



Supporting Engagement in Activities
in people with Huntington's Disease



ENGAGE-HD

PHYSICAL ACTIVITY WORKBOOK

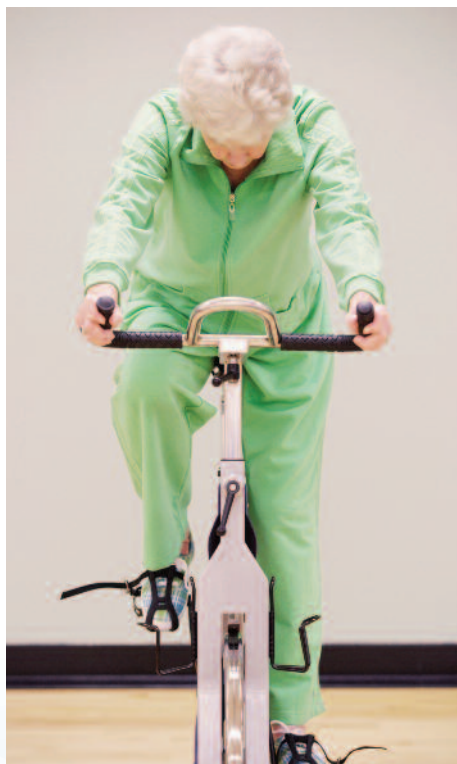
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EXERCISE – WHO ME?



PHYSICAL ACTIVITY AND EXERCISE - WHAT ARE THEY?

Physical activities are any activities that get your body moving – these can be things such as gardening, walking the dog, or taking the stairs.

Exercise is a form of physical activity that is specifically planned and structured, for example riding a stationary bike, doing an exercise DVD or a yoga class.

The aim of the Move to Exercise programme is to encourage people with HD, like you, to stay active – in whatever way that works for you.

There are many different ways that you can be “active”. For example, you can be active in short sessions at different times throughout the day. You could also set aside specific times of the day and week to do your “exercises”.

As part of the Move to Exercise programme, we will be asking you what is important to you to be able to be active. We want to work with you to find what works best for you to start and stay active.

BENEFITS OF REGULAR PHYSICAL ACTIVITY

It is well known that regular exercise is good for everyone. Regular physical activity is important for both physical and mental health of all adults, not just people with neurological conditions. By working to stay as active as possible, you can continue to do the things you enjoy for longer.

EXERCISE – WHO ME?

WHAT DO YOU THINK ARE THE BENEFITS OF STAYING ACTIVE?

What other people with HD and their carers say:

"...The more I could do, the more I felt like everyone else..."

"...What I was just saying to myself – this is an important kind of thing and I have to do it. I have to do it because it can be beneficial for my balance and my walking..."

"...I enjoyed the balance exercises... I've seen a difference...they were fun...I think it has helped with my balance...Going up and down stairs is easier... before it was one step and then the next and now it is better..."

OVERCOMING CHALLENGES TO GETTING STARTED

I AM NOT MOTIVATED TO EXERCISE

Starting and keeping going with a new exercise or physical activity programme is not easy for most people, and even more so for people with HD. Here are some of the things that other people with HD have told us they find difficult and some of our suggestions of things that may help.

It is natural for everyone to occasionally feel unmotivated to do exercise or other things they know they really should do. With HD, this can be a part of the disease and can be even more difficult to overcome.

Possible strategies:

- Try to set small achievable targets to be active every day
- Consider making your exercise programme part of a set routine
- Keeping a diary/record of your daily activity may help you to see your progress
- Ask your friends and family to encourage you or even exercise with you

What other people with HD and carers say:

"...When you mention 'exercise' people will start coming up with excuses.... You just think that'll be hard work.... but the balance needs to be right as in keeping it simple, and part of the routine..."

"...We've got a book now that we've put down everything she achieves... we set her goals together and we set a day we're going to try and achieve something new..."

Monday ✓ _____
Tuesday ✓ _____
Wednesday ✓ _____
Thursday ✓ _____

OVERCOMING CHALLENGES TO GETTING STARTED

I AM TOO TIRED TO EXERCISE

Sometimes people with HD feel very tired or fatigued, even if they haven't done very much. It can seem like it takes a long time to get anything done, and you can tire from doing even simple tasks. Researchers don't fully understand why this happens, but it may be partly due to excess energy demands from the disease.

