the goal may not have been specific enough. Change your goals, and be more specific on how you will work towards change.



## CYCLE OF CHANGE

The following diagram describes the stages that people go through when changing behaviour. Circle the stage that most applies to you in terms of how you feel about physical activity.



**Not interested in change:** You haven't yet recognised a need to be more active.

**Thinking about change:** You recognise the need to be more active and to exercise but haven't made any changes to your lifestyle.

**Preparing to change:** You have thought about ways to introduce exercise and have made tentative steps towards being more active.

**Making changes:** You have made significant adaptations to your activity levels.

**Maintaining change:** You have changed your lifestyle and are exercising on a regular basis. You feel confident that you can continue exercising in the long term.

**Relapsing:** You have stopped exercising. You can also lapse at any of the previous stages and this is normal. We hope that the skills you develop as part of your physiotherapy will enable you to get back to the 'making changes' and 'maintaining changes' stages after a relapse.

## EXERCISE

Your physiotherapist will review the exercises introduced last week and will work with you to adapt these and introduce new exercises as necessary. They will discuss with you strategies for incorporating these into your daily activity.

## BEFORE THE NEXT SESSION

- Complete the reflection form.
- Complete the 'Physical Activity Action Plan' (p12) and start to implement this into your day to day activity.
- Record progress using the 'Physical Activity Diary' (p13).
- Read the information about activity-rest cycles (next session).
- Think about specific times when you have either overdone things or have rested too much.

**REFLECTION**

What were the key learning points from this session?

Will I do anything differently as a result?

Are any of the exercises too easy for me?

How will I make them slightly more difficult?

Do any exercises aggravate my symptoms? Which ones?

How will I change them or what will I do to settle symptoms?

**PHYSICAL ACTIVITY ACTION PLAN**

Goal

What activity will you do?

How often will you do it?

When will you do it?

**PHYSICAL ACTIVITY DIARY**

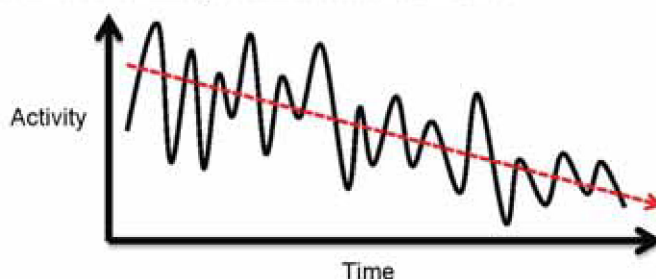
<b>Day</b>	<b>Activity Completed</b>	<b>Comments</b>

## PACING OF ACTIVITY

### ACTIVITY-REST CYCLES

It is common for people with joint hypermobility to overdo things when their symptoms are good and to avoid activity when their symptoms are bad. This leads to a 'boom and bust' pattern of activity and over time people become less fit and active. Avoiding extremes of both activity and inactivity is important in allowing you to better manage your symptoms.

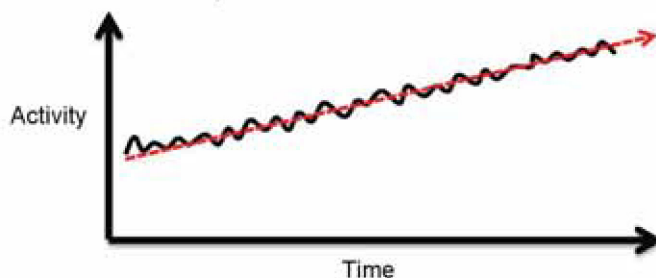
**NO!** – Over-activity leads to extreme symptoms which needs prolonged rest to settle down. Over time you can become less active.



**YES!** – Moderate activity followed by a short rest allows you to return to moderate activity more quickly.

### **Pacing**

Pacing means stopping an activity before your symptoms have been exacerbated. Over time you can become more active.



Although it is important to take regular exercise, you must also include adequate rest periods in between to prevent aggravating your symptoms. This allows the body to recover as it learns to adapt to a new exercise routine.

### **Planning in advance**

This is the key to successful pacing

- Decide on your priorities
- Plan how to distribute activities during your day/week
- Plan when you will take rest periods
- Stick to the plan (within reason)

Remember that it is often OK not to finish something in one go or to the highest standard, or to accept help with things. During rest periods, think about the use of ice, heat or TENS.

### **EXERCISE**

Your physiotherapist will review your home exercises and physical activity action plan. They will work with you to adapt these and introduce new exercises as necessary to your own personal circumstances so that you are supported in becoming more physically active.

### **BEFORE THE NEXT SESSION**

- Complete the session reflection form.
- Choose one day to day activity to try to incorporate the principles of pacing into.
- Read the information about dealing with set-backs (next session).

## **REFLECTION**

What were the key learning points from this session?

Will I do anything differently as a result?

Are any of the exercises too easy for me?

