HEALTHIER SELECT COMMITTEE

MINUTES OF THE MEETING HELD ON MONDAY 23rd NOVEMBER 2009

Councillors: Carol Jackson-Doerge *(Chairman)* (P), Geoff Findlay (AP), Paul Hewer (P), Owen Jeffery *(Vice-Chairman)* (AP), Gwen Mason (P), Quentin Webb (P)

Substitutes: George Chandler, Billy Drummond, Adrian Edwards, Alan Macro

Also present: Jan Evans (Head of Older People's Services), Amanda Joyce (Head of System Transformation), Bev Searle (NHS Berkshire West), Andrea Ching, (NHS Berkshire West), Jo Cozens (NHS Berkshire West), John Shaw (PRT Carers' Service), Jane McCarthy (Representing family and informal carers) and Jo Naylor (Principal Policy Officer).

PART I

12. APOLOGIES.

Apologies for absence were received from Councillors Owen Jeffery and Geoff Findlay.

13. MINUTES.

The Minutes of the meeting held on 30th June 2009 were approved as a true and correct record and signed by the Chairman.

14. DECLARATIONS OF INTEREST.

There were no declarations of interest received.

15. REVIEW OF END OF LIFE CARE.

In order to review the adequacy of end of life care in West Berkshire (Agenda Item 5) the Committee received a range of representations from individuals and agencies to gather evidence on local end of life services.

Ms Jane McCarthy – representing informal and family carers

Ms McCarthy attended the Committee to explain her experiences of the pressures that were placed on family carers delivering care towards the end of life.

Ms McCarthy described the "arduous journey" of a carer and the fact that they had "no life of their own". She described how officially end of life care started 6 weeks before death however, in reality, continuous care was required earlier than this.

She explained how help was more readily available for cancer sufferers than for those terminally ill patients with other conditions e.g. Motor Neurone Disease or the elderly whom often received only minimal help. She described how there were very few nurses available to provide the support for these other debilitating conditions and providing the necessary respite for carers.

Cancer services were better provided for with support from MacMillan Nurses when diagnosed and there was access to Newbury Cancer Care and the Rainbow Rooms at West Berkshire Community Hospital in the last days of life.

Ms McCarthy described the support available from the various Societies set up to support those with terminal diagnoses and from Care Managers within Adult Social Care. She explained services were available to get a patient up in the morning and put to bed at night. However, she expressed the view that generally individuals requiring support were left alone unless they had a crisis.

She described how two beds were available within West Berkshire Community Hospital for end of life care. However, she explained how one-to-one care for the patient was not possible (due to resourcing levels) and the patient often remained confined to their room. In these circumstances the patient's condition often deteriorated. She described how the pressure of care was relieved from the carer which was then often replaced by guilt that the care was not up to the standard they would like to see for their relative.

Ms McCarthy described how family carers delivering palliative care at home often feel that they could not cope and when this happened, the patient frequently ended up being admitted to hospital or a residential care home.

A further problem with the system was that if one chooses to die at home the patient had to cover this financially although the same did not apply if you were admitted to hospital.

Ms McCarthy explained how health, social care and the voluntary sector had to work closer together to prevent undue hospitalisation and instead use district nursing services to support people at home.

Ms McCarthy explained the need for a regular night-sitting service for family carers. Equally the Princess Royal Trust, along with Age Concern and Help the Aged could provide services to the patient, including befriending services, to provide some respite and relief for full-time carers.

A view was expressed that Crossroads carers could be trained in basic nursing to support those wishing to die at home and Marie Curie nurses could be involved for more intensive nursing support in the very last days of life.

Ms McCarthy explained how a joined up Palliative Care Team across the district, with all the agencies involved in the end of life care would help create a more efficient service and prevent demand on costly emergency admissions to hospital.

Members asked questions in relation to the gaps in the services and the lack of communication about what was available to carers. It was explained by Ms McCarthy that often carers were not told about who to contact when a patient was discharged from hospital nor what to expect when the patient was close to death.

Members asked about training for carers available from district or practice nurses and whether this was available in rural areas. Ms McCarthy reported that nurses might not have the time to train carers and journey to home visits in rural areas.

Ms McCarthy further explained how on some occasions hospitals were poor at informing the GPs of the patient's care needs. If the patient was sent home the carer often found themselves in a position of not knowing what to do or without the necessary equipment to make caring at home possible (e.g. provision of a commode, etc).

The Chairman thanked Ms McCarthy for her views and contribution to the review process.

