

Improving Palliative and End of Life Care for People Living with Long Term Neurological Conditions



A Report for Bath & North East Somerset PCT, as commissioned by the Commissioning Support Service

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Acknowledgement

The external consultant would like to thank everyone who took part in this project for their time, openness and frankness in the Focus groups and during individual interviews.

1. Introduction

1.1 This consultancy project was commissioned by Bath and North East Somerset Primary Care Trust (PCT) and Bath and North East Somerset Council through the Commissioning Support Service¹ to undertake qualitative research into the end of life experience of people living with long term neurological conditions.

1.2 The project brief emphasised the importance of describing the stories and experiences of people who may be reaching the end of their life and those of their carers. The focus of this report is therefore on individuals' accounts of living with a long term neurological condition and what their preferences would be in facing end of life issues. It identifies a number of themes that arose and makes recommendations to enable Commissioners to use resources in the most effective way and improve care pathways for individuals.

2. Methodology

2.1 The project commenced in April 2008 and adopted the following methodology:

- Planning and preparatory work to identify participants for Focus Groups and individual interviews in consultation with key stakeholders;
- Making sensitive arrangements for the Focus Groups and individual interviews;
- Facilitating two Focus Groups and undertaking agreed individual interviews
- Documenting the stories and experiences of participants;
- Drafting and submission of a final report.

It was overseen by a Project Steering Group comprising representatives of the Commissioning Support Service, the Multiple Sclerosis (MS), Motor Neuron (MND) and Parkinson's Disease (PD) organisations.

2.2 The MS, MND and PD organisations identified and contacted individuals to take part in the project. This resulted in twenty-one (21) individuals being interviewed. Seven (7) individuals with MS were seen in two Focus Groups. A further thirteen (13) individuals were seen in their own homes and one (1) person was interviewed by telephone. The latter group comprised three (3) people with MND, six (6) people with PD and five (5) carers.

2.3 Two lessons were learnt at an early stage. Firstly, the original project brief, specifying that two mixed Focus Groups would be facilitated by the external consultant, needed modification. The brief anticipated one group would be nine individuals diagnosed with MS, MND or PD and the other group would comprise of nine carers. From discussion it quickly became apparent that individuals might need to be seen in their own homes as the nature of their disability would make travel difficult. It was also considered inappropriate to bring together 9 individuals who had not previously met and expect them to talk about their own dying and death. The interviewing sample was adapted accordingly. Secondly, it proved difficult to make appropriate contact with individuals who were known to fulfil the requirements of the project. This was eventually achieved through the voluntary organisations. The involvement of other key

¹ The Commissioning Support Service was established by the MS Society, the Motor Neurone Disease Association and the Parkinson's Disease Society in 2007 to provide management services to Primary Care Trusts, Strategic Health Authorities and Adult Social Care Departments across England.

professionals (e.g. specialist nurse) at an early stage would have been beneficial to the project in identifying and approaching individuals to be interviewed.

2.4 The project also encountered the complex issue of defining an appropriate point prior to 'end of life' when it would be reasonable to expect individuals to identify and discuss their care needs. This is discussed further in Section 4 below.

3. National and Local Context.

3.1 Effective support for people needing palliative or end of life care has the potential to have a great impact on the experiences of both service users and carers. It enables the efficient use of resources across the whole health and social care system. This has increasingly been recognised as an issue that is relevant across the policy agenda and has been highlighted as a national priority in a number of Government initiatives. The most notable examples of policy direction include the following:

- **'Building on the Best'**² accepts that if people want to die at home, then they and their families should have access to the services needed to make this possible. It is recognised that this requires effective medical care and pain control of symptoms and professional support that promotes personal dignity.
- The **'National Service Framework for Long Term Conditions'**³ states that an estimated 350,000 across the UK need help with daily living because of a neurological condition and 850,000 people care for someone with a neurological condition. Quality Requirement 9 of the NSF addresses the need for palliative care services for people in the advanced stages of neurological conditions and the importance of enabling people to make choices about end of life care. It states 'People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms; offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.'
- **'Our Health, Our Care, Our Say: A New Direction for Community Services'**⁴ sets out the government's vision of more effective health and social care services outside hospitals. To deliver this, it identifies five areas for change: more personalised care, services closer to people's homes, better coordination with local councils, increased patient choice and a focus on prevention as much as cure. The White Paper focuses on three themes for a new strategic direction for all care and support services that people use in their communities:
 - Putting people more in control of their own health and care;
 - Enabling and supporting health, independence and well-being
 - Rapid and convenient access to high quality cost effective care.
- Lord Darzi's **NHS Next Stage Review** includes several recommendations around end of life care:

² 'Building on the Best: Choice, Responsiveness and Equity in the NHS' Department of Health 2003 Stationery Office: London UK

³ 'The National Service Framework for Long Term Conditions' Department of Health March 2005.

⁴ 'Our Health, Our Care, Our Say: A New Direction for Community Services' Department of Health 2006

- People should have an end of life care plan, including preferences on place of death - and this should be registered electronically
 - There should be greater investment to support people to die at home
 - Integration of services should be improved (between GP practices and hospital specialists and between health and social care) for people with long term conditions
 - End of life service providers should be commissioned to co-ordinate end of life care
 - There should be more proactive community care to reduce emergency admission and lengths of stay
 - All organisations should meet existing good practice guidelines for end of life - i.e. the Gold Standards Framework
- **End of Life Strategy** was due for publication by the end of 2007. However, with the NHS Next Stage Review focusing on end of life care as one of eight key areas of care, it was deemed premature to publish a strategy before the Review work had been completed. The Review work on end of life care is being led by local clinical pathway groups in each Strategic Health Authority (SHA) and clearly has the potential to inform and strengthen the national strategy. Ministers had decided to publish the national strategy in parallel with Lord Darzi's NHS Next Stage Review final report which was launched in June 2008. Its publication is still awaited.
 - PCTs are also expected to apply the learning gained from the **operating framework 2007/08 baseline reviews of end of life care services** to inform future commissioning decisions.

3.2 Bath and North East Somerset PCT is responsible for commissioning local healthcare services for a population of over 184,000 people. The PCT's aim is to help individuals achieve their potential and improve healthcare, health and well-being, and to reduce inequalities. The PCT has produced a strategic framework⁵ which reviews local needs and performance and sets out the emerging direction for the NHS in Bath and North East Somerset for the period 2008-2011, taking into account local health priorities and emerging national targets and standards.

3.3 It identifies eleven areas of excellence where, with additional focus, services can make a significant difference to healthcare, health and wellbeing standards to achieve excellence over and above national expectations. One area is improving end of life care.

3.4 In October 2007, the PCT submitted an outline financial plan to the Strategic Health Authority for the period 2008/9 - 2010/11. This includes end of life care as an 'Emerging area of excellence' and the expectation is that there will be significant progress made in 2008/09. The plan includes outcomes to improve end of life care:

- People are offered a genuine choice in health care and are empowered to make choices;
- People are treated with respect and dignity

To achieve these outcomes the PCT has three stated ambitions:

⁵ Bath and North East Somerset PCT Strategic Framework for Health and Well Being 2008-2011 (November 2007)

- all those who need palliative care will have access to appropriate services regardless of diagnosis by 2009
- the Gold Standard Framework and the Liverpool Care Pathway (attached as Appendix 1) for the dying (or an equivalent) will be adopted in primary/community and secondary care settings respectively
- the number of people who die in hospital who had previously expressed a preference to die at home will be reduced

The PCT acknowledges that good end of life care is complex in its delivery, requiring the use of multiple resources and the skills of a wide range of professionals to meet the needs of the patients and carers. It also requires good communication pathways and good coordination between organisations.