How will I make them slightly more difficult?

Do any exercises aggravate my symptoms? Which ones?

How will I change them or what will I do to settle symptoms?



## DEALING WITH SET-BACKS

### **DEALING WITH SET-BACKS**

The course of joint hypermobility is extremely variable and it is normal to have occasional set-backs when your symptoms are worse. Set-backs may be attributed to 'over-doing it' but can also be unexplained and unpredictable. It is understandable to have negative thoughts during a set-back but remember that it will pass and it is not a sign that your condition is getting worse. It is important that you are able to effectively manage set-backs. GP intervention is rarely necessary.

#### **Plan for managing set-backs**

- Reduce vigorous activity until symptoms start to improve.
- This does not mean bed-rest; just avoid any unnecessary activity for 2-3 days.
- Think about using medication, ice, heat or TENS. Remember that TENS may be used during light activity.
- Think carefully about your posture and whether this can be used to relieve symptoms.
- Plan for how you will manage emotionally – can you use relaxation or techniques to distract you?

#### **Recommended exercise during a set-back**

- Continue range of movement exercises (moving all your joints throughout their available range) (p29 onwards).
- Reduce or stop strengthening exercises (p34 onwards).
- The key is to get a balance between rest and activity so that you avoid increasing symptoms.

#### **Getting moving after a set-back**

- Build up exercises and physical activity gradually once the symptoms have settled.
- Re-establish an action plan to steadily allow you to return to your previous level of activity.

### **RELAXATION**

Relaxation can help you to cope better with pain, relieve stress and help sleep. Muscle tension can increase pain and this technique aims to reduce that tension. It takes only 5-10 minutes and can be done in sitting or standing so can be used anywhere such as when you sit down with a cup of tea. Practise it daily so that you can gain confidence in using it as a technique when you need it.

#### **Deep Breathing Exercises**

If you feel anxious or short of breath, these exercises may help and can be used as part of relaxation:

- Stand or sit up straight to expand your chest.

- Relax your shoulders.
- Put one hand on your tummy, just below your ribs.
- Take a slow, deep breath in through your nose, and feel your hand move outwards.
- When you have fully expanded your lungs, slowly breathe out through your mouth, feeling your tummy relax.
- Repeat 4-5 times.

### **Mini-relaxation Techniques**

If you feel anxious, stressed, tired or in pain, this may help you relax:

- STOP what you are doing and try to find somewhere to sit or lie down.
- Take several DEEP BREATHS to slow your breathing.
- Picture a relaxing scene (such as walking on a beach) to distract your attention.
- TIGHTEN muscles, hold for 5 seconds and RELAX. Start at the shoulders and move through each group of muscles. This will relieve muscle tension.
- Feel the TENSION RELEASE from your muscles to feel lighter and looser.
- HOLD ONTO THAT FEELING of relaxation by staying in a calm, relaxed position for a few minutes before going back to activity.

Relaxation techniques are a learned art but do not work for everybody. Further information is available online here:

[www.patient.co.uk/health/relaxation-exercises](http://www.patient.co.uk/health/relaxation-exercises)

### **EXERCISE**

Your physiotherapist will review your home exercises and physical activity action plan. They will work with you to adapt these and introduce new exercises as necessary to your own personal circumstances so that you are supported in becoming more physically active.

### **BEFORE THE NEXT SESSION**

- Complete the session reflection form.
- Write a personal plan for managing a set-back.
- Read the information on taking control (next session).

## **REFLECTION**

What were the key learning points from this session?

Will I do anything differently as a result?

Are any of the exercises too easy for me?

How will I make them slightly more difficult?

Do any exercises aggravate my symptoms? Which ones?

How will I change them or what will I do to settle symptoms?

**PERSONAL PLAN FOR MANAGING A SET-BACK**

What activities should I avoid or reduce and how?

What facilities do I have for pain relief (e.g. heat and cold)?

What exercises shall I continue to do?

Are there other ways that I will manage it (e.g. relaxation)?

## TAKING CONTROL

### **TAKING CONTROL**

Most people with hypermobility cope very well day to day but occasionally it impacts on wider aspects of life and that is completely understandable. It is important to accept that set-backs and some of the issues below may happen from time to time. Discuss these issues with family, friends, colleagues and health professionals. Not giving up is an important first step to taking control.

If you are particularly concerned about some of these issues then your GP may refer you for more specialised care. The Hypermobility Syndrome Association ([www.hypermobility.org](http://www.hypermobility.org)) can also be a useful source of support.

**Anxiety:** Set-backs are part of the condition and waiting for the next episode or dealing with a current episode can be stressful. But remember that set-backs pass. Plan for dealing with them, be kind to yourself and use relaxation techniques.

**Defiance:** It is common to want to push through the pain and just get on with life. But remember the principles of pacing – holding back slightly will allow you to better manage your condition and stay active.

