



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

"THE SOONER YOU START THE BETTER"

This resource provides information and tips and hints on how to make a physical activity plan that is unique for a person with Huntington's disease. The resource was developed by researchers at Cardiff University, the Huntington's Disease Association of England and Wales, Carer's Trust Wales and carers and people with Huntington's disease. The exercises are based on the Move to Exercise resource that was developed by specialist physiotherapists and occupational therapists specifically for people with movement problems. You can find the 'Move to Exercise' video here <https://www.hda.org.uk/professionals/resources-for-professionals/resources-from-other-organisations>

Carers have told us that it helps if a professional provides advice, so here is what the World Health Organisation says about physical activity:

"PHYSICAL ACTIVITY HAS GENERAL HEALTH BENEFITS SUCH AS IMPROVED SLEEP, IMPROVED QUALITY OF LIFE AND HELPS IN MANAGING ANXIETY AND DEPRESSION"

Physiotherapy research shows that for people with Huntington's disease, **exercise can improve balance confidence, mobility, independence, posture and breathing.**

So, keeping flexible and strong helps with ordinary things like getting dressed, climbing stairs and getting out and about.

This resource includes information on safety, advice on how to plan physical activity and exercises that can be done to help someone with Huntington's disease stay physically active.

Thank you to all the carers and people with Huntington's disease who helped create and test this resource. You can see what they have said in the quote boxes throughout.

Please scan this QR code when you use this resource. If you have any feedback, please contact Una Jones jonesuf@cardiff.ac.uk



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

SAFETY FIRST

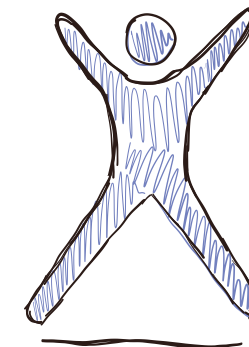
A big concern for carers is that the person with Huntington's disease may fall. This may happen due to the chorea movements and poor balance. However, not being active means that someone may get weaker and their balance get worse, so there needs to be a safe way to go about being active. Here are some tips on safety:

- The person with Huntington's disease can learn how to get up from the floor if they do fall
- The exercise space should be well lit and clear of obstacles e.g. small tables, rugs, pets
- Keep something sturdy nearby for support e.g. kitchen work surface/table
- Appropriate footwear should be worn e.g. shoes that support the foot and won't fall off
- Appropriate clothing that does not get in the way of being active
- Keep hydrated
- Make sure any equipment is safe to use
- If exercising alone, keep a phone nearby just in case you need it
- Stop and rest if there is any acute or severe pain or dizziness



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING



PLANNING PHYSICAL ACTIVITY

The “Physical Activity Tool for Huntington’s Disease” (pages 22-23) was developed with people with Huntington’s disease, their carers and healthcare professionals. You can use this to chat about physical activity, set some goals and plan being active. Physical activity is any body movement, not just exercise or sport. So, dancing while waiting for the kettle to boil is physical activity!

Being motivated to do something can be a big challenge for people with Huntington’s disease. This can be helped by having a choice of what to do, feeling that there will be benefit and that there is some reward in being physically active.

Some rewards that may help motivate being active are - watching an episode of a TV programme, cup of tea/coffee... Whatever works for you.

When making the plan, it is important to think about what is stopping someone being active and then work out what other support you/they may need and who you can ask for advice.

Carers told us that these are some of the things that help plan activities:

“INVOLVE FAMILY AND FRIENDS IN PLANNING AND SUPPORTING ACTIVITY”

“PLAN WHAT IS NEEDED FOR THE ACTIVITY - HATS, GLOVES, WALKING AID, SNACKS, WATER, SPECIAL EQUIPMENT E.G. SWIMMING GOGGLES”

“PLAN OUT THE WEEK AHEAD USING A DIARY OR WHITEBOARD”

“PLAN ACTIVITIES THAT ARE FAMILIAR & ENJOYABLE”



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

BE REALISTIC AND FLEXIBLE IN THE PLAN

ALLOW TIME FOR THE ACTIVITY - OR FIT THE ACTIVITY TO THE TIME THAT YOU HAVE.

THINK OF SHORT AND FREQUENT ACTIVITIES.

GETTING STARTED

It is often difficult to start being active or to increase activity. Here is some advice on how to start a chat about being active with someone who isn't usually active, someone who does some activity and someone who is now finding it difficult to stay active.

SOMEONE WHO HAS NEVER DONE ANY SPORT/EXERCISE/ACTIVITY

That's OK!

1. Find something that the person with HD would like to do or enjoys.
2. Have a look together at the activities in this book and chat about what they'd like to do.
3. Then think together of how the activity could be linked with the thing they'd like to do.

Start gently and build up, for example:

- They would like to buy something new
- Park the car a short distance away from the shop, walk around the shop/shopping centre before buying the item.
- Check steps on a phone.
- Have a treat to something special as a reward.
- This is increasing their physical activity. They can then start to increase the distance they walk or doing some of the exercises in the book.

SOMEONE ALREADY DOING SOME SPORT/EXERCISE/ACTIVITY

Well done!

1. Think of what else they would like to do.
2. Increase the activity gradually.
3. The aim can be to do exercise that makes you breath hard, 3 times per week and do strengthening exercises 3 times per week.

You can use the exercises in this book to help you to make an activity plan.

IT'S GETTING HARDER TO DO SPORT/EXERCISE/ACTIVITY

That's OK!

1. Find something that the person with HD likes doing.
2. Think of how they could make the activities a little easier to do e.g. chair exercises rather than standing.
3. Plan how to get the balance between keeping active, keeping safe, enjoying activities and having enough energy for other things.

'Little and often' may be better than long activities.

KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

BEING ACTIVE

Try some of these exercises/activities and see which ones are the most enjoyable for you.