4. Definition of End of Life and End of Life Care

4.1 A crucial aspect of this project was developing an understanding of the meaning of the term '**end of life**'. Such understanding was essential to identify the individuals to be interviewed and to consider how they might view their 'end of life care' needs.

4.2 It was quickly apparent from initial discussions with stakeholders that the definition of its beginning is variable according to individual and professional perspectives and the nature of long term neurological conditions. Many interviewees also pointed out their death was likely to be caused by something other than MS, MND or PD - for example, heart failure, stroke, or pneumonia -and therefore end of life must be related to more than just the neurological condition diagnosed. As one interviewee put it "*MS people don't die of MS*".

4.3 Guidance⁶ suggests that the beginning of end of life is marked by a comprehensive professional assessment of supportive and palliative care needs and the use of indicators that help in making decisions about end of life:

- Would you be **surprised** if this person were to die in the next 12 months;
- The person with advanced disease makes a **choice** for comfort care only;
- The person with advanced disease is in **special need** of supportive/palliative care;
- **Clinical indicators** of end stage illness - general physical decline, weight loss, dependence in most activities of daily living, and condition specific indicators.

End of life does not normally begin earlier than one year before death and for most individuals it may come much later than that. For individuals with long term neurological conditions such as MS, MND and PD, however, there is no predictable patient journey to end of life.

4.4 In this situation it proved difficult to construct a sample of individuals who had clearly reached a point where their condition was approaching 'end of life' and who would be amenable to taking part in the project. It could also have been inappropriate to interview people at the end of life as they may well not have been in a physical, mental or emotional state to respond. Following discussion with the Project Steering Group and BANES PCT, it was agreed that interviews with individuals with a diagnosis of a long term neurological condition would provide commissioners with valuable information on the earlier stages of a patient's journey and would still offer insights into potential

⁶ 'Building on Firm Foundations' The National Council for Palliative Care and NHS End of Life Programme, June 2007

improvements in end of life care. Interviewees also suggested that this was appropriate: “*it’s about making a long slow decline bearable*”.

4.5 A diverse range of individuals with a diagnosis of MS, MND or PD were invited to take part in the project. Based on the guidance, a majority of those eventually interviewed would not be described as being at the end of life. Interviewees with MS and PD were a self-selected group of individuals with a diagnosis of a long-term neurological condition ranging from a few months to several years, facing an unpredictable patient journey to end of life. They nevertheless offered important insights into end of life needs.

4.6 End of Life Care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both the individual and their family to be identified and met throughout the last phase of life and into bereavement. For the purpose of this project it was defined to include management of pain and other symptoms and provision of psychological, social, spiritual and practical support⁷. End of life care is expected to be underpinned by:

- An active and compassionate approach to care that ensures respect for and dignity of the individual and their family;
- Partnership in care between the person, family and health and social care professionals;
- Regular and systematic assessment of the patient and carers needs incorporating the individual’s consent at all times
- Anticipation and management of deterioration in the individual’s state of health and well-being;
- Advance care planning in accordance with the individual’s preferences;
- Individual choice about the place of care and death;
- Sensitivity to personal, cultural and spiritual beliefs and practices;
- Effective co-ordination of care across all teams and providers of care (in statutory, voluntary, and independent sectors) who are involved in the care of the patient and family⁸.

5. Choice and Dying at Home.

5.1 A majority of interviewees (13) reported a preference for end of life care and for dying at home, but acknowledged that when death approaches they may prefer to stay at Dorothy House a local hospice as the service has an excellent reputation for palliative care. This shift in preference was based on a concern that community services and home care may not be available to the extent required or that the service quality may not be as high as expected.

5.2 Many however believed that palliative and hospice care was only a priority for cancer patients. It was a common view that people diagnosed with a long term neurological condition were not afforded the same priority. This is supported by national evidence⁹ as summarised in Table 1 below, which shows that few people with conditions other than cancer die in hospices. The analysis also shows that while overall 19% of the total population dies at home and 67% in hospital, a far greater proportion of

⁷ Ibid

⁸ Definition from ‘Operating Framework 2007/08: PCT baseline review of services for end of life care April 2007.

