

TEACHERS COLLEGE COLUMBIA UNIVERSITY





ENGAGE-HD Physical Activity Workbook

Version 2 (UK Version)



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Introduction and Background

Over the last 10 years, our group (Busse and Quinn) have been conducting research on the benefits of exercise and physical activity for people with Huntington's disease (HD). One of our earliest intervention trials was focussed on the evaluation of Move to Exercise (Khalil et al. 2012), an exercise DVD that we developed for people with HD. This was followed by a trial that established the safety and feasibility of a community based exercise intervention and a further trial that focussed on home based training and walking (COMMET-HD, Busse et al. 2013; TRAIN-HD, Quinn et al 2014).

More recently, the ExeRT-HD trial helped us to demonstrate that a short-term exercise intervention is safe, feasible, and importantly led to improvements in fitness and motor function in people with HD (Quinn et al., 2016). The results from these and other studies were also used to develop a walking project for people with HD as a way to increase physical activity. People who took part in the walks felt that they had more confidence and could do more in their day to day activities because of this confidence.

Given that people with HD may have difficulty in sustaining physical activity, we also developed the ENGAGE-HD Physical Activity Programme. This study programme (Busse 2014; Quinn 2016; Busse 2017) combined the Move to Exercise DVD, the ENGAGE-HD Physical Activity Workbook and physical activity coaching to help people with HD increase their physical activity in a way that fitted in with their own lifestyle. People with HD tell us that important aspects that help them stay active are that they:

- 1. Feel supported to engage in activities of their own choosing and based on their own initiative.
- 2. Feel that problems in relation to them being able staying active are understood and accommodated.
- 3. Are supported to safely achieve their personal activity goals within the limits of their individual environments.

We have now revised the original ENGAGE-HD Physical Activity Workbook and you are now looking at ENGAGE-HD Physical Activity Workbook Version 2.

Our research suggests that people with HD (and people at risk) will benefit from this individualized approach to planning for regular physical activity with help from a knowledgeable healthcare professional. This planning can begin at an early stage-before symptoms are evident and throughout progression of the disease.

We hope that you find this workbook helpful and can start to see the benefits of being physically active.

How to use this workbook

This book has been developed with the support and advisement of people with Huntington's disease (HD), carers, healthcare professionals and care advisors. People with HD and their carers can use this book by working with their healthcare professionals (who, in this workbook, we call your *physical activity coach*). Your coach will explain the importance of exercise and physical activity and will help you to identify any barriers there may be to exercise and develop ways to overcome these barriers. Ideally, you and your coach will develop a **partnership** – you will work together to develop a programme that best meets your needs and fits with your lifestyle.

The World Health Organization (WHO) recommends that everyone should be physically active as regular activity improves fitness and reduces the risk of heart problems, stroke and depression. It is recommended that adults do at least 150 minutes of moderate intensity exercise throughout the week and that people with poor mobility should do physical activity to improve balance and prevent falls 3-4 days per week. The American College of Sports Medicine (ACSM) also recommend that alongside the moderate intensity exercise, people should also carry out muscle strengthening exercises, flexibility exercises and exercises that improve balance and coordination.

This amount of exercise might seem overwhelming and you might also think – *does this apply to me as I have HD?*

Increasing physical activity is important

for everyone whether they have a health condition or not. You can use this workbook to help you to develop your personal goals, and how to achieve them taking into consideration the impact HD has on your life. You will also be able to track your goals.

For example, you may want to be able to walk 5 blocks so that you can go to the local shops or visit a neighbor. To be able to do this you may need to improve your balance and have confidence in walking on the street. You will need to work with your physical activity coach to decide what exercises suit you for improving balance and how you can gradually increase the distance that you can walk.

You may also want to add in strengthening and flexibility exercises. The exercises could be performed with the aid of a DVD or on an app that you could download onto your phone or tablet. You could also use an app on your phone or a walking monitor to measure whether you are increasing how much you are walking.

The workbook provides examples of how to overcome any challenges to being active, e.g. lack of motivation, tiredness and needing help to do exercise. There are also quotes from people with HD who have taken part in exercise and walking programmes that may help you to get started and keep being physically active.

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 Engage-HD programme is to encourage people who have symptoms of HD or who have the gene for HD – like you – to be active in whatever way that works for you.