Possible strategies:

- Work out when you have the most energy – morning? afternoon? and build your exercise and physical activity programme around that
- Prioritize what really needs to be done, and do that when you have the most energy
- Try to adopt a set routine for going to bed and waking up, and aim for at least 6-8 hrs of sleep each night

What other people with HD and their carers say:

"...feeling tired is a bit of a problem but it is about managing it and having some flexibility around our routine when that happens..."

"...Obviously people with HD do have difficulties to start new activity. However, making physical activity part of the routine would make it easier to maintain..."

OVERCOMING CHALLENGES TO GETTING STARTED

THE EXERCISES MY COACH/THERAPIST HAS GIVEN ME ARE CONFUSING

Many people with HD can have subtle problems with memory, thinking and planning activities. This can make following an exercise routine a struggle.

Possible strategies:

- Ask your coach to help you find exercises that you like to do, get them to practise more difficult ones with you and find out what works for you

- It is helpful to start off with just a few exercises and as you get more confident you can add in more or do different ones
- Ask another person – such as a friend, spouse, or carer - to watch you as you do the exercises and to help you if you have problems remembering



What other people with HD and carers have said:

"...I wanted balance exercises and so we worked it out together. If there was something I did not like we did not do it. Sometimes we went for a walk outside and sometimes I said I did not want to do it that day and we did something else..."

OVERCOMING CHALLENGES TO GETTING STARTED

MY BALANCE IS TOO BAD TO EXERCISE

Balance, coordination and strength can all be affected in people with HD. While some of these are directly as a result of the disease, the problems can be made worse by lack of activity. Practising activities that challenge your balance and require strength and coordination can help you to improve what you are able to do.

Possible strategies:

- Exercise in a safe place – make sure the room is free of clutter; keep a chair behind you or next to you, in case you lose your balance
- Start off by doing exercises or activities that you feel confident in doing
- Gradually take on more challenging tasks or activities as you start to find things easier

What other people with HD and carers have said:

*"...Start off small and slowly. That's what it was it was the slightest little thing like getting up out of the chair... that's how it started!
Small steps to larger steps..."*

"...At the beginning she was worried about falling over ...now the support it is mainly a sort of encouragement, the structure..."

OVERCOMING CHALLENGES TO GETTING STARTED



I NEED HELP TO DO THE EXERCISES

Difficulty with balance and lack of strength, or just unfamiliarity with a task can affect your confidence in performing a new task or activity. At first, you may not have the ability to perform a new or challenging task without help or supervision – this is ok. Carers, friends and family can be a really important part of a successful exercise programme for people with HD. If you have someone who is able to be with you when you exercise, this can be very beneficial.

Possible strategies:

- Ask another person – such as a friend, spouse, or carer – to help you do the exercises, or to watch you while you do them
- It is important that the person you choose to ask for help will take the time to listen to you
- Join a club or group where there is help nearby – some local gyms offer this support

A carer's view on supporting exercise:

"...An important thing for me was getting to know

her... and understanding what works for her...and what she liked, that was sort of critical. Now, we enjoy the exercise and activities together..."

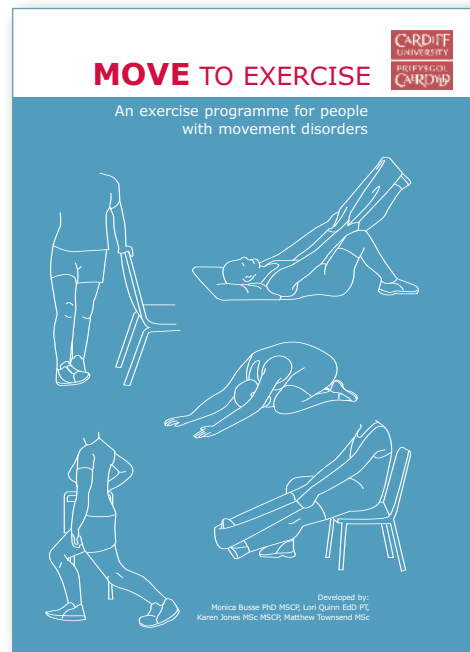
"...I see my role as... enabling her to stay independent. Not doing it for her. It's having the time, the patience and the understanding..."