⁹ Source: Office of National Statistics 2001

those suffering diseases of the nervous system die in non-NHS hospitals and other communal establishments.

		NHS	Non-NHS	Hospice	At home	Other communal establishments
Cancer	% of total deaths	49.5%	7.5%	15.7%	22.2%	5.1%
Diseases of the Nervous System	% of total deaths	40.2%	26.4%	1.4%	12.7%	19.3%
Diseases of the Respiratory System	% of total deaths	62.3%	12.6%	0.2%	13.2%	11.7%
All Mortality	% of total deaths	56.2%	10.5%	4.3%	18.6%	10.4%

Table 1 Deaths from cancer and other causes, England and Wales, 2001

5.3 Generally, interviewees rejected institutional care as a choice for end of life care: *“definitely no institution if it’s like those available”*. One resource - Helen Ley, Leamington Spa - was cited as a good example of a purpose-built, specialist facility for MS, but other institutions were described as *“being full of ancient people unable to communicate with all kinds of medical problems”*. These generic facilities were described as *“totally crushing”* and the lack of a specialist MS resource within the BANES area was regarded as *“depressing”*.

5.4 Some individuals were concerned to spare their carers emotional distress and the exhaustion of providing personal care. In particular, many interviewees wished to spare their sons and daughters the embarrassment of undertaking personal intimate care or meeting end of life needs. They were not aware of the availability of specialist palliative care at home or confident in service quality. As a result, a significant number of interviewees said they would consider paying privately for care and support, as confidence in institutional (residential care) or 24 hour specialist home care/palliative services for their particular needs was low.

5.5 Interviewees were anxious that their preference to die at home should be seen as a personal choice rather than being as a result of a policy direction. One Focus Group recounted difficulties when professionals sought to impose their own wishes and preferences upon them. Interviewees expressed a wish to *“take risks in our own homes”*. However, some interviewees acknowledged that their physical, health and care needs may change, carers may not be able to cope or become exhausted and there may be insufficient support to the family as intensive care may be necessary. Some interviewees were concerned that intensive home support would be costly. They therefore wanted the opportunity to amend their choice as palliative care in an institution may become more appropriate.

5.6 There has been little change in the relative number of home deaths. Given the ‘Choice’ agenda, rising expectations of healthcare and greater affluence of the

population, it might have been expected that the patterns of service provision would have developed in ways which more closely reflect individual expressed preferences.

5.6 Greater awareness of care and support available at end of life and increased confidence in service quality is likely to lead to increased demand in future years. The experiences of people diagnosed with MS, MND or PD suggests **specialist home care/palliative care** services are perceived as being for cancer patients only. At the same time available data indicates the number of people dying and being cared for at home remains relatively static.

Recommendation 1: BANES PCT should ensure that individuals and their carers are aware and confident of their right to die at home with appropriate supportive services.

Recommendation 2: BANES PCT should ensure hospice care is available locally for people with a long term neurological condition who require palliative or end of life care.

6. Information Needs

6.1 Significantly, many interviewees were not aware of what information and support was available to them and did not feel well advised. This ranged from information at the point of diagnosis; advice on entitlement to benefits; guidance on what to expect as the neurological condition progressed and where to get further information; availability of night time cover; communication tools as conditions resulted in the deterioration of verbal ability; and advice on Living Wills, Dying with Dignity and the legal position.

6.2 A significant proportion of interviewees believed doctors and other professionals were reluctant to give information due to the unpredictable nature of the patient journey. They perceived a lack of openness about the way the condition might progress. A fear of litigation was cited for the perceived lack of information and advice relating to Living Wills and Dying with Dignity and for other aspects of professional behaviour. One distressing incident reported by a carer involved a patient's written preferences not being accepted as "*they were not on the officials forms*". This resulted in unnecessary discomfort at the end of the patient's life.