Mr John Shaw, Chief Executive – PRT Carers' Service

Evidence was received from Mr Shaw the Chief Executive of the PRT Carers' Service. He described his involvement in the End of Life Care Group which was started by the PCT 18 months ago, to consider access to end of life care across the Berkshire West PCT area, and includes representatives from the three Councils.

Mr Shaw explained the central Government priority of improving end of life care services. He described the significant amount of work done by the PCT staff, the PRT Carers' Service and others to pull together a strategy on end of life care and to ensure the strategy translated to improvements on the ground. He said improvements were sought in the context of a very challenging financial environment for the respective agencies. The implementation of national guidance, which he described as good guidance, emphasised the need to involve patients and carers.

He described the taboo of end of life care and the difficulty receiving the carers' perspective. Mr Shaw explained the need to gather information and evidence from carers about their experiences.

Mr Shaw described how better communications and training were required to notice when a patient's condition was deteriorating and becoming a terminal diagnosis. The need for better planning and liaison between professionals and with palliative care colleagues was needed to ensure a smoother transition between these stages.

Mr Shaw advocated that services should be looked at from the perspective of the carer and judgements made about the effectiveness of services alongside statistical evidence. He outlined three areas to improve upon:

- Carer perspective – gathering direct information
- Early identification of entering end of life
- Training for agencies so that sensitive issues affecting the patient were communicated and discussed.

Members asked about whether feedback should come from other family members, not quite so close to the patient as the carer, to provide a different perspective.

Mr Shaw responded to explain how the PCT was working with GPs to achieve the GP Gold Standards Framework (GSF) and to engage with carers as much as possible.

He explained the sensitivity of requesting feedback after a carer had experienced bereavement. Some doctors might be reluctant to ask such questions and an opportunity to receive feedback might therefore be missed.

One Member asked if a 'blog' type approach could be explored as a mechanism for carers relaying their concerns and how best to capture the data e.g. report, questionnaire, etc.

Mr Shaw felt it was really about finding a way of allowing the carer to reflect honestly on the services. He reminded Members of the process of adjustment that was required for individuals that had been carers and the transition to the role of former carer.

It was within the remit of GP to talk to the carer and ask their views on what they would do differently in order to gather this qualitative data.

The challenge of data gathering and ensuring a commonality between the questions and what was recorded was discussed by Members.

Members also highlighted the importance of training for carers on what was available to them and better communication. Westcall out of hours services was also mentioned and the need to improve the transmission of information about patients with end of life care needs.

Mrs Jan Evans – Head of Older People's Services – West Berkshire Council

Mrs Jan Evans (Head of Older People's Services) explained how there was an established intermediate care team comprised of both Adult Social Care and the NHS.

She described a survey undertaken by a Service Manager within Adult Social Care to elicit the views of GPs and district nurses on end of life care services. She described that the sample size was not statistically significant but that 11 out of 14 surgeries in West Berkshire had been surveyed.

The questions covered in the survey were described (see Powerpoint slides attached to the minutes) and it showed that 76% of individuals, the majority, had died from Cancer but other diseases such as Motor Neurone Disease, Parkinson's disease, Dementia and Chronic Obstructive Pulmonary Disease (COPD) had also been causes of death.

Mrs Evans described the difference in the number of applications for Continuing Healthcare Funding in West Berkshire compared to Wokingham. A much lower number of applications in Wokingham were possibly attributable to joint health and social care teams and a preferred model West Berkshire would like to work towards. Currently, social care funding for end of life care required a means-tested assessment to be carried out during an incredibly difficult time for the patient.

Mrs Evans described the funding arrangements for the people who died at home, demonstrating the proportion funded by West Berkshire Council in relation to NHS and other ways.

She also described the two main causes of emergency admissions into hospital at the end of life as:

- Lack of family carer respite time (particularly night-time cover)
- The requirement for greater medical and nursing care at the very end of life.

It was felt the survey provided a good benchmark of current problems in West Berkshire around end of life care and highlighted in summary:

- Service shortfalls included overnight and day time respite to carers;
- Overnight nursing input;
- Lack of community based flexible care service;
- Weekend access to West Berkshire Council and Berkshire West PCT services.

Members welcomed the summing up of the key issues and invited the Andrea Ching of NHS Berkshire West to present the views of the PCT.

