

## **Introduction**

Frank Gardham House is an 8 bedded in-patient unit for people suffering with Huntington's disease, located at Guild Park in Preston. This is an inherited progressive, irreversible, degenerative disease of the nervous system, caused by a faulty gene which leads to damaged nerve cells within the brain.

The Trust and its PCT partners have undertaken a review of this service to explore the most appropriate model of care for people with Huntington's Disease. The purpose of this paper is to present the case for change and to describe the alternative arrangements made to replace Frank Gardham House and re-provide the service.

## **Background**

Frank Gardham House opened approximately 14 years ago in 1997 and at that time had contracts with a number of PCTs across the North West Region. The service was commissioned to provide two main functions.

- 2 beds are used to assess people in the early stages of the disease. This assessment function lasts for up to 8 weeks and following this the patient is generally returned home or moves on to more supported living.
- The other 6 beds are for NHS continuing health care.

## **Commissioning Arrangements**

Of the three PCTs who remain part of the contract, two have not used an assessment bed within the last 2 years (East & Blackpool) and one PCT has not used an assessment bed or admitted a patient for continuing care in the same period (Blackpool). The other PCT has had only one admission (East). Of the two continuing care patients remaining on the unit one is from Central Lancashire and one is from East Lancashire.

The Trust and its PCT partners have been working together to review the current service arrangements and to identify the most appropriate way of delivering this service in the future. It is proposed that the most appropriate solution would be a community based model with the use of continuing care beds in nursing homes, for the small number of patients who require this service. A small community based team would be available to support this transition and ensure that patients and their families are supported.

## **The Case for Change**

Over a period of 4 – 5 years the number of PCTs commissioning services has reduced to the current 3 which are Central, East and Blackpool PCT's. There has been a reduction in the number of patients requiring an assessment and on average over the last 12 months only 50% of the assessment beds have been occupied. Admissions have reduced significantly over the last 2 years and at present only two continuing care beds are currently in use. Increasingly, more appropriate and cost effective private independent nursing beds are being used which are often nearer to the main carer.

The continuing health care patients do not require specialist mental health nursing they require full physical end of life care.

Assessments can be provided in the community rather than in an inpatient setting such as Frank Gardham House.

Frank Gardham House, although maintained to a high standard with single rooms, does require investment to bring it up to modern standards with en-suite facilities. The building is small and would require significant investment to make it fit for purpose. Whilst the location is therapeutic it is not particularly accessible being set at the rear of the old Whittingham Hospital site.

The unit also operates an out-patient facility every six weeks and this is led by a Consultant specialising in genetic disorders from Manchester. The facility could be re-provided from alternative LCFT premises such as Ribbleton Hospital.

The unit has strong links with the Huntington's Society based in Liverpool. They have attended the relative Carers Support Group which is run from the Frank Gardham House site although this has reduced in frequency and the attendees have dwindled over recent years. Again this could continue with provision from Ribbleton or other venues.

### **Staffing Implications**

Frank Gardham House has a total staffing establishment of 15 whole time equivalents. As a result of retirements and vacancies within the Trust it is anticipated that there are sufficient posts for staff to be re-deployed to other areas. Therefore no compulsory redundancies are anticipated and a formal process will be undertaken in line with the Trust's organisational change policy.

### **Proposal**

It is proposed that the service provided from Frank Gardham House should be re-provided in the community and specialist care homes as described in the case for change. There are several reasons why this is being proposed:

- It does not represent the best use of resources to run a unit at such a low level of occupancy.
- There are more appropriate facilities that are able to provide the continuing healthcare facilities required by the two remaining service users
- The Trust will continue to provide support, care and treatment for people with Huntington's Disease by the alternative arrangements described.

The Trust has spoken to the relatives of the two continuing care patients and they are supportive of the proposal. Patients would be re-located to a nursing home that is equipped to support people with this condition and that is near to the main carers home. There would be no funding issues as the PCT's would continue to fund their care until end of life. A dedicated nurse has been identified to work with the families of the two people remaining in the inpatient service to co-ordinate the smooth transition to nursing home placements.

Transition for these patients would be a high priority. Staff would visit and work alongside nursing home staff to ensure that a high standard care and established routines are maintained. Initially this would be for a period of 2-4 weeks. In addition a dedicated nursing team will be established to work within the community. The role of the team would be to visit these patients on a weekly basis after the initial transfer. The team would also provide community based assessments for new patients and support for those patients with a diagnosis who are living in the community. The carer's support group and consultant led outpatient clinic will also be maintained by the dedicated nursing team from a location in the community.

The Trust will continue to work with the Huntington's Society North West who will act as a critical friend and ensure that a high level of care is maintained during the transition to the alternative provision.

**Recommendation**

That the above proposal is accepted and Frank Gardham House closes when the alternative provision described is available, anticipated to be during January 2012.

## **Appendix**

### **Information about Huntington's Disease**

If a parent has this disease each child has a 50:50 chance of inheriting the faulty gene. All who inherit the gene will, at some stage, develop the disease which usually manifests itself between 30-50 years of age. Symptoms are classified under three types: Movement, Cognitive impairment and Mental Health.

Individuals require access to early diagnosis, which would involve assessment of symptoms, family history and access to scans such as CT, MRI and PET scans. It is vital that all have access to timely diagnosis including genetic testing/counselling to assist in management of symptoms and planning for the future (both for themselves and family).

Tests will usually determine whether someone has inherited the faulty gene, but it will not indicate the age at which they will develop symptoms. Testing is of particular importance where individuals and family members are planning to have children.

Approximately 50% of people with Huntington's Disease exhibit changes in behaviour to the degree that they give rise to problems. In decreasing order of frequency, the most common problematic behaviour changes are:

- Aggression and violence
- Suspiciousness; and
- Poor temper control.

Frequently, people with HD develop psychiatric symptoms that are often underestimated and unrecognised. The estimated rates of depression and/or psychosis are between 21% and 56% and, for personality and behavioural disorders the rates are between 24% and 70%.

Eventually an affected person will need help with more and more aspects of his or her life and, ultimately he or she will become totally dependent on the help of others. As the disease progresses it is therefore vital that a coordinated multi-disciplinary service is available to address the varied cognitive and mental health symptoms that may arise at any stage of the disease.