6.3 Some good examples of available information were cited such as "Thumbprint" and the PD magazine but the level of access to information reported was extremely varied. One interviewee was told "*to go on the internet*" which can be a source of a great deal of further information. However, whilst the PD website was described as helpful, interviewees did not believe the internet should "*replace a personal conversation*". In particular, it was stressed some older people do not have access to the internet.

6.4 The specific palliative and end of life information which the interviewees reported that they would like to receive included a complete prognosis, outcomes of medical investigations, what to expect in physical terms, where to go for additional support, practical issues such as finance, equipment and housing, nutrition and hydration advice, treatments, oral hygiene, and pain management. One positive by-product of the Focus groups arranged for this project was the information exchange that took place between participants. This reinforced the conclusion that patchy access to information was experienced by many service users and carers.

6.5 Exercising choice about the care, support and preferred place of delivery at the end of life requires comprehensive, timely, relevant information to be available to individual

service users and carers in a range of formats. Information, advice and support will also enable people to make informed decisions about their end of life preferences. This needs to cover local services from the NHS, social care, the hospice, care homes and voluntary sector services in a consistent way. Here, the involvement of the voluntary sector to initiate information prescriptions would be a positive step forward.

Recommendation 3: BANES PCT to facilitate an audit of current information available for people with a long-term neurological condition in need of palliative or end of life care is essential.

Recommendation 4: BANES PCT to commission through the voluntary sector organisations the development of an Information Strategy with the aim of enabling service users and carers to access a comprehensive range of information about what to expect as end of life approaches and services available is essential for people to make informed choice about their care.

Recommendation 5: BANES PCT and BANES Council to identify a role of advocate, navigator or broker is required to help service users and carers navigate the complex care pathway of palliative care into end of life.

7. Professional Practice and Roles.

7.1 The subject of professional practice and attitudes generated passionate contributions. Interviewees were keen that professional practice reflected the principles of being treated with dignity and respect. However, there were many accounts of *“staff shying away from talking about death”* and a lack of openness about *“the various ways the condition might progress and result in death”*, making it difficult for a person to express their wishes and preferences at end of life. Interviewees described an overriding need for empathy; instead they reported that *“staff don’t put themselves in your shoes”*. There was a common plea for *“understanding of the person you are and my wishes being taken into account”*. There was a strong desire to be seen as a whole person rather than a list of symptoms or *“some-one with a physical disability therefore intellectually impaired”*. *“People see my walking frame and talk loudly to me assuming I’m stupid”*. *“It is important people remember who you are”* i.e. a person with talents, achievements, and a wealth of experience.

7.2 The overriding wish was for *“sensitivity to what a person actually wants or needs”* and to be listened to, especially if their choice of care and support did not accord with the professional viewpoint. This meant for some interviewees they *“would not be jollied along when you know you can’t do anything”*. Others wanted honesty and a sense of humour even when talking about death and dying - *“some people are too terribly careful which is irritating”*.

7.3 Examples were given of general medical and nursing staff demonstrating a lack of understanding about long-term neurological conditions - *“Doctors who do not understand the condition say you’re demented”*. When communication became a problem for a patient with MND the carer described an inappropriate response from ward nursing staff and for another patient *“she was put (inappropriately) on a bedpan”*. Another carer described *“waiting for 4/5 months for a botox injection to get the mucous out of the patient’s mouth. “Professionals are so busy they don’t understand the impact. Professionals are detached”*. In contrast, a specialist MND volunteer worker was seen as an invaluable support and Dorothy House Hospice was repeatedly commended as a high quality service. *“It’s the rapport that makes it special. Good teamwork absorbs the sadness”*

7.4 Professional practice should reflect a person centred approach which means that all aspects of an individual's life are taken into account when assessing palliative care and end of life needs, often involving a number of different professionals and agencies across health and social care. The Department of Health¹⁰ stated that:

'Patients with long term conditions need high quality care personalised to meet their individual requirements'.