Make a plan of how the most enjoyable exercises/activities can fit into your life. Use the physical activity tool on pages 21 and 22 to think about activities and set some personal goals and plans.

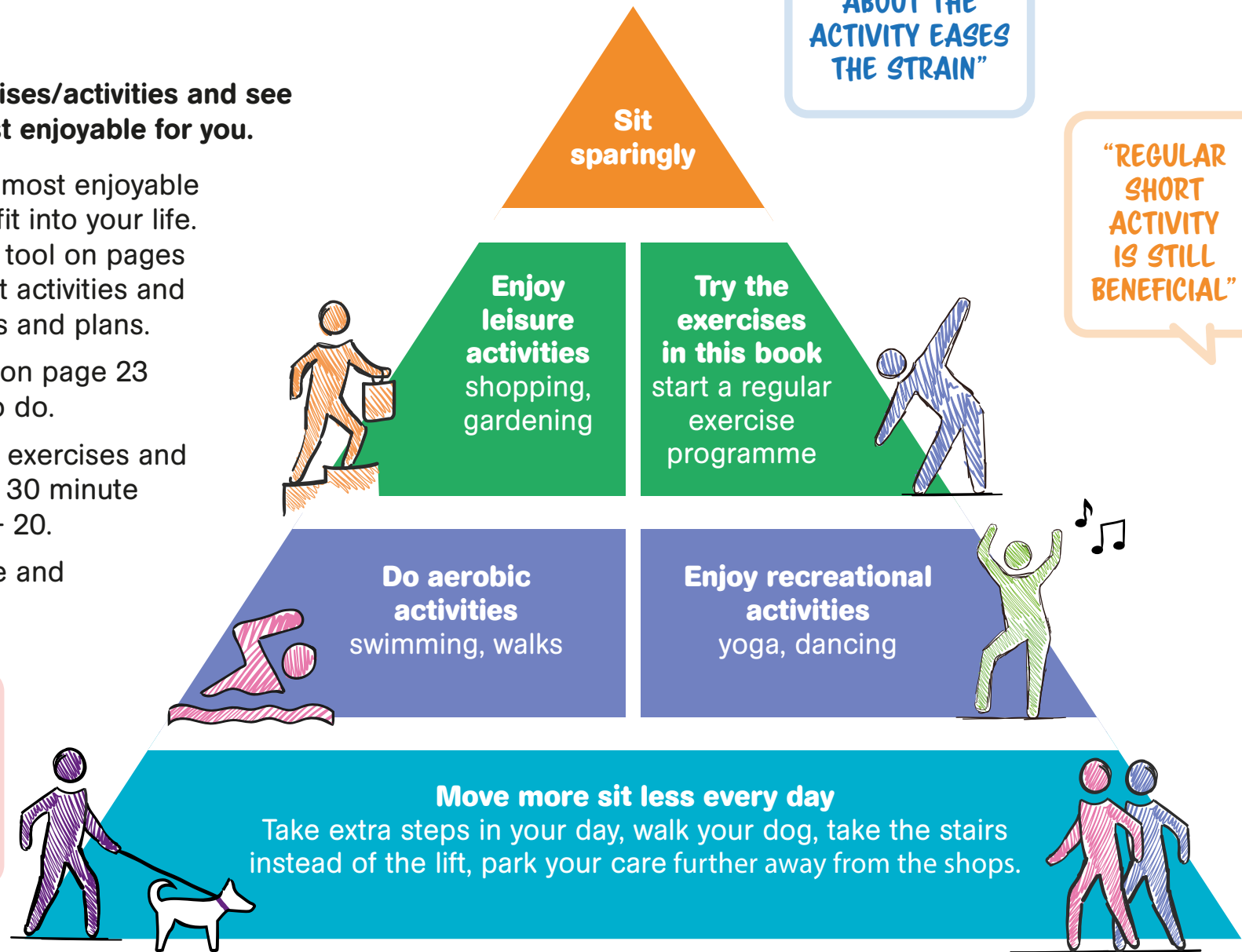
Use the weekly planner on page 23 as a reminder of what to do.

We have grouped some exercises and activities into 10, 20 and 30 minute sessions, see pages 16 - 20.

Remember - move more and sit less every day.

“GETTING AGREEMENT ABOUT THE ACTIVITY EASES THE STRAIN”

“REGULAR SHORT ACTIVITY IS STILL BENEFICIAL”



“PEOPLE WITH HD FEEL SECURE IN DOING WHAT THEY HAVE ALWAYS DONE”

KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

FLEXIBILITY

If you are stiff, it is harder to do things like getting dressed, getting things from high cupboards and being physically active. These activities are designed to improve your flexibility and can be done anywhere.

Wear loose comfortable clothes.

Build up slowly and aim to gradually increase the number of activities that you do and the parts of the body that you stretch.

If you feel dizzy, stop and rest.

Also try: stretching, yoga, tai chi, pilates.