Mrs Andrea Ching – Programme Manager (End of Life Care) – NHS Berkshire West

Mrs Andrea Ching described the two in-patient specialist units, at the Sue Ryder service in Nettlebed, South Oxfordshire and Duchess of Kent House in Reading, available for end of life care for West Berkshire residents. Equally, it was acknowledged that access to end of life care services was fragmented across West Berkshire. She also explained that there were indeed a high number of emergency admissions at the point of death.

She described the taboo of the subject and even as professionals the subject of death was rarely discussed. Mrs Ching explained how in West Berkshire 1103 deaths were recorded in 2007 of these only 21% were in the patient's own home despite the fact that nationally most people said they would prefer to die at home.

She described the need for strong local alliances between health, social care and the voluntary sector in providing community based care. She described the PCT's commitment to providing:

- Improved choice for patients;
- Improved standards of care;
- Better training, education of health and social care staff;
- Better use of acute hospital beds.

She raised in particular the work underway to provide daytime, twilight and night-time support for carers. She further emphasised the extended twilight service and the roving out of hours nursing support, where new mobile technology was being introduced to ensure patient records and their current requirements were readily available. This information would also be accessible to all professionals dealing with the patient's care.

A Member asked about the realignment of systems so all the different agencies could effectively work together. The PCT reassured the Committee they were working to get this right. Mrs Ching also described the introduction of a single point of access to help coordinate the required care for patients and their carers. They were improving the communication between the PCT and West Berkshire Council to achieve closer joint working.

Mrs Ching emphasised how staffing levels of daytime nurses had been increased and how elements of the joint working model operated in the Wokingham Borough were being replicated in West Berkshire.

The Chairman asked about funding for services in West Berkshire. Mrs Searle (Director of Partnerships and Joint Commissioning, NHS Berkshire West) confirmed that the increased funding nationally announced for end of life care was not ring-fenced to these specific services nor a specific amount allocated to West Berkshire. The role of the PCT was to ensure equitable access for all.

Members asked about the timeline for seeing real improvements. It was explained that recruitment was in progress and early next year the improvements to community based services would be implemented.

Equally Mrs Searle reported on the financial challenges facing NHS Berkshire West and the need to balance carefully how investments were made whilst improving quality and cost effectiveness of services. She reiterated earlier comments that unplanned admissions to hospital were not the best use of resources or the experience that patients or their families might choose.

Members further questioned whether all proposals had been fully costed and how the coordination of all the volunteers, voluntary bodies and other agencies could be achieved. Bev Searle (Director of Partnerships and Joint Commissioning, NHS Berkshire West) explained how all the different agencies as listed in Appendix 1 of Item 5b on the Agenda were indeed effectively engaging within the End of Life Care Group to improve end of life care services.

Bev Searle described the IT system for storing patient care pathway details and the need for additional equipment to meet end of life patients' needs was noted. Members were informed that the initiatives being introduced should reduce emergency admissions but access to traditional services would still be available.

RESOLVED that:

(1) Members noted the findings of the End of Life Care Group (Item 5b of the Agenda).

(2) Carer feedback should be recorded and used to improve end of life care services also the Committee urged NHS Berkshire West to find easier ways to capture carers' views using the internet and other electronic technology.

(3) A summary report and key recommendations on end of life care be developed and brought back to the 19th January 2010 meeting of the Healthier Select Committee.

16. REPORT OF THE PATIENT ADVICE AND LIAISON SERVICE (PALS).

The Committee considered a presentation from Jo Cozens (Patient Advice and Liaison Service Manager – NHS Berkshire West) (Agenda Item 6). She explained that 3942 enquiries had been received by the Patient Advice and Liaison Service (PALS) in 2008-09 which was up by 15% on the last financial year.

The highest number of enquiries related to access to NHS dentistry. Dental capacity had been increased and NHS Berkshire West are seeking to deliver a communications strategy so the message reaches the public about increased dentistry provision.

Ms Cozens explained how the service resolved individual issues of concern that affected residents in this area. The widespread concern about dentistry led to PALS informing individuals of their nearest NHS dentist, and ensuring local information about available services is published on a monthly basis. PALS information has enabled the PCT to map the areas in which the calls were coming from to inform commissioning decisions about where to invest in additional dental services.

She described the difficulties relating to '0844' numbers operated by some GPs and dental practices and issues relating to podiatry as described in the report at Item 6 on the Agenda.

Ms Cozens described the PCT approach to World Class Commissioning and the focus on receiving patient feedback as part of this process to improve services.