This suggests enabling people to die with dignity in a setting of choice with appropriate care and support requires a well trained workforce sensitive to all the key issues at the end of life. As a result, all assessment and planning along the care pathway needs to be person centred, which means people with a long term condition, receiving palliative or end of life care, are treated with respect and dignity.

7.5 It was notable that a number of interviewees found it helpful to talk about end of life issues within this project and expressed their appreciation to the interviewer for the opportunity to talk about personal and intimate matters relating to their own dying and death. Interviewees explained they would talk to a person about end of life care based on the personal qualities of the individual, such as sensitivity, rather than their professional status.

7.6 People want their wishes about their care, including palliative and end of life care to be listened to and understood. This requires sensitivity, understanding and training of all professionals involved with the aim of improving end of life care in all settings. The aim should be to increase staff awareness, empathy and knowledge about the needs of dying people and ensure a consistency of approach.

Recommendation 6: BANES PCT and BANES Council should ensure the health and social care workforce including doctors, nurses; home care staff and allied professionals receive training in a person centred approach to ensure they have the ability to engage in sensitive discussion about end of life care.

7.7 It was reported that staff need time and resources to spend with people at the end of life. This is important to meet carer's needs too. Whilst there is a specialist PD nurse, an equivalent resource is not available to either people with MS or MND. Such resources would facilitate a person centred approach and ensure the needs of people with MS or MND are listened to and understood. The availability of an expert palliative care and supportive resource, such as a palliative care nurse, would enable the Primary Care Trust to offer training and education to a wider group of staff.

Recommendation 7: The Primary Care Trust should consider the appointment of specialist staff in roles such as a palliative care nurse and/or MS and MND nurse to:

- **Be a specialist resource for service users and carers**
- **Provide pain and symptom management**
- **Influence palliative care management at all levels**
- **Provide palliative care and end of life care training to staff.**

8. Carers

¹⁰ 'The National Service Framework for Long Term Conditions' Department of Health March 2003.

8.1 It was apparent that family members who care for and support people with long term neurological conditions are vital to the well-being and quality of life of the individual. The importance of carers and their needs has been recognised in legislation and government policy since 1995 and in June 2008, the Prime Minister launched the Government's new **National Carers Strategy**. Ministers have highlighted that the Personalisation agenda is of key importance in improving support for carers. The National Strategy requires a focus on the carer as well as the person using a service, and legislation requires authorities to address carers' needs. Proposals include an extension of the 1999 Strategy for Carers to reflect carers' rights, direct payment regulations, carers' assessment and carers' grants.

8.2 The carers interviewed for this project stressed the importance of meeting their needs in sustained and creative ways. They raised many issues including:

- Advice on hereditary factors;
- The need to listen to carers who have a wealth of information on the patient's condition;
- Concern that the carer may die first, particularly as a number were ageing;
- The need for flexible support such as respite;
- The pressure of changed financial circumstances when the carer gave up full time work.

Financial concerns were a major issue, as some carers allowances meant other state benefits were stopped, "*the financial problems become a burden to the patient who then feels guilty*", "*the patient is expected to stay at home.....a financial contribution would be helpful (for a stair lift)*".

Carer exhaustion was a constant challenge, as the reality of caring for a family member at home became apparent. The Carers Network (MND) was described as "*most important*" and a valuable support.

8.3 The provision of **Bereavement support** or appropriate literature would have been welcomed when a family member died suddenly. "*It was hard to initiate contact. I would like to have been put in touch with someone*". There was a sense of abandonment after a period of intense involvement with medical services, which was no longer there after the patient had died.

8.4 The availability and capacity of carers to cope with the challenges they have to face and so support patients increases the likelihood of a home death, and decreases hospital admissions.¹¹ The task for professionals is to recognise fully that carers play a vital role in the well-being and welfare of the individual who faces the end of life.