“TRY USING A
DVD OR ONLINE
VIDEO”



NECK STRETCH

- In sitting or standing
- Keep your shoulders down
- Bring your right ear toward your right shoulder, hold for 3 seconds
- Bring your head back to the middle
- Bring your left ear toward your left shoulder, hold for 3 seconds



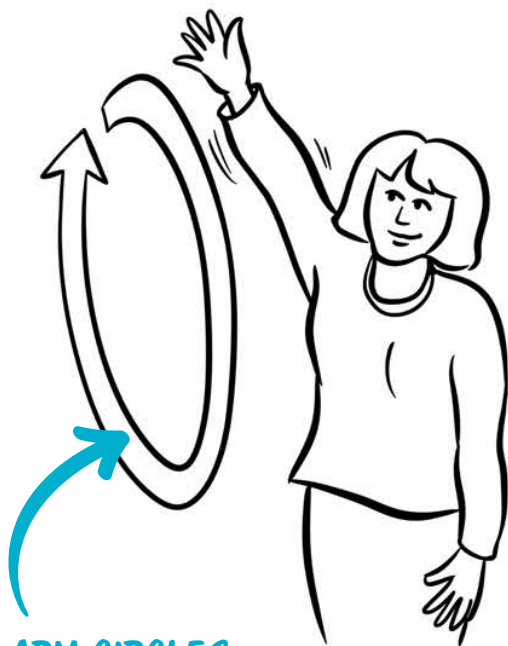
SHOULDER ROLLS

- In sitting or standing
- Shrug your shoulders up towards your ears
- Now slowly roll them backwards and downwards whilst trying to squeeze your shoulder blades together

KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

FLEXIBILITY



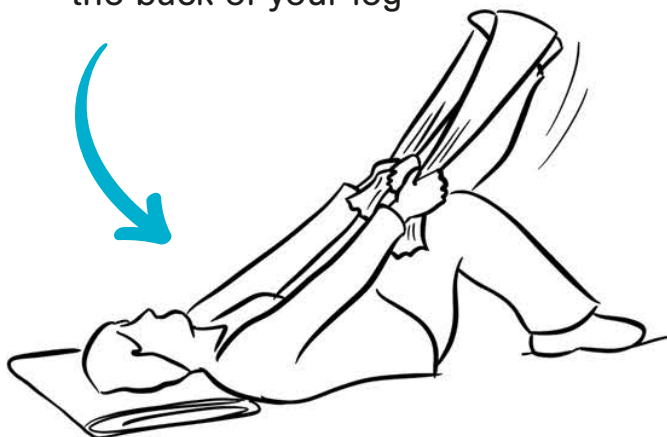
ARM CIRCLES

- In sitting or standing
- Keeping your elbow straight, move your right arm in a big circle in a forward direction
- Repeat in a backward direction
- Now repeat with your left arm in both directions



HAMSTRING STRETCH

- Lying on the floor, wrap a towel around your foot and pull your leg up towards your body, keeping your knee straight and your foot bent
- You should feel the stretch in the back of your leg



CALF STRETCHES

- In standing, step back with one leg, bend your front knee and lean forward. Keep your back knee straight, and you should feel a stretch in the back of your calf
- If you do this in sitting, wrap a towel around the ball of your foot, pulling your upper foot towards your body
- Feel the stretch in the back of your calf



CHILD'S POSE

- Start by lying on your stomach, move onto all fours, then gently sit back on your heels
- Keep your arms stretched out in front of you
- Try to sit all the way back on your heels

KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

BALANCE

People with Huntington's disease often have poor balance. Physiotherapists recommend that both balance and balance confidence can be improved by exercises.

Balance exercises can progress like this:

- Standing feet side by side holding on to something.
- Then try not holding on.
- Then try with eyes closed.
- Then try tandem standing.
- Then try one leg standing.

Remember safety first and make sure that you have support – either a person or e.g. table nearby when doing balance exercises.

Also try yoga, tai chi, pilates, bowls.

“YOU NEED TO FEEL SAFE OR IT WON'T BE ENJOYABLE”

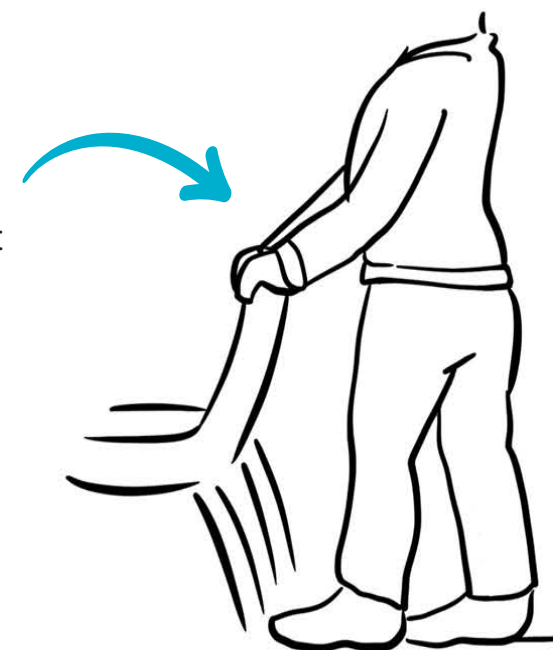


STANDING EXERCISE

- In standing, try to maintain your balance
- If you feel comfortable in this position, close your eyes for up to 10 seconds, but be sure your hands are near to the chair for support if you need it

TANDEM STANDING

- Place one foot in front of the other. If you can, put the heel of your front foot against the toe of your other foot
- If you are unable to keep your balance in this position, put your front foot to the side but as close to the other foot as is comfortable
- If you feel comfortable in this position, let go of the support while keeping your hand nearby



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

BALANCE

STANDING ON ONE LEG

- In standing with support, bend one knee so you are standing on one leg
- If you lose your balance, put your foot down, regain your balance and try again
- If you feel comfortable in this position, let go of the support while keeping your hand nearby



SIDE LUNGES

- Standing with the chair at your side, take a comfortable step out to the side, bending your knee over your ankle
- Use the chair for balance if needed