HOW TO BE MORE ACTIVE?

- Try to move more and sit less
- Make being active a part of your routine by finding activities that you can easily fit into your daily life
- Think of your time to be active as a scheduled appointment, and mark it on your calendar.
- Use the activity pyramid to help you plan your week



HOW TO BE MORE ACTIVE?



MOVE TO EXERCISE DVD

The Move to Exercise DVD is designed specifically for people with Huntington's disease. The DVD has 5 sections: a) Flexibility and Warm up; b) Balance and coordination; c) Circuit Resistance Training; d) Strengthening; e) Cool down and relaxation.

There are a range of ways in which you could use an exercise DVD. You and your coach can work together to decide which sections are most appropriate for you and what will work for you.

What other people say about using the Move to Exercise DVD

"...the visual cues of the DVD make it easy to do..."

"...the DVD particularly helped me to understand what I was supposed to be doing. I enjoyed it and feel that it improved my balance and speed of walking..."

HOW TO BE MORE ACTIVE?

HOME WALKING PROGRAMMES

Going for regular walks is one very easy way to be active that you can fit into a regular routine. You can walk on your own, with a partner or with a group.

We know of one such group that was developed specifically for people with HD, and incorporated a weekly outdoor walk with the support of physiotherapists. Up to 15 people walk together, and the

groups are varied in terms of walking speed and duration. Regular walking groups may be available in your area.

If you already walk regularly, your coach will work with you to make sure you are doing the most appropriate programme for achieving health benefits. If you do not do any regular walking, your coach can help you to develop your own targeted walking programme.



DEVELOPING A PHYSICAL ACTIVITY PLAN

WHAT PHYSICAL ACTIVITY DO YOU DO NOW?

We would like you to think about how active you are in and outside your home. If you look at the diagram opposite, we want to know where you spend most of your time and how you can be more active.



DEVELOPING A PHYSICAL ACTIVITY PLAN

WHAT REGULAR PHYSICAL ACTIVITY OR EXERCISE DO YOU DO AT THE MOMENT?

WHAT STOPS YOU FROM DOING REGULAR EXERCISE OR PHYSICAL ACTIVITY?
WHAT COULD YOU DO ABOUT THIS?



DEVELOPING A PHYSICAL ACTIVITY PLAN

WHAT MIGHT YOU WANT TO TRY? WOULD YOU CONSIDER BRISK WALKING, GARDENING, DANCING, SWIMMING, CLIMBING STAIRS OR HILLS, OR A SPECIFIC EXERCISE PROGRAMME SUCH AS THE MOVE TO EXERCISE DVD?



GOALS AND TARGETS

Many people find that having goals to work towards helps to motivate them. This can give you a sense of hope about the future especially about those things that are most important to you. Thinking about the future may not be easy for people with HD but goals can be short term, and can be as simple as focussing on learning a new activity or task, or one that you previously did that you are struggling to do now. Your coach can help you work through some possible goals and make suggestions. However, it is important that these are goals that are specific, realistic and most importantly, meaningful to you.

You can use this section to record your goals related to physical activity and what you think you can do.

MY GOALS

TARGET DATE

SAFETY AND MONITORING - SOME IMPORTANT INFORMATION

You should always aim to exercise within your own personal ability.

When exercising you may

- Feel warm
- Possibly have an awareness of your heart beating faster

You should still

- be able to hold a conversation
- not feel dizzy or exhausted.

Starting a new physical activity or exercise programme can mean that you may initially feel some muscle aching or tiredness after exercise but this should resolve on its own.

If you are concerned please discuss this with your coach. Some days you will be able to do more and some days you won't be able to do so much, this is normal. If you are not used to exercising it is best to build up gradually. It is possible that at the start, you may do more than you should. If this happens, take a few days of rest and work with your coach to modify your daily activity plan.

If at any time when you are exercising, you feel severely short of breath or cannot breathe, stop immediately, rest. Contact your coach to discuss this and what you should do about your exercise programme. We may ask you to see your GP for advice.

We recommend that you use Borg's Scale of Perceived Exertion, which is shown here, to monitor your activity levels.

- During your activities, you should aim to achieve moderate to somewhat hard levels (3-4 on the BORG scale).
- Monitoring how hard your body is working can help you adjust the intensity of your activity level.
- You should record your ratings in the weekly activity diary that accompanies this book.