**Depression or lack of motivation:** It is natural to have negative thoughts and reduced enthusiasm but these feelings normally pass and it is important that you then become active again. Plan how you can get through the low periods by using relaxation or being active with other people to support and motivate you.

**Fatigue:** It is well known that pain can cause fatigue. Effective pacing will again help you to manage this. Although it takes time to master pacing, it is worth persisting with.

**Fear and uncertainty:** People with joint hypermobility have told us that they fear using long term medication or simply fear for the future. Importantly, there is no evidence that people with joint hypermobility get worse over time. Becoming active and improving your ability to manage your condition is likely to help you reduce reliance on medication.

**Frustration:** The unpredictable nature of joint hypermobility can be very frustrating. Although an element of unpredictability is likely to remain, actively managing your condition should give you much more control.

**Lack of understanding from others:** Hypermobility people have told us that they sometimes feel 'different' and that family, friends and work colleagues often don't understand. Speak to them, share this and other written information with them, explain your condition and how you are trying to manage it – that will help them to encourage and support you.



**Social impact:** Hypermobility can sometimes interfere with some of the things you would like to do, for example making it tricky to play with children, or go to the cinema or pub. With a little creativity you can adapt how you do things or find other activities that you can enjoy with others. Your physiotherapist might be able to advise you.

#### **Will I get osteoarthritis (OA)?**

There is no strong evidence that people with joint hypermobility are more likely to develop OA. In fact there is some evidence that people with joint hypermobility might be less likely to get OA of the small joints of the hand or the knee. The general health benefits of being physically active are likely to be much more important than any possible negative effects.

From our experience, people with joint hypermobility do not injure themselves when they become more active so any changes in your condition are likely to be positive.

#### **IF NEGATIVE FEELINGS DO NOT PASS**

Sometimes negative feelings keep going despite your best efforts to cope. If this happens, it is important to seek help. For example, if more than half the time you feel low or not able to enjoy things as you used to, and this has gone on for more than two weeks, it would be a good idea to talk to your GP. Alternatively please mention how you are feeling to your physiotherapist who will help you to access further support. There is no need to struggle on with difficult feelings on your own.

Some additional information and resources are available here:

Information about self-management of long-term physical conditions:

[www.myconditionmylife.org](http://www.myconditionmylife.org)

Expert patient programme: [www.expertpatients.co.uk](http://www.expertpatients.co.uk)

Depression Alliance provides support groups and self-help strategies for individuals struggling with depression:

Tel: [REDACTED] [www.depressionalliance.org](http://www.depressionalliance.org)

Royal College of Psychiatrists has many helpful leaflets about different problems:

[www.rcpsych.ac.uk/mentalhealthinformation.aspx](http://www.rcpsych.ac.uk/mentalhealthinformation.aspx)

Mental Health Foundation has information about various sources of support:

[www.mentalhealth.org.uk/help-information](http://www.mentalhealth.org.uk/help-information)

MIND – general mental health advice:

Tel. [REDACTED] [www.mind.org.uk](http://www.mind.org.uk)

Online forum for discussing mental health problems:

[www.mentalhealthforum.net](http://www.mentalhealthforum.net)

SANE offers information, crisis care and emotional support:

[www.sane.org.uk](http://www.sane.org.uk)

### **EXERCISE**

Your physiotherapist will review your home exercises and physical activity action plan. They will work with you to adapt these and introduce new exercises as necessary to your own personal circumstances so that you are supported in becoming more physically active.

### **BEFORE THE NEXT SESSION**

- Complete the session reflection form.
- Complete the personal plan for taking control (p25).
- Read the information on long term management and staying active (next session).



**REFLECTION**

What were the key learning points from this session?

Will I do anything differently as a result?

Are any of the exercises too easy for me?

How will I make them slightly more difficult?

Do any exercises aggravate my symptoms? Which ones?

How will I change them or what will I do to settle symptoms?

**PERSONAL PLAN FOR TAKING CONTROL**

Do I need to share information about my condition with others? Who? What information will I give to them?

Are there different ways to do the things that I used to enjoy with other people? Or other activities that we can try?

Do I need to speak to my GP about negative thoughts?

What else can I do to take control of my condition?

## LONG TERM MANAGEMENT, STAYING ACTIVE

### **CONTINUING EXERCISE**

It is important to identify how you will continue to be active in the long term. Making it fun and/or doing it with friends or family means you will be more likely to continue being active.

#### **Exercise referral scheme**

Your GP or other healthcare professional may be able to refer you to a local exercise referral scheme. These schemes provide support and guidance by qualified instructors for people with stable medical conditions, whose quality of life can be maintained or improved through taking part in regular physical activity.