Recommendation 8: The PCT needs to ensure:

- **Carers are identified and receive appropriate support;**
- **Voluntary sector and carers' projects also focus on the needs of carers of people with long term neurological conditions who may be receiving palliative or end of life care;**
- **Continued training for health professionals in awareness of the needs of carers.**

¹¹ Grande GE, Addington-Hall JM & Todd CJ 'Place of death and access to home care services: Are certain patient groups at a disadvantage?' *Social Science & Medicine* 1998

9. Access to Services

9.1 Home visits to interview people were conducted in central Bath and surrounding rural areas. Interviewees in **rural locations** described the challenges of attending for hospital or primary care appointments when transport was not available. There was the difficulty of using taxis due to a lack of wheelchair access and the associated high cost to attend appointments. Rural transport was virtually non-existent in some locations. Dial a Ride was a positive bonus for some people. There was also a lack of appreciation on the part of some professionals to the challenges of using public transport *“Why go to Frenchay for a 10 minute procedure and a 3 hour journey”*.

9.2 Access to services appeared to be dependent on the quality of **General Practitioner (GP) support**. Those interviewees who had understanding and supportive GP's were more likely to receive appropriate services e.g. night time support. Others were unaware such a service was available.

There were also examples of some interviewees initiating contact with a range of agencies and having to give the same personal information to several professionals, *“it's nice when you only have to tell one person”*. One good example of services being joined up across sectors involved a carer initiating a **professional network** meeting at home. The interviewee described this as a *“family tree of carers”*. In these circumstances, the whole range of care and support was coordinated, *“if you get the kind of support we have then it works well”*.

9.3 A majority of interviewees believed good quality end of life care included being *“as free from pain as possible”*. However, some interviewees believed staff were more reluctant to administer **pain relief** in case this action was subject to misinterpretation and litigation. One carer recounted an experience where a patient's written preferences - a wish not to be resuscitated - were misunderstood and he received no pain relief: *“they took it the wrong way and thought he didn't want anything”*.

9.4 Coordination of care for individuals across a number of health care settings - primary care, hospital and community settings, and social care - was not consistent. It was evident that care for people with a long term neurological condition was the responsibility of a range of health and social care professionals working in general and specialist settings. This complexity will continue as the patient moves through the care pathway towards end of life care. Developing palliative care networks in the way initiated by one carer in BANES will ensure a coordination of services and continuity of care.

9.5 Consistency of access and equality is an important consideration when commissioning services to cover rural areas. The research on distance to services is equivocal. Some studies report no relationship between death at home and urban or rural living. Others have found that terminally ill patients living a long distance from the nearest hospital are more likely to be cared for at home, while those living close to a hospice or hospital are more likely to die there.¹²

Investment in home services, like night time support, can in the long term be expected to release hospital beds for use in other areas and therefore make best use of resources. Lack of adequate palliative care home services may, however, lead to unnecessary hospital admissions and have adverse effects on carers.

¹² Higginson et al. 'Do social factors affect where patients die: an analysis of 10 years of cancer deaths'. *Journal of Public Health Medicine* 1999

Recommendation 9: BANES PCT should consider palliative and end of life audits on practice which would contribute to any work on equity, and the reduction of all forms of health and health care inequalities.

Poorly controlled symptoms such as unrelieved pain may often precipitate late stage hospital admissions. The importance of physical comfort at the end of life is of paramount importance.

Recommendation 10: The PCT's ambition to adopt The Gold Standards Framework and the Liverpool Care Pathway (Appendix 1) for the dying should be progressed in primary/community and secondary care settings respectively, as service users need to access consistent pain and symptom control whether cared for at home, or in a care or hospital setting.