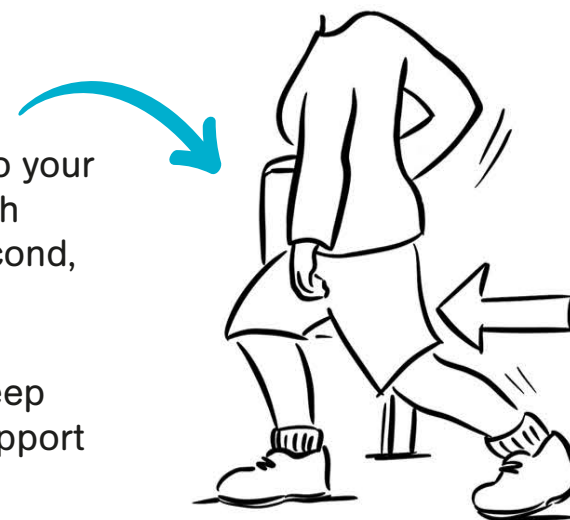


THROWING A BALL, DANCING

- You can throw a ball or bean bag when sitting upright on a chair
- Throw a ball for a dog and pick it up when it is returned to you
- Dance when waiting for the kettle to boil

FORWARD LUNGES

- Standing with a chair near to your side, take a step forward with your right leg, hold for a second, and then return to the starting position
- Use the chair to help you keep your balance if you need support



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

STRENGTH

Being strong helps with day to day activities and walking and reduces the risk of falls. Strength training involves making muscles work harder by working against a resistance. This resistance can be your own body weight or weights such as cans of food, bottle of water.

In order to strengthen muscles, you need to work to the point where you may need a short rest before continuing.

Try to do 8-12 repeats of an exercise, which is 1 set. You can gradually increase the number of sets up to 3 per exercise. Do exercises for legs, arms, back and abdomen.

Remember to start gradually and build up over a number of weeks

Also try: pilates, running, outdoor gym, rowing.

STRENGTHENING AT HOME

- You can strengthen your legs by climbing up and down stairs, if this is safe for you to do. Gradually increase the number of times you climb the stairs every day
- Gardening – digging, lifting pots are all working against resistance and can strengthen your muscles. Pace your self and do jobs over a number of days if needed



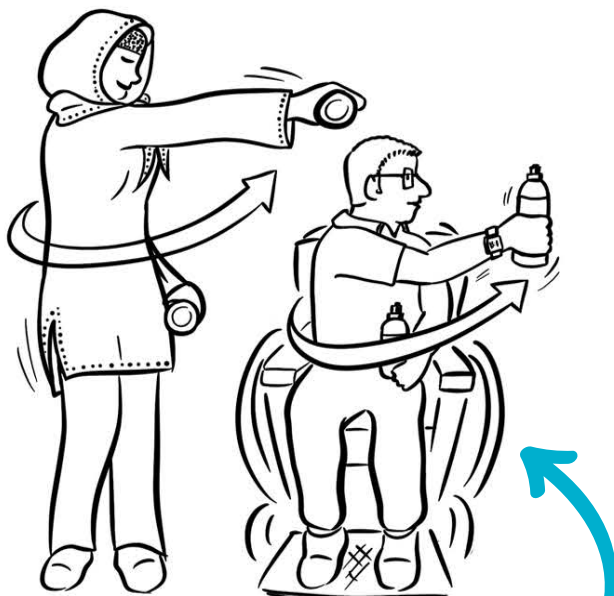
STRENGTHENING AWAY FROM HOME

- Cycling and hill walking can help strengthen your legs, if you are safe to do so
- Gradually increase the distance or time that you cycle or walk
- Remember to wear the right type of clothes and bring water and a phone with you

KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

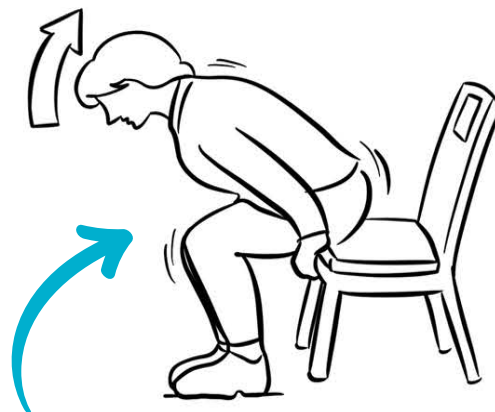
EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

STRENGTH



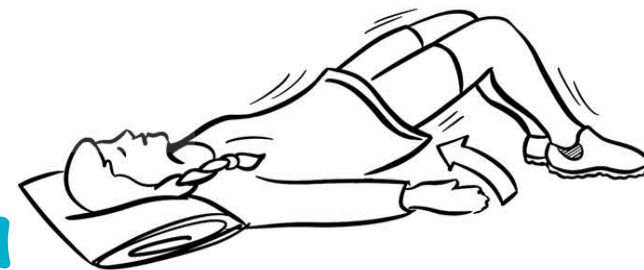
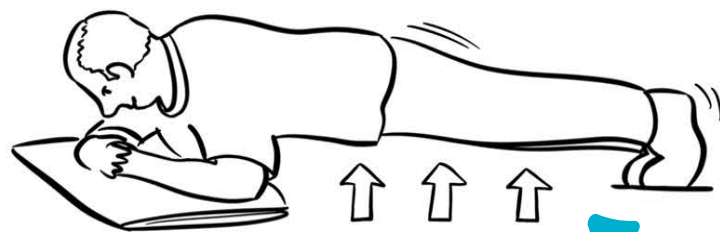
TRUNK EXERCISES WITH WEIGHTS IN SITTING OR STANDING

- Holding a weight in each hand, reach with your right hand across your chest to the left side. Turn your body as far as you can comfortably move
- Return back to centre, and then repeat to the other side
- Gradually increase the weight and number of sets



SIT TO STAND EXERCISES

- From a sitting position, lean forward over your thighs and come to a standing position
- Once you have your balance, carefully lower yourself back into the chair
- Gradually increase the number of sit to stands and take a rest between sets



BRIDGING

- Bend both of your knees so that your feet are flat on the floor
- Gently tilt your pelvis, as if you are imprinting your back into the floor
- Now, lift your hips up into the air, while still holding your pelvis level
- Try and hold for 10 seconds, rest and try again

PLANK

- Lying on your stomach, prop yourself up onto your elbows
- Now, curl your toes under and lift yourself up onto your feet, while staying supported on your elbows
- Try not to lift your hips up too high in the air. Hold this position for as long as you can (up to 10 sec)
- Rest as needed and then try again

KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

FITNESS AND PHYSICAL ACTIVITY

There are many ways to stay active and keep fit at home and outside.