#### **Local facilities**

Familiarise yourself with your local leisure facilities. This could include swimming pools, leisure centres, gyms, parks and cycle and walking paths. Swimming can be good because it reduces the demands on your joints. Tai Chi and Pilates classes can also be good for muscle control but ensure that instructors are fully qualified. Many parks have exercise equipment that you may be able to use. Being active does not need to cost money.

#### **Local classes or groups**

Check out your local community centres or leisure centres for classes or activities that you enjoy or that you think you might like to try. It could be anything from going to the gym, an exercise class, a local walking group or salsa dancing.

#### **Other resources**

There are some good online resources to help support you to be more active as follows:

Change 4 Life:

[www.nhs.uk/Change4Life/Pages/change-for-life.aspx](http://www.nhs.uk/Change4Life/Pages/change-for-life.aspx)

NHS Choices:

[www.nhs.uk/LiveWell/Fitness/Pages/Fitnesshome.aspx](http://www.nhs.uk/LiveWell/Fitness/Pages/Fitnesshome.aspx)

Walking for Health:

[www.walkingforhealth.org.uk/get-walking](http://www.walkingforhealth.org.uk/get-walking)

### **PROGRESS SINCE BEGINNING TREATMENT**

Reflect on your progress since starting treatment. Hopefully you will be:

- Feeling some benefits from being more active.
- More confident in performing exercises.
- Less anxious when you have symptoms.
- Able to set yourself personal goals.
- Able to plan activity/exercise in advance.

- Able to pace better (i.e. stop before symptoms are aggravated).

**What next.....?**

- Make an individual plan for continuing exercise.
- Expect to have periods when you are less active, don't meet your goals or have reduced motivation – this is normal. The key is to re-engage as soon as you can.
- Try to use coping strategies such as action planning with more easily achieved goals during these times.
- Reward yourself when you achieve your goal.
- Remind yourself of the benefits of having an active lifestyle.

**DEALING WITH A RELAPSE IN PHYSICAL ACTIVITY**

- Reflect on what might have contributed to you being less active – what can you change to get you active again?
- Don't blame yourself – everybody goes through good and bad phases of being physically active.
- Remember how good you felt when you were more active.
- What did you do to become active at the start of the programme? – go back and read your reflections.
- Start again with small steps and set new goals.

**Finally.....**

- Complete a personal plan for continuing exercise.
- Gather information on suitable exercise classes locally and think about joining something that you enjoy.
- Remember that you have this handbook for future reference, in addition to booklets from Arthritis Research UK and the Hypermobility Syndrome Association.

**PERSONAL PLAN FOR CONTINUING EXERCISE**

What type of activities/ exercise do I enjoy?

What facilities for these activities are available locally?

What are the advantages and disadvantages of taking part?

When do I plan on doing these activities and how often?


## HOME EXERCISES – STRETCHING & POSTURE





The exercises below are specifically to stretch tight muscles or to get achy joints moving and are in addition to more general physical activity. Some also aim to get to think about your posture. Your physiotherapist will guide you as to which are most relevant for you and how to adapt or progress them. **You are not expected to do them all.**

Remember:







- **Quality of movement** is key – always keep control of the movement.
- It is important to be aware of beginning your exercise in your neutral joint position before commencing.
- Using a mirror can sometimes help you to see where your body is in space.
- Stretches should be held for up to 20-30 seconds. Aim for 3-4 repetitions.
- A little bit of discomfort is OK.
- Plan carefully for how you can build the stretches into your daily routine and how you can make them more enjoyable (e.g. do them watching your favourite TV episode)





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<input checked="" type="checkbox"/>	Illustration	Instructions	Notes
1 <input type="checkbox"/>		<b>Neck Posture</b> Sit upright. Pull your chin in, keeping your neck and back straight (not tipping your head up or down). Hold at the end position and feel the stretch in your neck.	

<p>2</p> <p><input type="checkbox"/></p>		<p><b>Shoulder Posture</b>          Sit or stand.          Keep upper arms close to the sides and elbows at right angles. Turn forearms outwards and squeeze shoulder blades together.</p>	
<p>3</p> <p><input type="checkbox"/></p>		<p><b>Shoulder (1)</b>          Stand leaning on a table with one hand. Let your other arm hang relaxed straight down. Swing your arm forwards and backwards.</p>	
<p>4</p> <p><input type="checkbox"/></p>		<p><b>Shoulder (2)</b>          Stand facing a wall. Place a towel on the wall with both hands flat on the towel. Slide the towel up the wall as far as comfortable. Then reverse back down the same way.</p>	
<p>5</p> <p><input type="checkbox"/></p>		<p><b>Shoulder (3)</b>          Stand sideways against a wall. Hold your arm up with the back of the hand towards the wall. Slide arm gently up the wall as far as is comfortable.</p>	