Recent research has shown that exercise and physical activity are particularly important for people with neurodegenerative diseases such as HD. Exercise has been shown to improve fitness, motor symptoms, walking ability and balance in people with HD. It may be particularly important to develop a routine early in the HD lifecycle. Studies in Parkinson's disease, another neurodegenerative disease, have shown that exercise in the earliest stages can potentially alter the progression of the disease. Research is underway to see if this can also be shown in people with HD.



Your Physical Activity Coach

Your physical activity coach will work with you to find what works best for you to start and stay active. 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". In using the Engage-HD workbook with your coach, you will be establishing what is important to you to be able to be 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.

What other people with HD say:

"...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..."

"....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..."

What spouses and spousal caregivers of people with HD say:

"The physical activity regime is helping her to cope with the disability and to feel confident about movement and exercise within the environment, so that there's a confidence that she could have to remain independent."

What Do You Think Are The Benefits Of Staying Active?





What spouses and spousal caregivers of people with HD say:

"It seems to keep her a lot less wobbly whereas before when she wasn't doing as much exercise her movements were greater."

"I suppose in terms of trying to maintain some sense of normality from doing those things is a big feature for her to go for that walk it's involving some level of physical activity which can constitute as exercise...the longer we can kind of keep it in place, the better off we're going to be."

What formal carers of people with HD say:

"Her motivation is for her mobility to be increased, which it has through the exercises she's been doing, she's achieved that, and now she can join in with the family on holiday"

Overcoming Challenges

2

We have found that many people with HD or at risk for HD have similar challenges when faced with starting any new programme, particularly a new exercise routine. We understand that there are many factors to consider, such as:

- **Social** Is this something my friends and family are doing? Will they exercise with me?
- Environmental Where can I exercise? I don't have space to exercise at home.
- **Prior beliefs** I have never been much into sport or exercise. Exercise is too difficult.
- **Past experience** I tried a yoga class once and it was terrible.

Starting up an exercise programme can be complex, and so we have gathered information from other people with HD to share a few of the challenges that other people have faced and some strategies to overcome them.

I don't have enough time

Not having enough time to exercise is the most common reason that people tell us that they do not exercise. We understand that living with, or being a risk for, a chronic disease such as HD can be difficult, and can make scheduling any activities hard to prioritise. But it is important to think about exercise like you would any other prescription that a doctor would give you. "If exercise could be packaged into a pill, it would be the single most widely prescribed and beneficial medicine in the nation."

Dr. Robert Butler, founding director of the National Institutes on Aging, NIH



Possible strategies:

- Try setting aside a bit of time, even 10 minutes, every day to do some exercise
- Use your clock/watch/phone to set an alarm to remind you to exercise
- Consider doing flexibility exercises while listening to the radio or watching television
- One of the best strategies for managing time is to schedule exercise into your daily routine

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. 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.

Here are some suggestions to help keep motivated:

• There are many ways of being active - it doesn't have to be one specific thing that you do, consider different activities to keep your physical activity interesting

- Pick something you think you will enjoy and doesn't seem a chore
- 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
- Focus on the positive benefits you can achieve from being more active

What other people with HD 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 their routine..."

What other people with HD say:

"...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..."

I am too tired to exercise

Sometimes people with HD feel very tired, 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.

- Work out when you have the most energy – morning? afternoon? – and build your exercise and physical activity programme around that
- Prioritise 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
- Remember to eat well and drink water before and after exercise
- Try varying the amount of exercise that you do when you are tired and when you have more energy.

2

Possible strategies: What other people with HD 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..."

I am not sure I can do the exercises correctly

Many people with HD, even in the very earliest stages, can have subtle problems with memory, thinking and planning activities. This can make following an exercise routine a struggle. 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 helpful.

Difficulty with balance and lack of strength, or just unfamiliarity with a task can affect your confidence in performing a new task or activity. While some of these problems are directly as a result of the disease, the problems can be made worse by lack of activity. Practicing activities that challenge your balance and require strength and coordination can help you to improve what you are able to do.





Possible strategies:

- Ask your coach to help you find exercises that you like to do, get them to practice 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. Or even better – ask them to exercise with you!
- 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
- Join a club or group where there is help nearby – some local gyms offer this support



What people with HD 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."

A formal carer's views 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."

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

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

Let's Get Moving!!

3

What's the best activity for me?

There are a range of different activities and exercise programmes that can help you achieve your goal to be more active. There is no one correct exercise programme – but there are some key elements that you should try to address when developing a programme to optimise your health and well-being.