Physiotherapists recommend aerobic exercise of moderate intensity three times per week to improve fitness. Moderate intensity is when you can talk during the activity, but could not sing!

Remember safety first, wear appropriate, clothing, keep hydrated, bring a phone if going alone.

Try things that make you breathe a bit harder than when at rest.

"WE LIKE WALKING
IN PLACES WE
KNOW WELL"

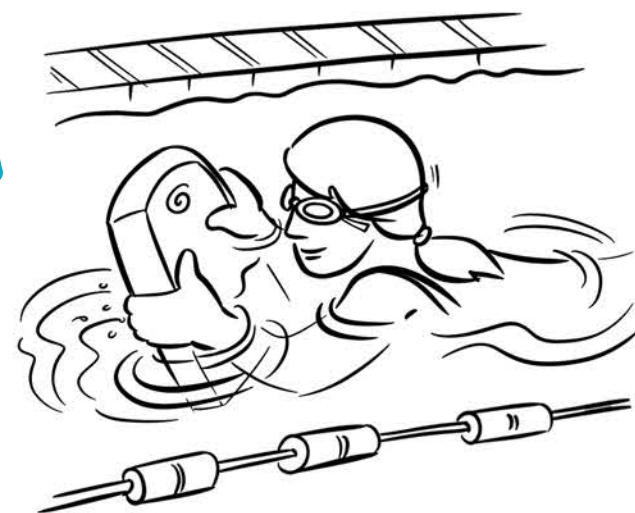


BEING ACTIVE & FIT AT HOME

- Filling and emptying the dishwasher
- Putting out the bins
- Cleaning
- Gardening
- Follow a fitness programme online
- Dance in the kitchen

BEING ACTIVE & FIT AWAY FROM HOME

- Walk to the shops
- Take the stairs instead of the lift
- Park away from the shop/work and walk the rest of the way
- Swimming or water exercises
- Walking football



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

RELAXING AFTER BEING ACTIVE

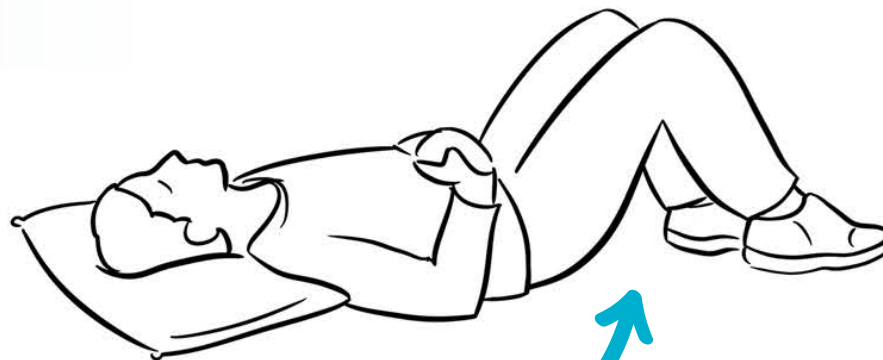
Relaxation exercises can be helpful to reduce tension both in muscles and in the mind.

Relaxation is a skill that needs practice therefore gradually increase the time spent on the exercise.

You can listen to relaxation recordings, sit peacefully by water, meditate or do breathing exercises – whatever works for you.

Also try yoga, tai chi, mindfulness.

“GET A ROUTINE GOING”

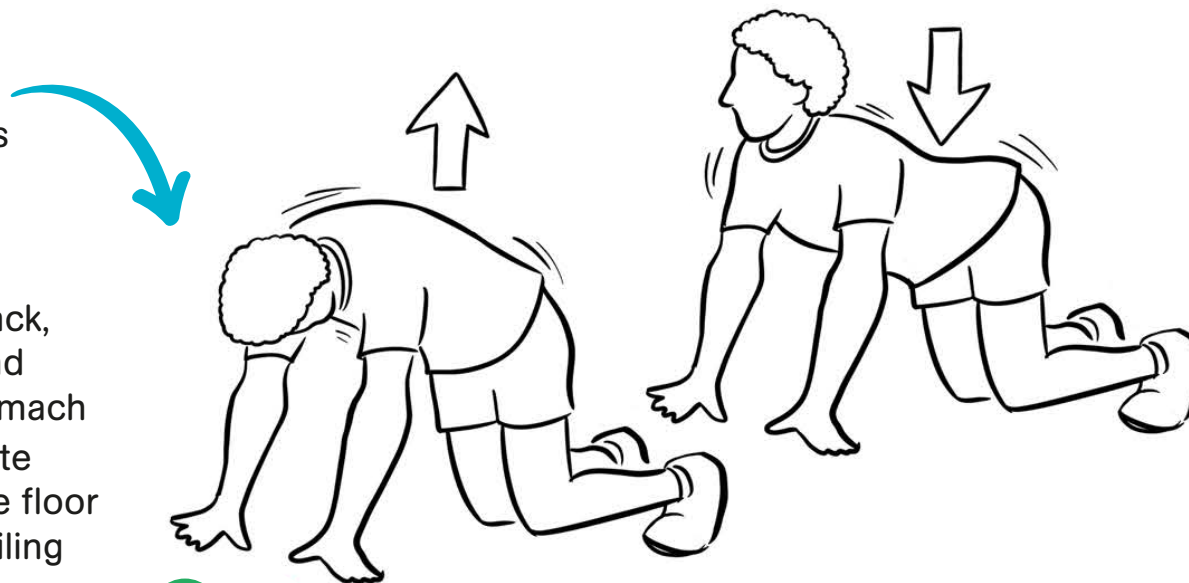


BREATHING EXERCISES

- Lying on your back, with your knees bent, place your hands on the lower part of your stomach, and inhale deeply through your nose and feel your tummy rise
- Exhale through your mouth, and relax
- This could also be done in sitting