BORG RATING SCALE

0 - Nothing at all
1 - Very light
2 - Fairly light
3 - Moderate
4 - Some what hard
5 - Hard
6
7 - Very hard
8
9
10 - Very, very hard

RECORDING YOUR ACTIVITIES AND PROGRESS

An important part of any physical activity programme is monitoring what you have done. This can serve a few purposes:

- To be sure you are working to your plan and goals
- To determine if anything is too easy or too hard
- To document progress on different exercises or activities

MONITORING YOUR ACTIVITY USING A Pedometer

We will give you a pedometer that can help you to count and keep a record of how much you do each day.

Most inactive people walk less than 5,000 steps a day, and some may only walk 2,000 steps a day.

You should be aiming to gradually increase your daily steps. Your coach can help you to decide on a daily step count that is realistic and achievable and you can use a diary to record walking activity and any other exercise or physical activity. Diaries are useful as they allow you to see where you have started and what you have achieved over time.

On the following page, we provide an example of how you can use this diary to record your activities and daily steps.



http://yamaxx.com/digi/cw_300_e.html

RECORDING YOUR ACTIVITIES AND PROGRESS

EXERCISE DIARIES – EXAMPLE OF HOW TO COMPLETE

Date	DVD						WALKING		Pedometer reading (steps) Other activities		COMMENTS (Borg level, how did you feel?) Other activities
	Section					Total Time (min)	Distance	Time	Activity	Time / reps	
	1	2	3	4	5						
5/10/14	✓	✓		✓	✓	30			5690 steps		4
7/10/14							1 mile	25 min			4; able to walk a bit quicker
8/10/14	✓	✓			✓	20			Dance class	45 min	Felt a bit tired after dance class...maybe a bit too much
10/10/14							1 mile	30 min	Raking leaves	30 min	3 (walking); felt less tired today

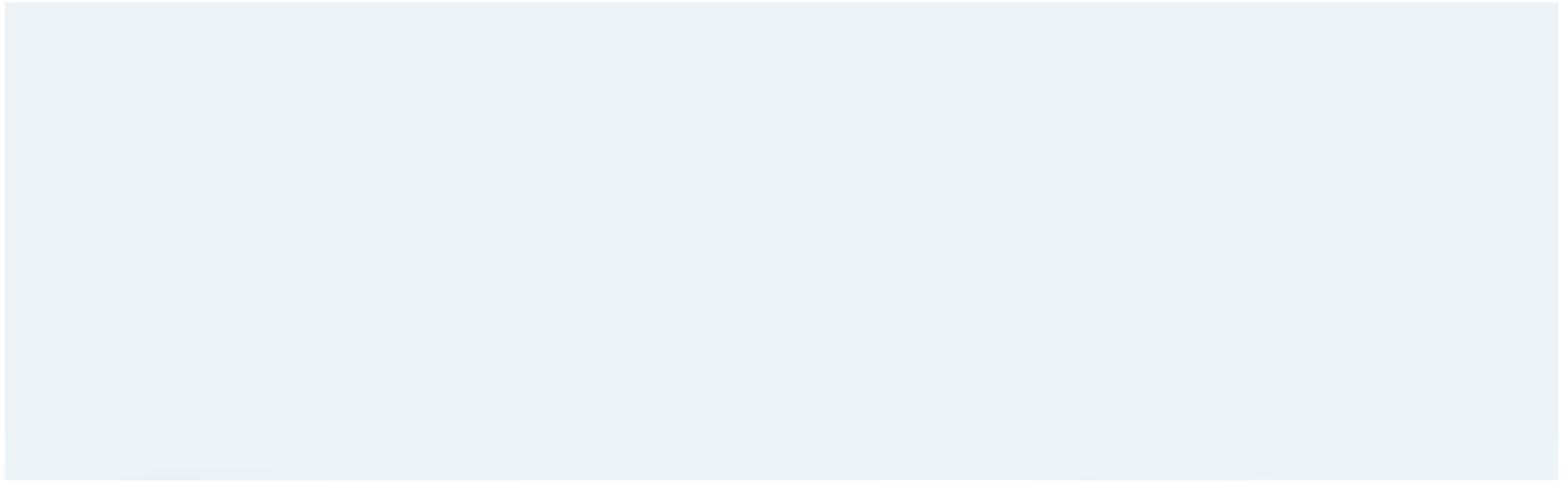
MY PHYSICAL ACTIVITY PLAN

HERE IS A PLACE TO RECORD THE DETAILS OF THE PLAN YOU AND YOUR COACH HAVE AGREED ON. YOU SHOULD RECORD THE ACTIVITIES, NUMBER OF TIMES PER WEEK, AND ANY OTHER INFORMATION.