<p>6</p> <input type="checkbox"/>		<p><b>Wrist</b> Sit or stand. Forearms horizontally in front of you and palms together. Push palms together for 5 seconds. Relax.</p>	
<p>7</p> <input type="checkbox"/>		<p><b>Hand (1)</b> Straighten fingers and then slowly bend them into a hooked position.</p>	
<p>8</p> <input type="checkbox"/>		<p><b>Hand (2)</b> Touch your thumb to each fingertip, trying to bend at each finger and thumb joint. Try and make the shape formed by thumb and fingertip as round as possible. Then touch your thumb to each finger joint.</p>	
<p>9</p> <input type="checkbox"/>		<p><b>Lumbar Rotation</b> Lie on your back with knees together and bent. Slowly roll your knees from side to side.</p>	
<p>10</p> <input type="checkbox"/>		<p><b>Back (1)</b> Lying on your back with knees bent. Put your hands in the small of your back. Rock your pelvis backwards to press down on your hands.</p>	
<p>11</p> <input type="checkbox"/>		<p><b>Back (2)</b> Lying face down, leaning on your elbows/forearms. Keep the arch in the small of your back. Squeeze shoulder blades together.</p>	

<p>12</p> <input type="checkbox"/>		<p><b>Back (3)</b> Lying face down with both your hands at shoulder height. Straighten your elbows and lift your upper trunk as far as comfortable. Keep your pelvis and legs relaxed on the bed/floor. Squeeze shoulder blades together.</p>	
<p>13</p> <input type="checkbox"/>		<p><b>Hip (1)</b> Stand with one knee bent on a chair. Bend your upper body backwards keeping the knee immobile. You will feel the stretch in your groin.</p>	
<p>14</p> <input type="checkbox"/>		<p><b>Hip (2)</b> Stand straight with one knee bent and the foot supported on a stool as shown. Bend your straight leg stretching the front of the thigh on the other leg.</p>	
<p>15</p> <input type="checkbox"/>		<p><b>Thigh</b> Stand with the leg to be stretched on a step/footstool. Flex your ankle and push the heel towards the footstool keeping your knee straight. Then bend your upper body forwards from your hips keeping your back straight. You should feel a stretch behind your knee and thigh.</p>	

<p>16</p> <input type="checkbox"/>		<p><b>Calf (1)</b> Stand in a walking position with the leg to be stretched straight behind you and the other leg bent in front. Take support from a wall or chair. Lean your body forwards and down until you feel a stretch in the calf of the straight leg.</p>	
<p>17</p> <input type="checkbox"/>		<p><b>Calf (2)</b> Stand with your feet together facing a wall, leaning against it with your arms and back straight. Let your body drop towards the wall keeping heels on the floor. You should feel the stretching in your calves. Remember your posture – tuck chin in and squeeze shoulder blades together.</p>	
<p>18</p> <input type="checkbox"/>		<p><b>Calf (3)</b> Stand on a step with both heels over the edge. Hold on to a support. Let the weight of your body stretch your heels towards the floor.</p>	


## HOME EXERCISES – STRENGTHENING





The exercises below are specifically to strengthen muscles and improve proprioception and are in addition to more general physical activity. Your physiotherapist will guide you as to which are most relevant for you and how to adapt or progress them. **You are not expected to do them all.**






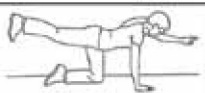
Remember:





- **Quality of movement** is key – always keep control of the movement.
- It is important to be aware of beginning your exercise in your neutral joint position before commencing.
- Using a mirror can sometimes help you to see where your body is in space.
- Start with as many repetitions as you can manage whilst still being in control of the movement (even if this is only 2-3 repetitions). Over time, aim for 8-12 repetitions (this is called a 'set').
- As you gain more control, you can progress by doing more repetitions, more sets, or increasing speed slightly.
- A little bit of discomfort is OK.
- Plan carefully for how you can build the exercises into your daily routine and how you can make them more enjoyable (e.g. do them watching your favourite TV episode)
- Once you feel able, think about progressing to exercise classes such as Tai Chi or Pilates






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<input checked="" type="checkbox"/>	Illustration	Instructions	Notes
19 <input type="checkbox"/>		<b>Shoulder Rotation</b> Stand keeping your upper arm close to the side and elbow at a right angle. Hold a rubber exercise band between both hands. Pull the band by turning your forearms outwards.	