CAT/CAMEL EXERCISE

- Start on your hands and knees, with your knees directly underneath your hips, your hands underneath your shoulders and back flat. Lay your hands out flat
- Now as you take a deep breath in, arch your back, pulling your belly button away from the floor and bending your head so that you look at your stomach
- Now exhale and move your spine in the opposite direction, pushing your belly button towards the floor and lifting your head up to look towards the ceiling



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

CHOOSING ACTIVITIES THAT SUIT THE ABILITIES AND LIKES OF THE PERSON WITH HD.

Here are some ideas for exercises/activities. Gentle, moderate and strenuous will be different for each person, so choose activities that suit the person's abilities.

As a guide, you can think of a scale of 0 -10, with 0 being no exertion and 10 being maximum exertion. On the scale:

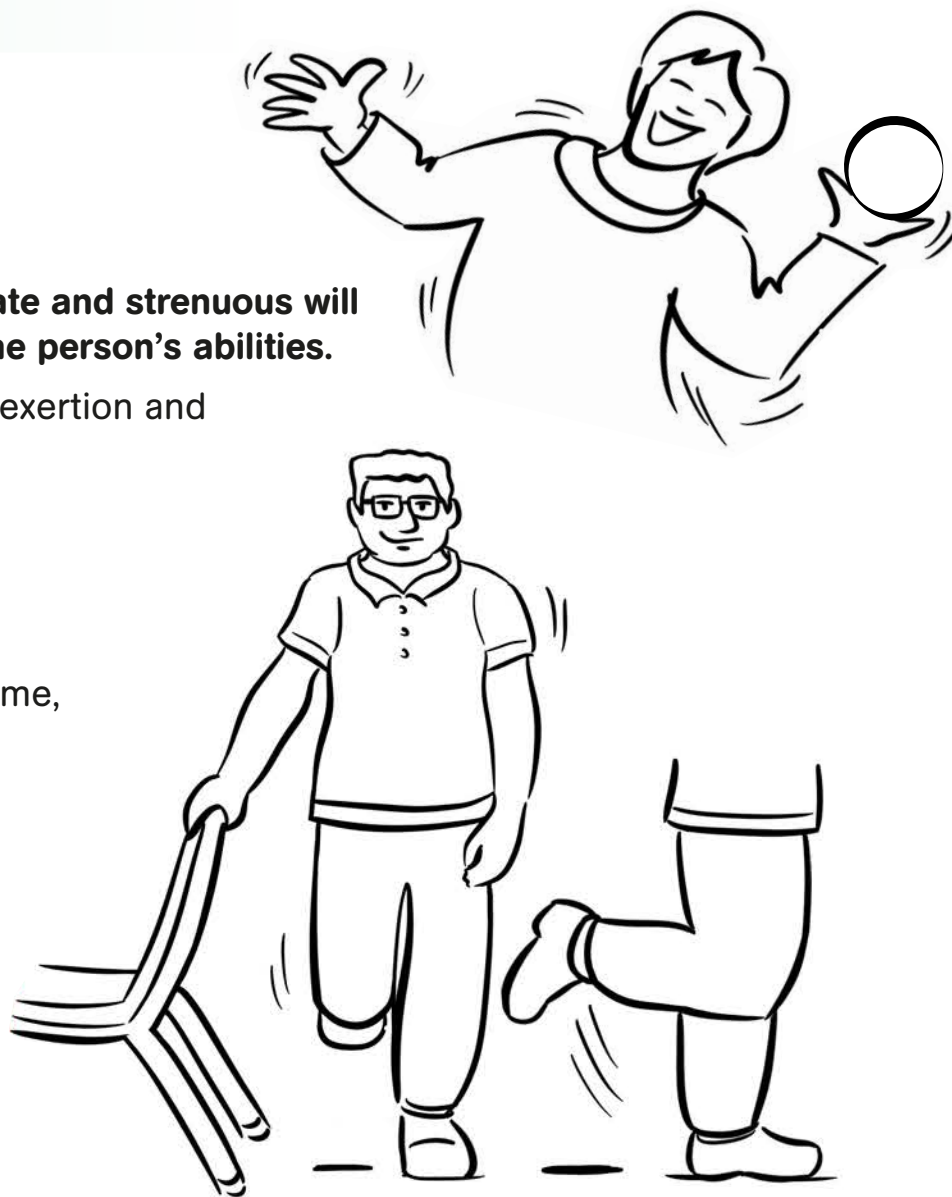
- Gentle activity would be 2-3,
- Moderate activity would be 4-5,
- Strenuous activity would be 6-8.

Remember you can increase or decrease your activity over time, depending on how you feel and your symptoms.

Choose things that the person may like to do and you can mix and match across the examples.

Take a rest between activities if needed.

We have grouped some of the exercises and activities explained in this book into 10, 20 and 30 minute sessions.



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

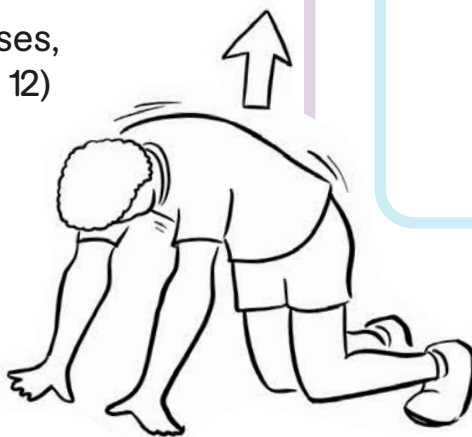


10 MINUTES OF ACTIVITY

Take a rest between activities if needed.