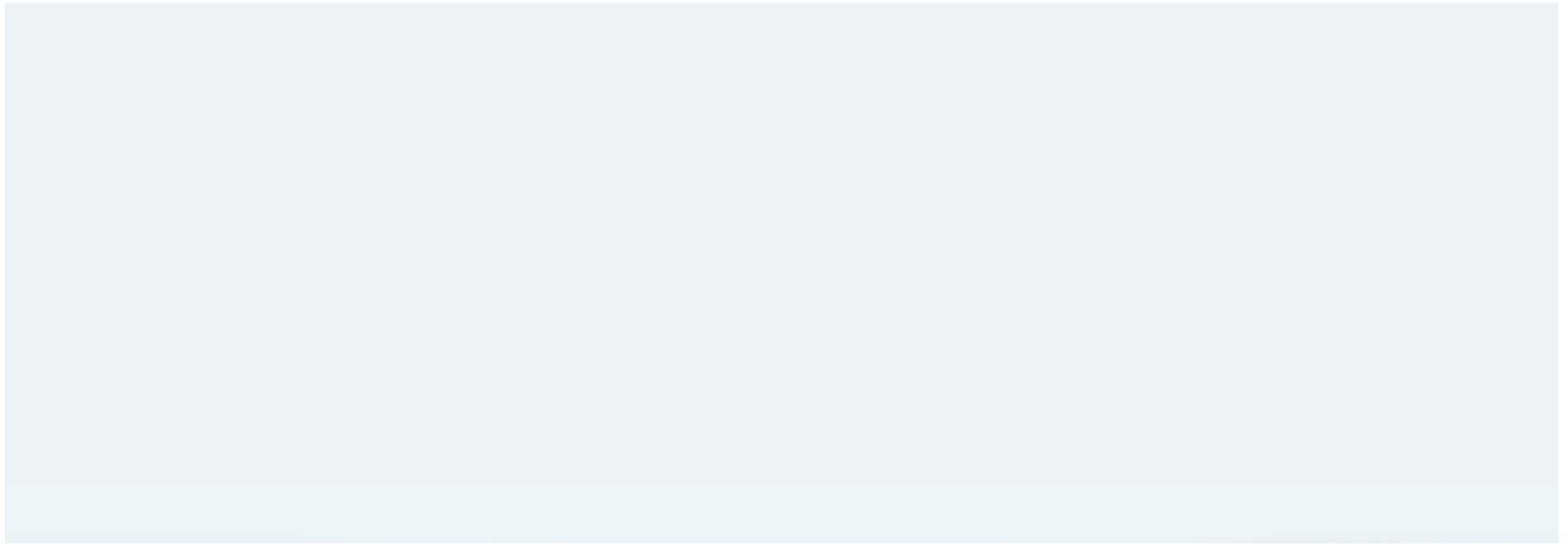


PLANNING FOR FUTURE ACTIVITIES

NOW LET US THINK ABOUT OTHER WAYS YOU CAN BUILD REGULAR PHYSICAL ACTIVITY INTO YOUR LIFE.