<p>20</p> <input type="checkbox"/>		<p><b>Shoulder</b>          Standing with a good posture. Hold a rubber exercise band in one hand with this arm down and across your body (so that your hand is over the opposite pocket). Pull the band up and across your body (letting your thumb lead the movement as if you are taking a sword out of your pocket and raising it up over your head).</p>	
<p>21</p> <input type="checkbox"/>		<p><b>Shoulder/Elbow</b>          Stand facing a wall with your arms straight and hands on the wall. Do push-ups against the wall keeping your body in a straight line. Remember your posture – tuck chin in and squeeze shoulder blades together.</p>	
<p>22</p> <input type="checkbox"/>		<p><b>Wrist Extension</b>          Place your forearm on a table with wrist over the edge and back of your hand facing up. Put a weight around your hand or hold a tin of beans. Slowly bend your wrist up.</p>	
<p>23</p> <input type="checkbox"/>		<p><b>Thumb/Finger Extension</b>          Place your forearm on a table with thumb and index finger together and a broad elastic band around them. Pull the thumb and index finger apart as far as possible. Repeat with thumb and the other fingers.</p>	






<p>24</p> <input type="checkbox"/>		<p><b>Thumb/Finger Flexion</b> Support your forearm on a table, with putty between your thumb and index finger. Push the thumb and index finger together and then stretch them apart. Repeat exercise with thumb and other fingers.</p>	
<p>25</p> <input type="checkbox"/>		<p><b>Trunk – 'Angry Cat'</b> On all fours. Keep your elbows straight and your head relaxed. Squeeze shoulder blades together. Draw your tummy button and pelvic floor in and arch your back like an angry cat. Relax and repeat.</p>	
<p>26</p> <input type="checkbox"/>		<p><b>Trunk Extension</b> Lying face down, arms behind your back. Lift your upper trunk off the floor and pull your shoulder blades together. Look down at the floor while doing the exercise.</p>	
<p>27</p> <input type="checkbox"/>		<p><b>Trunk Core (1)</b> Crawling position. Find your neutral spine position. Keep this position and then slowly lift one arm and then return to the starting position. Do not allow your back to sag.</p>	
<p>28</p> <input type="checkbox"/>		<p><b>Trunk Core (2)</b> Crawling position. Find your neutral spine position. Keep this position and then slowly lift one leg straight back and then return to the starting position. Do not allow your back to sag as you do this.</p>	
<p>29</p> <input type="checkbox"/>		<p><b>Trunk Core (3)</b> Crawling position. Find your neutral spine position. Keep this position and then slowly lift the opposite arm and leg to the horizontal position whilst not allowing your back to sag down. Hold 5-10 seconds and then return to the starting position. Repeat with the other arm and leg.</p>	




<p>30</p> <input type="checkbox"/>		<p><b>Trunk Core (4)</b> Place a wobble board/cushion on a firm surface (chair or table). Sit on the board keeping an upright posture. Tilt your pelvis to the right side and then to the left side keeping your shoulders level.</p>	
<p>31</p> <input type="checkbox"/>		<p><b>Trunk Core (6)</b> Place a wobble board on a firm surface (chair or table). Sit on the board keeping an upright posture. Tilt your pelvis alternately forwards and backwards keeping your upper trunk upright.</p>	
<p>32</p> <input type="checkbox"/>		<p><b>Trunk Core (6)</b> Sit on a gym ball. Find your neutral spine position and recruit your tummy muscles. Try to maintain this position whilst slowly challenging your balance with the following:</p> <ul style="list-style-type: none"> <li>• Lift alternate feet off the floor</li> <li>• Lift your arms above your head</li> <li>• Catch and throw a ball against the wall or to another person</li> <li>• Shift your bodyweight in a circular direction by moving your pelvis and try to maintain your balance</li> </ul>	
<p>33</p> <input type="checkbox"/>		<p><b>Hip Extension (1)</b> Lie on your back with knees bent. Squeeze your buttocks together and lift your bottom off the floor. Return to starting position.</p>	



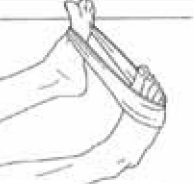

<p>34</p> <input type="checkbox"/>		<p><b>Hip Extension (2)</b> Lying on your back with knees bent. Lift your hips up and keep them straight. Straighten one leg, put it back down and repeat with the other leg. Remember your posture.</p>	
<p>35</p> <input type="checkbox"/>		<p><b>Hip Extension (3)</b> Stand straight holding on to a chair or at kitchen surface. Bring your leg backwards keeping your knee straight. Do not lean forwards. Squeeze your bottom muscles.</p>	
<p>36</p> <input type="checkbox"/>		<p><b>Hip Extension (4)</b> Stand with a rubber exercise band around your ankle. Pull the band by bringing your leg straight backwards as far as you can, then slowly return to resting position.</p>	
<p>37</p> <input type="checkbox"/>		<p><b>Hip Extension (5)</b> Lying face down. Bend your knee to a right angle and lift your foot towards the ceiling.</p>	
<p>38</p> <input type="checkbox"/>		<p><b>Hip Extension (6)</b> Lying face down. Lift your leg towards the ceiling keeping your knee straight.</p>	