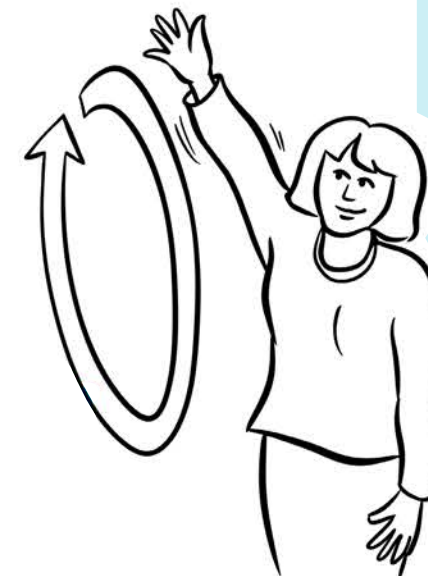
GENTLE ACTIVITY

- 3-5 neck stretches each side (page 7)
- 3-5 shoulder rolls each side (page 7)
- 3-4 minutes of standing balance exercises, taking a rest when needed (pages 9-10)
- 3-4 minutes of sit to stand exercises, taking a rest when needed (page 12)
- 3 minutes relaxation e.g. breathing exercises or cat/camel exercise (page 14)



MODERATE ACTIVITY

- 3-5 arm circles (page 8)
- 3-5 calf stretches (page 8)
- Dance to 2 songs, taking a rest when needed
- 3 minutes relaxation e.g. breathing exercises or cat/camel exercise (page 14)



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING



10 MINUTES OF ACTIVITY

Take a rest between activities if needed

STRENUOUS ACTIVITY

- 3-5 calf stretches each leg (page 8).
- 30-60 seconds child's pose (page 8).
- 3-4 minutes walking briskly up and down the stairs, taking a rest when needed.
- 3-5 side lunges each side (page 10).
- 3-5 forward lunges each side (page 10).
- 3 minutes relaxation e.g. breathing exercises/cat/camel exercise (page 14).



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

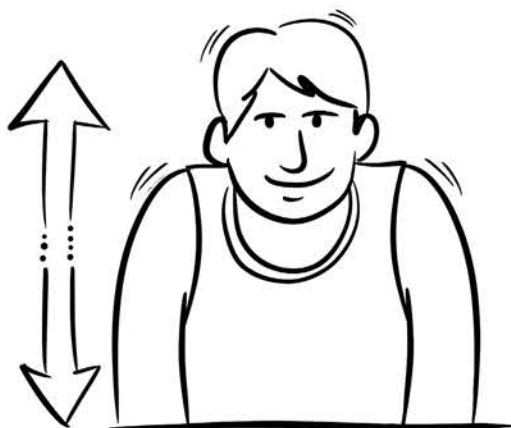


20 MINUTES OF ACTIVITY

Take a rest between activities if needed.

GENTLE ACTIVITY

- 5-8 neck stretches each side (page 7).
- 5-8 shoulder rolls each side (page 7).
- 5-8 arm circles (page 8).
- 3-4 minutes of standing balance exercises, taking a rest when needed (pages 9-10).
- 10-15 sit to stand exercises – take a rest after 5 stands (page 12).



- 3-4 minutes of trunk exercises with weights (page 12).
- 3 minutes throwing a ball or bean bag in sitting or standing.
- 5 minutes relaxation e.g. breathing exercises or cat/camel exercise (page 14).

KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

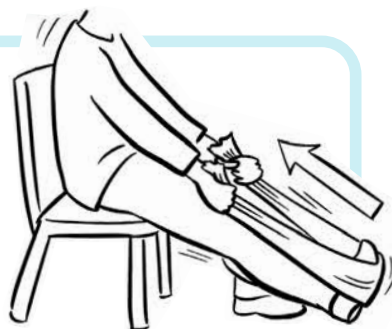


20 MINUTES OF ACTIVITY

Take a rest between activities if needed.

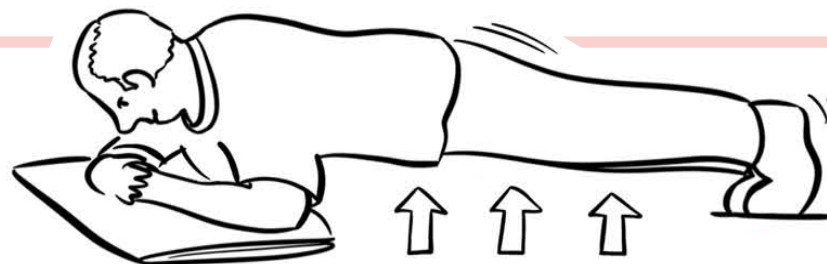
MODERATE ACTIVITY

- 5-8 arm circles (page 8).
- 5-8 calf stretches each leg (page 8).
- 30-60 seconds child's pose (page 8).
- Clean (part of) bathroom/kitchen or any other room in your house for 10-15 minutes.
- Or dance to a song for 5-10 minutes, taking a short rest when needed.
- 3 minutes relaxation e.g. breathing exercises or cat/camel exercise (page 14).



STRENUOUS ACTIVITY

- 5-8 calf stretches each leg (page 8).
- 5-8 hamstring stretches each leg (page 8).
- 5-8 minutes trunk exercises with weights (page 12).
- Spend 1-3 minutes doing plank exercise – hold for 10 seconds and repeat (page 12).
- Dance to 3 songs, taking a short rest when needed.
- 3 minutes relaxation e.g. breathing exercises or cat/camel exercise (page 14).