Members asked about the differences between a formal complaint and enquiries. Ms Cozens explained there was a more formal route for dealing with complaints which was dealt with by a separate member of staff within the Trust. Patients wanting to make a complaint were supported in doing so by PALS and the Independent Complaints Advocacy Service (ICAS).

She described the process of dealing with enquiries, ensuring that patients were given reassurance that any comments made would not be detrimental to the care they might receive in the future. The evaluation of PALS showed 99% positive feedback from patients on their experience of using the service.

Members asked about responsibility for actions and confirming items had been completed. Ms Cozens reported that the PCT Board Members would own these recommendations and be responsible for assuring delivery of the necessary actions plans.

RESOLVED that the update be noted.

17. SYSTEM TRANSFORMATION UPDATE.

The Committee considered a briefing note on the latest progress in implementing the adult social care change programme “Putting People First” (Agenda Item 7).

Amanda Joyce (Head of System Transformation) described how the Programme was half way through the grant funded period. She also stated how the formal project management approach was being taken and governance arrangements for the programme were in place.

She drew Members attention to Appendix A of Item 7 which highlighted the 7 component projects which made up the programme, explaining that work was underway in all of them and management arrangements were in place to deliver the change.

Members asked about the role of individuals opting for a Personal Budget and whether they could revert back to traditional services. Ms Joyce described how there was no compulsion to receive a Personal Budget and that a service user could opt for traditional services. Equally if a service user opted to managing their own care they could revert back to traditional services if necessary.

A further question was asked about brokerage services. Ms Joyce explained that the Council had its own staff trained to provide brokerage services as well as access to brokerage services externally. Checks were being put in place to review how the systems were working.

Members asked about safeguarding of how the money was spent. It was explained Care Managers would consider how the money was proposed to be spent as part of the Care Plan. Risk of financial abuse is something on the checklist for Care Managers to consider as well as whether service users are spending the right amount without under-spending on services.

Ms Joyce explained how a review of Phase One of the Personal Budgets project would inform what changes were needed to go forward. She also explained to the Committee how understanding peoples’ choices of services would drive supply and demand of services in the future.

Ms Joyce was congratulated by Members for the implementation of all projects in what was a relatively short period of time.

RESOLVED that the progress update be noted.

18. DEMENTIA STRATEGY.

The Committee considered a short presentation by Jan Evans (Head of Older People’s Services) on the Dementia Strategy Implementation Plan (Agenda Item 8). She described the key priorities for dementia services locally in West Berkshire.

Mrs Evans highlighted five key tasks to be addressed which required further work, these were:

- Improving awareness;
- Good quality early diagnosis;

- Good quality information for carers;
- Improved quality of care of people with dementia in general hospitals;
- Improved end of life care.

Mrs Evans also explained how some GPs were good at making referrals for patients to visit the Memory Clinic however not all individuals had equitable access to this type of service.

Members asked about the timescales for delivery of enhanced services. Mrs Evans agreed to complete the Action Plan with specific dates for completing actions.

Mrs Searle (Director of Partnerships and Joint Commissioning, NHS Berkshire West) mentioned a previous 3 year investment programme of £1.3 million awarded to the Berkshire Healthcare Trust for home treatment services for older people with mental health problems. It was also mentioned how gaps in accessing services still existed particularly for young people suffering with dementia.

RESOLVED that:

(1) The update be noted.

(2) The Head of Older People's Service update the Dementia Strategy Implementation Plan with timescales for the delivery of objectives.

(3) Bev Searle (Director of Partnerships and Joint Commissioning, NHS Berkshire West) reports back on the dementia services available for young people.

19. WORK PROGRAMME

The Chairman introduced this item (Agenda Item 9) and highlighted the key areas of work for the Committee.

Members raised a point in relation to the recent ambulance response time target failures for October 2009 and the 21% increase in call volume seen this month. The Chairman reassured the Committee that it would be followed-up in the task group which is reviewing response times locally and is due to meet on 3rd December.

Secondly a point was raised about the recent publication of a Berkshire Autistic Society report into services in West Berkshire. Mrs Evans reported on how the Chief Executive was considering the Council response to the Berkshire Autistic Society and this should be checked prior to reporting back at the January 2010 meeting.

RESOLVED that:

(1) The work programme be noted.

(2) The Principal Policy Officer clarifies with the Chief Executive the Council's response to the Berkshire Autistic Society's report into adult autism services in West Berkshire.

(The meeting commenced at 6.30pm and closed at 9.00pm)

CHAIRMAN ……………………………………………

Date of Signature: ……………………………………………