39 <input type="checkbox"/>		<b>Hip Extension (7)</b> Crawling position. Put a weight around your ankle. Kneel on one knee and straighten the other leg out behind.	
40 <input type="checkbox"/>		<b>Hip Abduction/Adduction</b> Lying on your back with a carrier bag under your leg. Bring your leg to the side and then back to mid position. Point toes to the ceiling.	
41 <input type="checkbox"/>		<b>Hip Abduction (1)</b> Lie on your side with knees bent and heels together. Keep heels together and raise your uppermost knee towards the ceiling like a clam. Do not allow your pelvis to roll backwards.	
42 <input type="checkbox"/>		<b>Hip Abduction (2)</b> Side-lying. Lower knees bent up and upper leg straight. Lift the upper leg up. Keep pelvis still, don't rotate.	
43 <input type="checkbox"/>		<b>Hip Abduction (3)</b> Stand straight holding on to a support. Lift your leg sideways and bring it back keeping your trunk straight throughout the exercise.	
44 <input type="checkbox"/>		<b>Hip Abduction (4)</b> Stand with a rubber exercise band around your ankle. Pull the band by bringing your leg out to the side as far as you can and then slowly return to the starting position. Again, make sure that the movement is slow and controlled.	

45 <input type="checkbox"/>		<b>Hip Adduction (1)</b> Lying with your knees bent and feet on the floor hip width apart. Keeping one leg still drop your other knee out to the side keeping your pelvis still. Keep your back flat on the floor during the exercise.	
46 <input type="checkbox"/>		<b>Hip Adduction (2)</b> Stand with a rubber exercise band around your ankle. Pull the band by bringing your leg straight forward.	
47 <input type="checkbox"/>		<b>Hip &amp; Knee</b> Lying on your back with a carrier bag under your leg. Bend and straighten your hip and knee by sliding your foot up and down the bed/floor.	
48 <input type="checkbox"/>		<b>Knee Extension (1)</b> Lie on your back. Place a cushion under both knees (slightly different from picture). Exercise your legs by lifting your foot up to straighten your knee (keep knee on the cushion).	
49 <input type="checkbox"/>		<b>Knee Extension (2)</b> Sit on a chair. Extend your knee in front of you and then lower slowly.	

<p>50</p> <p><input type="checkbox"/></p>		<p><b>Knee Extension (3)</b>  Stand in front of a table or chair holding on to the support with both hands. Slowly crouch keeping your back straight and heels on the floor. Stay down for approximately 5 seconds and feel then stretching in your buttocks and the front of your thighs. Stand up slowly.</p>	
<p>51</p> <p><input type="checkbox"/></p>		<p><b>Knee Extension (4)</b>  Stand against a wall with feet away from the wall and knees slightly bent. Place a ball between your knees. Squeeze the ball between your knees and release. Progress by moving your feet slightly further away from the wall or slide up and down the wall.</p>	
<p>52</p> <p><input type="checkbox"/></p>		<p><b>Knee Extension (5)</b>  Stand sideways on a step with one foot hanging over the edge of the step. Slowly bend your knee allowing your other foot to brush the floor.</p>	

<p>53</p> <p><input type="checkbox"/></p>		<p><b>Knee Extension (6)</b>  Stand on one leg on a step facing down. Slowly lower yourself by bending your knee. Return to starting position.</p>	
<p>54</p> <p><input type="checkbox"/></p>		<p><b>Foot Inversion</b>  Sit on the floor or on a chair. Put a rubber exercise band around your foot. Turn your foot inwards as if to look at the sole of your foot.</p>	
<p>55</p> <p><input type="checkbox"/></p>		<p><b>Foot Eversion</b>  Long sitting. Put a rubber exercise band around your feet. Turn the soles of your feet towards each other. Then turn the soles of your feet away from each other. Keep your knees facing the ceiling.</p>	
<p>56</p> <p><input type="checkbox"/></p>		<p><b>Leg Proprioception</b>  Stand on one leg on a wobble board/cushion. Move your weight first in one direction and then in another.</p>	

<p>57</p> <input type="checkbox"/>		<p><b>Walking Practise</b></p> <p><b>Comments:</b></p>	
<p>58</p> <input type="checkbox"/>		<p><b>Walking</b> Walk for ____ (distance) in ____ minutes</p>	
<p>59</p> <input type="checkbox"/>		<p><b>Stairs</b> Walk up and down stairs. Walk ____ steps in ____ seconds</p>	
<p>60</p> <input type="checkbox"/>		<p><b>Marching</b> March in place for ____ seconds</p>	

61 <input type="checkbox"/>		<b>Running</b> Run for ____ (distance) in ____ minutes	
62 <input type="checkbox"/>		<b>Cycling</b> Time: ____ Weight load: ____	
63 <input type="checkbox"/>		<b>Rowing Machine</b> Time: ____ Weight load: ____	

## **ACKNOWLEDGEMENTS**

This booklet is based upon information originally contained in the 'Enabling Self-management and Coping with Arthritic Knee Pain through Exercise' (ESCAPE-knee pain) programme (Hurley et al 2007). It was previously adapted from the original twelve-session intervention to a six-session intervention (Domaille et al 2006, Palmer et al 2013b) and has now been adapted further to be specific to joint hypermobility syndrome (JHS).

