



# How to realize integrated multidisciplinary care in HD? Organize it in a care chain

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## Aims

By organizing a managed care network with integrated specialized services that meet the needs of the patient and his informal caregivers in all stages of HD we aim to:

- increase quality of life
- increase efficiency of care
- reduce costs
- postpone admission to a nursing home

## Why integrated care?

Often there are gaps in the care for patients with HD. This causes harrowing situations, a lot of personal suffering, a loss of capacity in the patient's system and high care costs. Gaps are often caused by:

- A lack of knowledge about HD amongst health care professionals
- Patients not knowing where to go when they have questions about HD
- Patients not being well directed to the appropriate care and treatment

In many cases admission to a nursing home can be postponed if the proper support is given to both the patient and the patient's system.

## Methods

Three Expert Centres in the Netherlands started:

- A central desk for information about HD
- A tailor-made multidisciplinary treatment advice, based on the patient's needs
- Multidisciplinary organized treatment in the patient's own environment
- Structural evaluation and fine-tuning of care through consultation and communication
- Dissemination of knowledge to local health care professionals
- Coordination of care by a case manager who is a member of the multidisciplinary team

The Expert Centres are nursing homes that have formed a care chain with other specialist organizations for HD like hospitals and mental health care. In these care chains knowledge is being exchanged and generated in order to improve patient care. Additionally the Expert Centres receive regular feedback by the Dutch Huntington's Disease Association about patient needs.

## Results

- An easily accessible and high quality integrated care program
- Dissemination of knowledge to patients, informal caregivers and (local) professionals
- Throughout the country patients receive comparable care and treatment

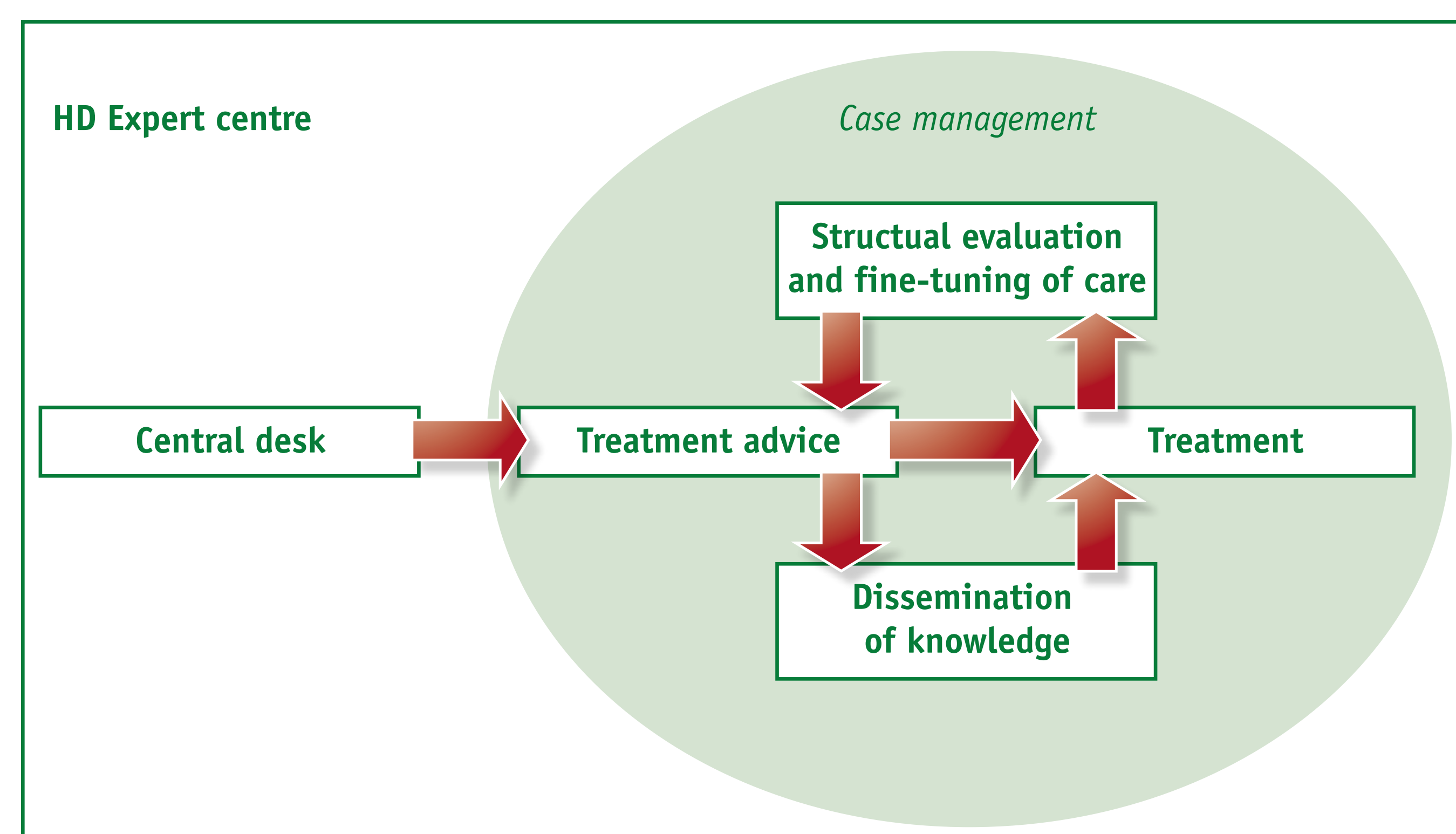
## Conclusion

Integrated multidisciplinary care increases the standards of care and the quality of life of HD patients and their informal caregivers. The burden of informal caregivers decreases, the patients functioning improves and gaps in health care will be closed. Nursing home admission can be postponed and costs are reduced.

## Future plans

- Developing a network with national coverage of professionals specialized in HD
- A joint education program is in development
- Every specialist organization for HD participates in a care chain

Patient X: "Now I know I have HD"  
 What is our answer to HD-patients demands?



Organize integrated care!

