Personal experience concerning improvements in long-term care of patients suffering from Huntington's disease in United Kingdom within last 35 years

Osobiste doświadczenia dotyczące poprawy w długoterminowej opiece nad pacjentami z chorobą Huntingtona w Wielkiej Brytanii na przestrzeni ostatnich 35 lat

MIKE WOOLDRIDGE [1], DANIEL ZIELONKA [2]

[1] Rapkyns Care Home, Sussex Health Care, United Kingdom
[2] Department of Social Medicine, Poznan University of Medical Sciences Poland

© **Probl Hig Epidemiol 2009, 90(4): 641-643**

www.phie.pl

Nadesłano: 14.12.2009
Zakwalifikowano do druku: 26.09.2009

Adres do korespondencji / Address for correspondence
Mike Wooldridge
Rapkyns Care Home (Sussex Health Care). Guildford Road Broadbridge
Heath Nr Horsham West Sussex RH12 3PQ,
e-mail: mdwooldridge@btinternet.com

Dr Daniel Zielonka
Poznan University of Medical Sciences Poland, Department of Social
Medicine, European Huntington's Disease Network (EHDN)
5C Rokietnicka Street, 60-806 Poznan, e-mail: daniel.zielonka@gmail.com

This article shows how far go the changes in long-term care over the Huntington's disease patients from early 70-ties until nowadays. It concerns my evolving personal impression based predominantly on everyday clinical reality of working for people affected with Huntington's disease in United Kingdom.

In 1970 I came into contact with the first person with Huntington's disease. This was in a large mental hospital, which was home to over 1000 patients. They lived in wards which had large dormitories and day rooms and some patients were looked after in side rooms, which had a bed and a locker. These rooms were used for either difficult patients or those who could not be nursed in the main dormitory [1].

I was being shown around one of these wards by the nurse in charge and I could hear shouting coming from one of the side rooms as we walked down the corridor, not knowing why or who was making this noise. When we reached the room the noise had been coming from, the door was opened and on the floor inside sat a person in an opened-back nightdress. I was then told that this person had Huntington's disease and stayed in the room and made this noise all day. I was told not to worry about her, as she did not understand anything and nothing could be done for her, as this disease had no cure.

For the next three months I got to look after her and started to find out more about her. I learnt that she had a family and that her father had died of this disease. She had been in the hospital for over five years and had spent most of the time in this room. She was allowed visitors on Wednesday and Sunday afternoons for two hours. Her visitors consisted of her sister, daughter and grandson. She also told me that the reason for the screaming was because she got very bad headaches [2].

After meeting this person I could not believe that nothing could be done to help the patients with this disease and decided that I would find out more about it. Since then I have looked after many sufferers with this disease and have aimed to improve their care and quality of life.

In the back of my mind and the sufferers' minds is how their loved ones were cared for in the past in large mental hospitals [3].

Today sufferers have control over how they are cared for and where they wish to be looked after. Also today the staff have a better understanding of this condition and how it affects not only the sufferer but the family as well. We also have aids that help in caring for these patients and now have a multidisciplinary team consisting of neurologists, psychiatrist, psychologist, physiotherapist, dieticians, activity staff, nurses and HD advisers, etc [4].

A good example of contemporary care can be Rapkyns Care Home where all patients have their own room with personal belongings and they have profile beds, special seating and any other aids which make it easier for them to continue with their daily lives. They each have their own personal centred care plans and have a key worker who looks after them. These care plans are reviewed on a regular basis with the patient so that any changes in the person's needs can be met in any area of need. With this condition there are many areas of change from speech, eating, mobility and behaviour and no two patients are the same, so each patient needs his or her individual needs met [5].

The patients at Rapkyns Care Home are involved in everything at the home and make choices in their personal care, unlike in the old days when they were locked away in mental hospitals and never went out once admitted to the hospital. All the wards were locked and the patients just looked out the window at the world outside.

At Rapkyns Care Home we get involved with the community by working with schools, colleges and this year worked with a group of actors who put a play on in London about how Huntington's affects families. We all went to London to see it and met with the actors afterwards and gave them feedback on what we all thought of the play.

With the schools and colleges, we have worked with them showing how important communication is and what can be done to keep this up even when verbal skills are lost. This was done by getting the students to find out from the sufferers what they would like them to do for them [6].

Both patients and students benefited from this. They learnt from each other; students learnt that even with a disability it does not mean you cannot teach an able person something, also with poor communication it is still possible to enable someone to do what they want. We have open discussions with the patients about their care. Nobody can lie about what is going to happen as most of the sufferers have seen a relative die from this terrible disease. However, we can make a difference by allowing the patients to make choices on how they wish to be cared for and this allows them the control they were denied for many years and only the doctors made these decisions and patients were not asked. Patients are able to say if they want medication to help with the movement problems or not, as many sufferers do not find this a problem.

It is important to allow the patients to stay mobile for as long as possible and support them to do this with regular physiotherapy and offer aids which might help. They choose what food they want on the menu and have regular meetings to make changes to the menu. Along with the Activity Coordinator they make choices on activities they wish to do, such as art, gardening, outings, such as restaurants for meals, places to visit [7].

We also do advanced care plans where the patients make choices about such things as whether they wish to be peg fed or not. Where they wish to be cared for in the future and what they wish to happen, such as to be kept comfortable and pain free and nothing done to shorten life or prolong the suffering. Along with this, the families are supported and have the opportunity to speak with everyone involved in their loved ones' care.

The staffs are given regular training updates and opportunities to go on additional courses on Huntington's disease. This shows that care homes have a lot to offer sufferers with this disease, and they can make a difference to improve the way we care for these patients and offer them a better quality of life [8].

We are now making many improvements to this condition and by having contact with different

Rapkyns Care Home

countries, we can bring together ideas from each other. It can only lead to greater and better understanding for all to improve care for sufferers everywhere.

This is not something to hide away but something that everyone can help with. To improve the lives of these sufferers it is up to all of us to help remove the shame these families feel and let them know that we do care. Together we can improve the way they are cared for. We need to give the community a better understanding of this disease and how they can help to improve the care of these sufferers. We the professionals must lead in this by improving how we care for them and by talking to each other and exchanging ideas, which will help us do this.

Piśmiennictwo / References

1. Peacock CE, Harris R. Huntington's chorea: who cares? Health Trends 1989 Feb, 21(1): 15-7.
2. Nance MA, Sanders G. Characteristics of individuals with Huntington disease in long-term care. Mov Disord 1996 Sep, 11(5): 542-8.
3. Moskowitz CB, Marder K. Palliative care for people with late-stage Huntington's disease. Neurol Clin 2001 Nov, 19(4): 849-65.
4. Soltysiak B, Gardiner P, Skirton H. Exploring supportive care for individuals affected by Huntington disease and their family caregivers in a community setting. J Clin Nurs 2008 Apr, 17(7B): 226-34.
5. Dawson S, Kristjanson LJ, Toye CM, Flett P. Living with Huntington's disease: need for supportive care. Nurs Health Sci 2004 Jun, 6(2): 123-30.
6. Travers E, Jones K, Nichol J. Palliative care provision in Huntington's disease. Int J Palliat Nurs 2007 Mar, 13(3): 125-30.
7. Klager J, Duckett A, Sandler S, Moskowitz C. Huntington's disease: a caring approach to the end of life. Care Manag J 2008, 9(2): 75-81.
8. Aubeeluck A. Caring for the carers: quality of life in Huntington's disease. Br J Nurs. 2005 Apr 28-May 11, 14(8): 452-4.