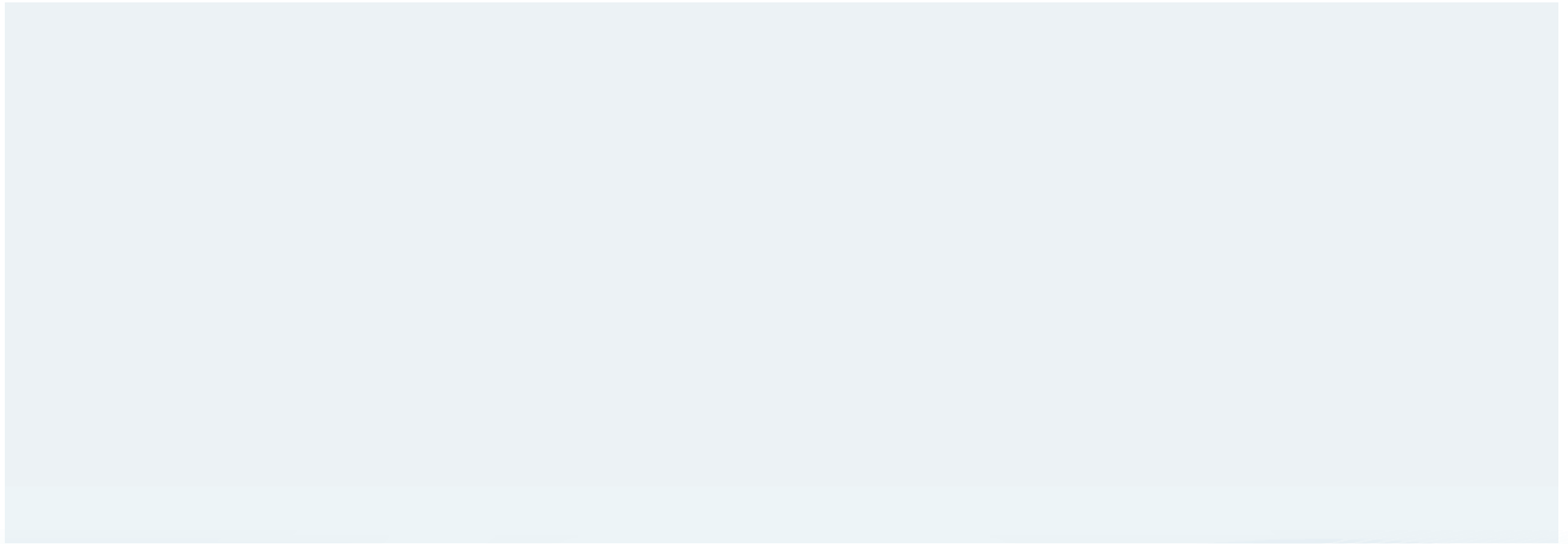
NOTES



NOTES



NOTES



USEFUL CONTACTS

Change4Life is a website that shares ideas for being active for people with a physical or other disability.

<http://www.nhs.uk/change4life/Pages/disability-activities.aspx>

The Ramblers supports a range of schemes across Britain that provide regular short and easy walks with trained leaders that are aimed at people who don't take much exercise or who need support to stay active.

<http://www.ramblers.org.uk/what-we-do/promoting-walking/led-walks/health-walks.aspx>

NHS Choices Get Fit for Free is a website that can help you find out about new ways and places to exercise for free.

<http://www.nhs.uk/Livewell/fitness/Pages/free-fitness.aspx>

The Conservation Volunteers Green Gym® is a scheme which inspires you to improve both your health and the environment at the same time. Experienced leaders guide you through a range of practical projects, giving you the opportunity to tackle physical jobs in the outdoors - improving your strength and stamina, boosting your practical skills and confidence and benefitting your local green spaces.

<http://www.tcv.org.uk/greengym>

The Huntington's Disease Association exists to support people affected by the disease and to provide information and advice to professionals whose task it is to support Huntington's disease families. <http://hda.org.uk/>

Inclusive Fitness provides accessible physical activity. There are now over 400 IFI Mark facilities nationally spread throughout the country, equipped with a range of IFI accredited fitness equipment with highly trained gym staff who are experts in providing advice on adapted physical activity.

http://www.efds.co.uk/inclusive_fitness/ifi_gyms

HDBuzz is an internet portal for the rapid dissemination of high-quality Huntington's disease (HD) research news to the global community, written in plain language, by HD clinicians and scientists. It covers laboratory and clinical research, with the aim of helping HD people to understand the latest HD science, on their own terms.

<http://en.hdbuzz.net/>

Active-HD is the website of the Cardiff Physiotherapy group who conduct research on physical activity in HD.

www.activehd.co.uk

The European HD Network is a platform for professionals and people affected by HD and their relatives to facilitate working together throughout Europe. It facilitates natural history studies and interventional trials meeting high standards and all participants involved can take a lead and propose, conduct and publish studies.

<http://www.euro-hd.net/html/network>

ACKNOWLEDGEMENTS

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Uned Ymchwil
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