We are grateful to all of the patients and clinicians who contributed to focus groups exploring their perspectives on physiotherapy for JHS. Thank you to the Hypermobility Syndrome Association and colleagues from Bournemouth University and the University of Hertfordshire who assisted with focus group recruitment. We are also grateful to the clinicians and patient research partners who helped to adapt and develop this booklet on the basis of findings from the focus groups.

Finally we are grateful to the patients and physiotherapists who piloted this intervention and provided us with detailed feedback. What we have learned has been incorporated into this version.

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## **FURTHER INFORMATION**

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[Redacted contact information]



**NOTES**

**Contact Numbers:**

**Physiotherapy Appointment Details:**

Date \_\_\_\_\_ Time \_\_\_\_\_

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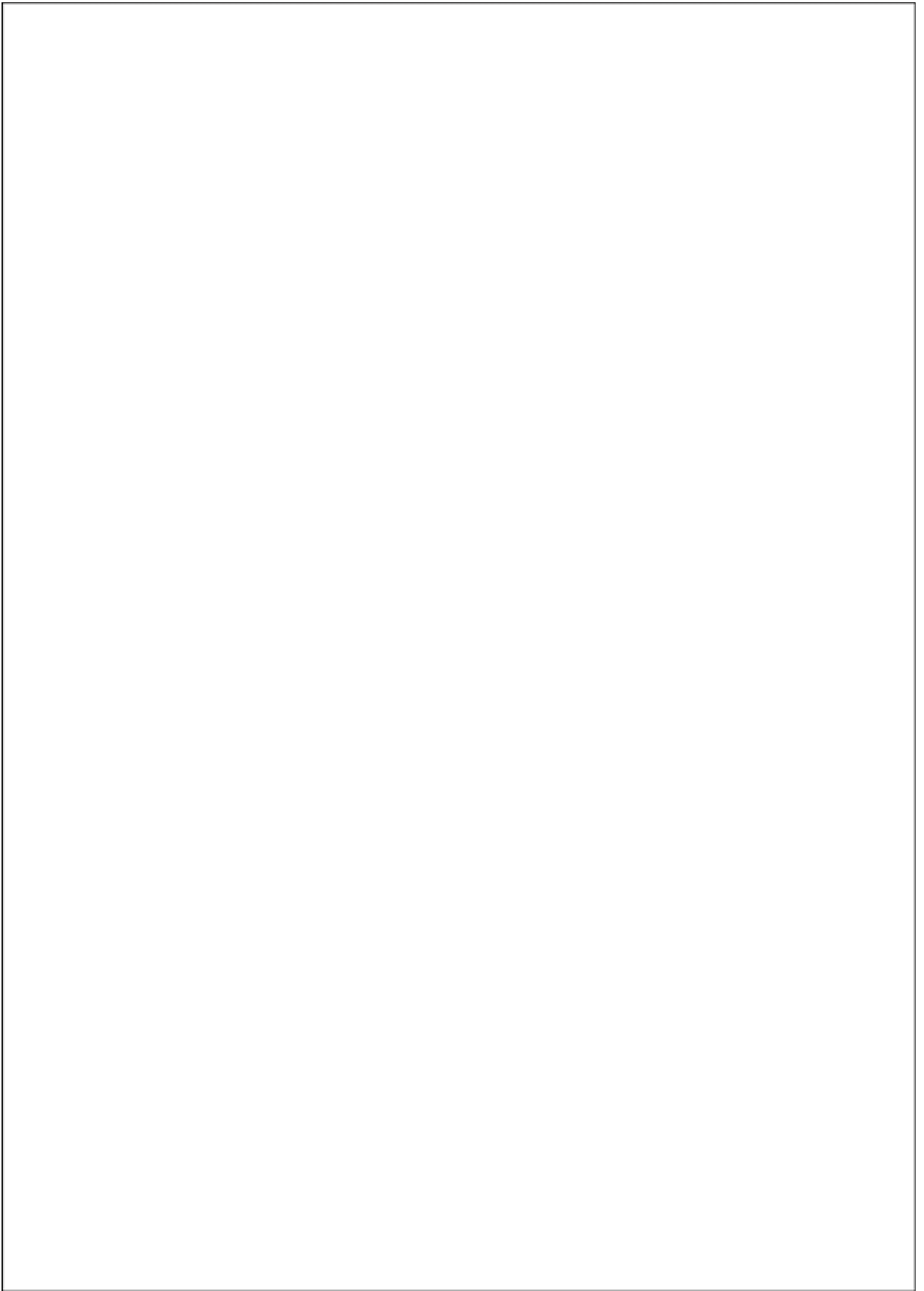
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**Other Notes:**

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