The World Health Organization recommends that individuals should **perform at least 150 minutes per week of moderate exercise or 75 minutes per week of vigorous exercise (or a combination of moderate and vigorous activity).**

Key Points

- 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



Start your weekly activity plan with the daily activities at the base of the pyramid, Enhance your fitness by choosing other activities on the pyramid. Move more sit less. More specifically, the American College of Sports Medicine recommends that an exercise programme includes the following four components:

Guidelines for Exercise:

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Aerobic (Cardio)	Resistance (Weights)	Flexibility (Stretching)	Neuromotor (Balance)	
Cycling treadmill or ellipticalAerobics or Dance class	 Weight-lifting Exercises such as push ups & sit ups 	YogaPilates	Balance exercisesTai Chi	

Suggestions for Activities

Here are some suggestions for different activities that you could consider to help you increase your physical activity levels:

Walking

Walking is an easy way to get physically active as it does not need any special equipment or clothing. You may want to increase the distance you walk within your own house, around the house, around the neighbourhood or in an area away from your home. Often it is easier to be motivated to walk if you are part of a group as you get to meet other people and visit different places. People with HD have enjoyed the social aspect of walking in a group and going to places where they may not have been before – even within their own town. You may prefer to walk with people who do not have HD and there are many walking groups across the country that you could join.

Your coach can help you work out the most appropriate walking plan for you. This could be a combination of walking on your own or with family and friends as well as going on organized walks.



3

People who have joined an organized HD walking programme have said:

"I feel the walking group has motivated me to get out and meet other people"

"My confidence, strength, my ability to walk properly again is coming back"

"I am normally in a better frame of mind when I finish the walks"

Aerobic exercise using an exercise bike or treadmill

A recent study in people with HD (Exert-HD) found that exercising on a bike three times per week for 12 weeks improved their fitness and motor function.

When asked how they felt after the sessions and what their thoughts on exercising were following completion of the programme participants responded with:

"I felt better every time"

"I was tired after the sessions, after a few weeks, I was less tired"

"I felt great, more energy!"

"I am going to join the gym, I want to keep going."

"I feel motivated to continue with exercise and will take out a gym membership."



Exercise DVDs or Computer and Smart phone Apps.

There are many phone apps, websites, and TV programmes that offer guided exercise programmes. It is worth exploring to see if these may be of interest to you and will keep you motivated to maintain a routine. You can work with your coach to see if any of these programmes are right for you.

Some exercise programmes can address multiple components at once. For example, group exercise programmes or Exercise DVDs often incorporate both balance and strengthening exercises together.



Move To Exercise DVD

The Move to Exercise DVD was 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 should work together to decide what exercises are most appropriate for you.

What other people with HD say about using the Move to Exercise DVD

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

"The visual thing of using the DVD makes is much easier to do it, because to do things that have to be committed to memory, particularly in my case [where] memory is a problem, is impossible"

"...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..."

Developing a Physical Activity Plan

To help you to develop a physical activity plan, we would like you to think about how active you are in and outside your home.

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?

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

5

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 focusing 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.



Goals And Targets



Safety and Monitoring

6

Be sure to check with your doctor first if you are beginning any new exercise routine. 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. You should 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 by itself. If you are not used to exercising it is best to build up gradually. 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 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. They may ask you to see your doctor for advice.

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

1-10 Borg Rating of Perceived Exertion Scale

0	Rest
1	Really Easy
2	Easy
3	Moderate
4	Sort of Hard
5	Hard
6	
7	Really Hard
8	
9	Really, Really, Hard
10	Maximal exertion

• 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 keep a record of your ratings.

Recording your 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

It is recommended that for general health benefits, people should walk about 10,000 steps per 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. Activity monitors, such as those worn on your wrist like a watch, may also be helpful in helping you stay motivated to exercise. They can count the number of steps you take each day, and can also track your exercise routines, and send you reminders to exercise or to get up and move if you are sitting too long.

Some people prefer low-tech options, such as keeping an exercise diary in a notebook. This can be useful as they allow you to see where you have started and what you have achieved over time.

To help you decide what approach addresses your needs best, we have listed some of the most common methods on the next page and some of the advantages (pros) and disadvantages (cons). When considering how you want to keep track of your physical activity and exercise think about your own situation, and how each method would fit into your usual routine.



Different methods of monitoring activity and exercise.

