

## More evidence points to Huntington's disease exercise benefit



Two studies show exercise benefits for some symptoms of Huntington's disease. Just don't believe everything you read.

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*A news article reports that a “breakthrough” program of physical, mental, and social stimulation could “halt Huntington’s progression”. Sounds pretty exciting — but does the science back up the hype?*

Most people can agree that exercise is good for the body and mind. Why wouldn't it be a good idea to keep Huntington's disease patients in shape? Most likely it would, but these 'obvious' ideas have to be formally tested before we can be sure. A number of health products proposed to be helpful to general health, such as specific vitamins, have later been found to be harmful.

An exciting article was recently published covering a study called the 'Huntington's enrichment research optimisation scheme (HEROS)'. The HEROS study looked at whether a program of physical, mental, and social stimulation could slow the progression of HD symptoms. A breathless article suggested remarkable results: that HEROS participants deteriorated at a 50% slower rate than patients who did not participate in the program. This sounds exciting, but let's take a closer look at the details.

### What, exactly, was found?

Reading scientific news reports often leaves one wondering, “how do researchers really know that?” No one can be blamed for not wanting to go through tedious research reports to find out. But that's what HDBuzz is here for. We can tell you this — the original study certainly does not claim that “participants deteriorated at a 50% slower rate than the control group”, as the headlines reported. So what does it show?

The researchers, led by Prof Mel Ziman at Edith Cowan University, asked HEROS study participants to carry out gym-based and home-based exercises as well as occupational therapy for 9-18 months. The researchers monitored aspects known to be affected in the early stages of HD, like weight loss, mental health, and cognitive function such as learning and memory.



The authors of several new studies have studied the effect of exercise, along with other rehabilitative approaches, in HD patients.

What they found was a general trend toward improvement in some of these symptoms, particularly problems with movement. Program participants didn't lose as much weight as the 'no exercise' group, and they scored just a bit better on some of the learning and memory tests. Researchers have already published an initial analysis of the early, or 'pilot', phase of the study, and are now working on publishing the longer term follow-up study.

These results do NOT mean that the exercise program "halted progression" as the title of the news article would have us believe. In order to do that, it would have had to completely stop every single symptom of HD. The authors of the HEROS study were careful to point out a number of areas that aren't improved by the program, including depression, which is an important source of problems for people with HD.

How does a study come to be misrepresented like this? Most likely, a combination of a press release lacking caution, and a reporter who didn't ask enough questions.

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## Size matters

An important factor with studies like these is how confident the researchers are of their results. For example, if the participants' responses to an exercise program differed wildly, with some responding very well and some not at all, then researchers would be less confident about the program's success than they would if all the participants responded equally well.

But every patient is different — you could never expect each person to respond the same way! Luckily, there's a way around this problem, which is to recruit more participants. The larger the group, the more confidence researchers have that the results they see are true and will translate to the real world.

The detailed report on the HEROS study is quick to point out that the results of the study must be interpreted cautiously, since it was made up of only 20 participants, hampering the confidence with which we can be sure this exercise program actually changes the symptoms of HD.

In addition, the full study has not yet been published, which means it has not stood up to the scrutiny of fellow scientists in the 'peer review' process. The key message here is that the results seem good, but we need more information to be definitive.

## Replication, replication, replication



Rehabilitation was useful for some signs of HD, such as balance and movement

Besides increasing the number of subjects, another way that scientists can improve the reliability of their findings is testing to see if they are ‘reproducible’. Experiments conducted in Europe should work the same way when they’re conducted in Australia, or Africa. This ongoing re-creation of one another’s results is an important way that science checks itself.

problems, but wasn’t as much help in other areas, including depression.

Luckily for those of us interested in HD treatments, another team of researchers lead by Jan Frich of the University of Oslo are also interested in improving the lives of HD patients with rehabilitation, including exercise.

These researchers recently described the results of a study conducted in Norway quite similar to the HEROS study run in Australia. In fact, the Norwegian scientists went a bit further, by actually admitting HD patients to 3 in-patient rehabilitation sessions, each lasting 3 weeks. So, over the course of a year, the patients involved received 9 weeks of intensive exercise and social activities.

Similar to the observations made in Australia at around the same time, the Norwegian scientists observe that rehabilitation and exercise lead to improvements in balance, walking ability and physical quality of life in HD patients. Interestingly, the Norwegian group did observe improvements in depressive and anxiety symptoms, which was not the case in the Australian study. What’s more, the Norwegian team’s results have been published in a peer-reviewed journal.

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## Mounting evidence in favor

The results of these studies support the idea that a sustained program of regular, exercise and rehabilitative therapy are of benefit to HD patients. It reminds us that, while we await therapies to prevent or delay the onset of HD, there are a number of beneficial things we can do to improve the quality of life of HD patients today. What we can’t conclude from these short studies is that the disease process in the brain is “halted” or reversed — but if people are walking, balancing and feeling better, that’s perhaps not the main issue when it comes to decisions around exercise.

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*The authors have no conflicts of interest to declare. For more information about our disclosure policy see our FAQ...*

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