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING



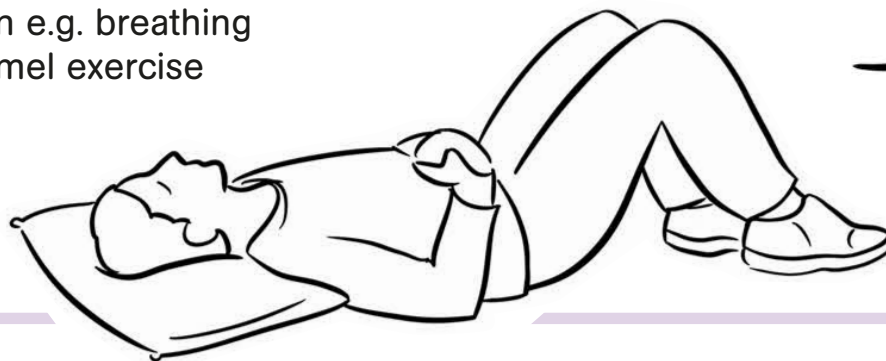
30 MINUTES OF ACTIVITY

Take a rest between activities if needed.



GENTLE ACTIVITY

- 5-8 neck stretches each side (page 7).
- 5-8 shoulder rolls each side (page 7).
- 5-8 arm circles (page 8).
- 20 minutes walk, stop for a rest when needed.
- 5 minutes relaxation e.g. breathing exercises or cat/camel exercise (page 14).



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING



30 MINUTES OF ACTIVITY

Take a rest between activities if needed.

MODERATE ACTIVITY

- 5-8 arm circles (page 8).
- 5-8 calf stretches each leg (page 8).
- 5-8 hamstring stretch each leg (page 8).
- Empty the bins around the house and put outside, stop to take a rest when needed.
- Tidy a room in house.
- 3 minutes relaxation e.g. breathing exercises or cat/camel exercise (page 14).



STRENUOUS ACTIVITY

- 5-8 arm circles (page 8).
- 5-8 calf stretches each leg (page 8).
- 5-8 hamstring stretch each leg (page 8).
- Jog/run 20 minutes, stop to take a rest when needed.
- 3 minutes relaxation e.g. breathing exercises or cat/camel exercise (page 14).



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

PLANNING PHYSICAL ACTIVITY

The Physical Activity Tool for Huntington's Disease.



PHYSICAL ACTIVITY AND HUNTINGTON'S DISEASE

PHYSICAL ACTIVITY BENEFITS:

- General health benefits
- Improved sleep
- Managing anxiety and depression
- Improved quality of life

SPECIFIC BENEFITS FOR HD:

- Improved balance confidence
- Improved mobility
- Improved independence
- Improved posture and breathing

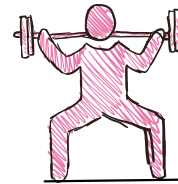
EXAMPLES OF PHYSICAL ACTIVITY AND EXERCISE



FITNESS



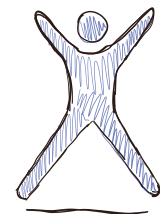
STRENGTH



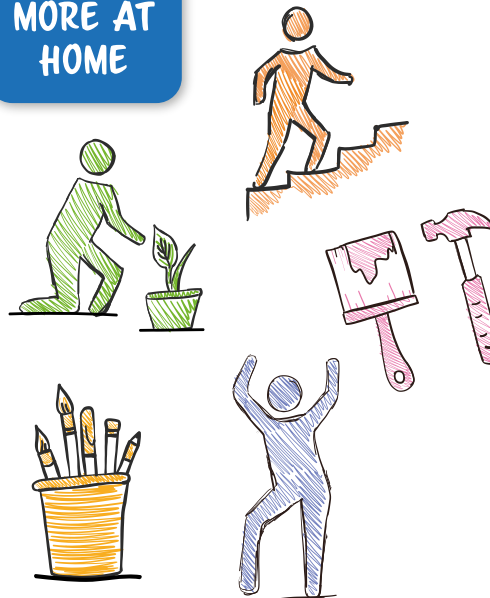
FLEXIBILITY



BALANCE



MOVING MORE AT HOME



MOVING MORE OUTSIDE



KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

PLANNING PHYSICAL ACTIVITY

The Physical Activity Tool for Huntington's Disease.



MY PHYSICAL ACTIVITY PLAN

Name:

Date:

WHAT'S IMPORTANT TO ME ...AND I LIKE DOING?

WHICH PHYSICAL ACTIVITY/ EXERCISE DO I DO NOW?

WHAT WOULD I LIKE TO BE ABLE TO DO?

WRITE YOUR THOUGHTS AND IDEAS HERE...

What will I do?

How often will I do it and where?

How will I track my progress?



Who can I ask for advice?

e.g. HD advisor, HD clinic, local leisure centre

What support do I need?

e.g. family, friends, carer

What is stopping me doing activity?

e.g. planning, movement problems

KEEPING ACTIVE WITH HUNTINGTON'S DISEASE

EXERCISES AND ACTIVITIES TO KEEP YOU MOVING

"BE FLEXIBLE WHEN THINGS CHANGE"

"DO THINGS TOGETHER OR WITH FRIENDS AND FAMILY"

PLANNING PHYSICAL ACTIVITY

When you have set some activity goals, this planner can be used to organise your physical activity within your week. You can print out the planner and have it as a reminder of what to do.

"USE MUSIC TO SUIT THE ACTIVITY"

"WE HAVE A DIARY SO THAT HE KNOWS WHAT IS COMING IN THE WEEK AHEAD"

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
Physical activity, exercise, rest							
Other activities e.g day out							
Did you enjoy the activity?							