Pros

Calendar	Diary	Smart phone	Activity monitor
 Simple Low cost Quickly review and set exercise goals Low maintenance – quick to complete 	 You choose what you want to record You choose how much detail to use Low cost 	 Wide range of software/apps to choose from Always with you Allows quick review of days' activity and previous days Allows interactive goal setting Can include GPS options to trace your actual walking route. 	 Low effort Range of styles and types to suit your taste and needs Can provide instant feedback on your activity levels Range of additional features such as heart rate monitoring, sleep tracking

Cons

Calendar	Diary	Smart phone	Activity monitor
 Not much room for detail Easy to forget Difficult to complete accurately relies on your own estimation of physical activity 	 High maintenance - Difficult to keep a detailed diary Easy to forget Can be difficult to complete accurately – relies on your estimation of physical activity 	 Can significantly shorten battery life Can be distracting If you forget to take it with you, you don't get a record of your activity Expensive if you don't already own a smart phone Often needs internet access to process your data 	 Expensive Can be distracting Need to be charged and synced to a phone or computer regularly (>weekly) If you forget to wear it, you don't get a record of your activity Often needs internet access to process your data

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 a plan for when and where you will carry out the activities.

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Useful Contacts

About Huntington's Disease

There are many national organisations that support people affected by the disease and provide information and advice to professionals whose task it is to support Huntington's disease families. You should look for details of what is available in your area. Here are some that we know about:

Huntington Disease Association (HDA): www.hda.org.uk/

European Huntington's Association (EHA): http://eurohuntington.org/

Huntington Disease Society of America (HDSA): www.hdsa.org

Huntington's Disease Youth Organisation (HDYO): http://en.hdyo.org/

Huntington's Disease Research

Huntington's disease research is highly global and collaborative. HD Buzz 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/

Research organisations

European Huntington Disease Network

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.ehdn.org/

Huntington Study Group (HSG)

The Huntington Study Group facilitates highquality clinical research trials and studies in Huntington disease (HD). HSG has an HD clinical research network of over 400 active and compassionate investigators, coordinators, scientists and HD experts at over 100 credentialed research sites across the globe dedicated to seeking treatments that make a difference and improving the quality of life and outcomes for families affected by HD. http://huntingtonstudygroup.org/

CHDI

CHDI Foundation is a privately-funded, not-forprofit biomedical research organization devoted to Huntington's disease. CHDI is the sponsor of three worldwide Huntington's disease observational study and registry called Enroll-HD that has participants in the US, Canada, Latin America, Europe, Australia/New Zealand; the aim is to recruit 20,000 HD family members around the world to build a research platform that will enable faster and smarter clinical trial recruitment. http://chdifoundation.org/

Physical activity and exercise resources

World Health Organization (WHO)

WHO developed the "Global Recommendations on Physical Activity for Health" with the overall aim of providing guidance on the frequency, duration, intensity, type and total amount of physical activity recommended for people of different ages. http://www.who.int/dietphysicalactivity/ factsheet_recommendations/en/

Huntington Disease Society of America

The HDSA has a webpage dedicated to workout tips for people with HD. http://hdsa.org/hd-workout-tips/

Active HD twitterfeed and YouTube channel



@Active HD

https://www.youtube.com/channel/UCH7_ed2__m kzXNWPZqVIosw

This twitterfeed and YouTube Channel is sponsored by the Cardiff University Huntington's Disease Center. This site provides updates Exercise and Physical Activity research in Huntington's Disease.

Change4Life

Change4Life is a website that shares ideas for being active for people with a physical or other disability. http://www.nhs.uk/change4life/Pages/disabilityactivities.aspx

Active Huntington's online resource

This is resource originally created by the Physiotherapy Working Group of the EHDN to support people with HD to be more active. It is now further developed in collaboration with and hosted by the EHA. http://eurohuntington.org/active-huntingtons/

The Ramblers

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/successful-shortwalks-and-health-walk-links

Walking for Health

Walking for Health offers free short walks every week. These walks have trained walk leaders and are for people with health conditions.

For walks in England https://www.walkingforhealth.org.uk/

For walks in Wales https://www.letswalkcymru.org.uk/

For walks in Scotland http://www.pathsforall.org.uk/pfa/healthwalks/find-a-health-walk.html

For Walks in Northern Ireland http://www.getalifegetactive.com/adults/walking

NHS Choices Get Fit for Free

This 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®

The Conservation 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

Inclusive Fitness

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

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workbook.



Neurorehabilitation Research Laboratory