10. Advanced Care Planning (ACP).

10.1 ACP is a process of discussion between an individual and staff involved in their care. It may involve family and friends. The individual then agrees that this discussion should be documented, regularly reviewed and communicated to key persons involved in their care. When ACP was explained to interviewees a majority were very positive about developing a care plan, "*it's a good idea so I don't have problems later on*". It was also seen as providing reassurance that an individual's needs would be met at the end of life. However, knowledge of the existence and role of ACP was limited. Understanding of the legal position of ACP and the Mental Capacity Act (2005) was variable and many interviewees expressed a desire to have more information.

10.2 Interviewees did not want to discuss palliative care or end of life care too soon. In part, this was because it meant confronting the reality of dying and death. All interviewees strongly supported the view "*it could only be when the patient is ready*". Some preferred to put off any discussion of dying and recognised there may be a point when "*it was rather too late to plan*". Others were keen to instigate ACP as soon as there was a marked deterioration in an ability to communicate. An ACP was seen as a valuable communication tool when there was the potential to lose the ability to speak or write. Interestingly, an expression used by many interviewees to "*take one day at a time*" gave a clear message that individual choice dictated when dying and death were to be discussed as there is "*no one point when you think you're at the end of your life*". It was emphasised that the content of discussion about palliative and end of life care would vary from person to person and therefore people should be treated as individuals.

10.3 Interviewees considered regular review as being vitally important in recognition of the progressive nature of long term neurological conditions as needs were likely to change. A number of interviewees sought reassurance that the ACP would be known to all staff involved in end of life care and carried out as specified by the individual.

10.4 The lack of knowledge of ACP suggests that the PCT needs to consider ways of raising the profile through guidance and information for individuals, families, carers, care providers and health and social care staff.

Recommendation 11: BANES PCT, working with partners, promotes the awareness and profile of ACP through the use of various communication channels and the production of guidance/information for all involved.

Recommendation 12: BANES PCT should ensure there is a protocol in place for how the ACP will be delivered; where the document is to be kept and how it will be shared by professionals involved in the care of the individual at different stages along the care pathway.

11. Conclusion

11.1 The experiences, preferences and needs of individuals interviewed with MS, MND or PD and their carers in BANES suggests there are areas for PCT commissioners to focus on that will influence the process of palliative and end of life care for the majority who wish to remain at home. Notably, the PCT's own ambition is for end of life care to be an 'Emerging area of excellence' with the expectation that significant progress would be made in 2008/09.

11.2 Therefore, attention to the following areas is likely to achieve the PCT's stated outcomes of people being empowered and offered choice, whilst being treated with respect and dignity: equal access to timely, comprehensive information and appropriate services; specialist staff roles such as a palliative care nurse and brokers; appropriate support to meet carers needs; implementation of The Gold Standards Framework, the Liverpool Care Pathway and Advanced Care Planning and the promotion of a person centred approach. Consistent access to palliative care services and coordinated care through professional networks is likely to reduce crisis situations arising for patients and carers and avoid inappropriate admission to hospital, particularly at the very end of life.

11.3 Clearly, gathering the end of life experiences of people with MS, MND or PD has presented challenges for this project. This may reflect the same challenges commissioners face as appropriate support for patients, for example, with motor neurone disease or late stage dementia clearly differ to supporting people with the terminal cancer or heart failure. The overwhelming conclusion is that commissioners may well influence outcomes for patients at end of life through the design of care pathways; awareness of ACP; training for professional staff and the introduction of specialist provision. Ultimately, outcomes will be dependent on what was most important to interviewees the quality of professional practice, underpinned by respect for the individual.

12. Summary of Recommendations

- 1. BANES PCT should ensure individuals and their carers are aware and confident of their right to die at home with appropriate supportive services.**
- 2. BANES PCT should ensure hospice care is available locally for people with a long term neurological condition who require palliative or end of life care.**
- 3. BANES PCT to facilitate an audit of current information available for people with a long-term neurological condition is essential.**
- 4. BANES PCT to commission through the voluntary sector organisations the development of an Information Strategy with the aim of enabling service users and carers to access a comprehensive range of information about what to expect as end of life approaches and services available is essential for people to make informed choice about their care.**
- 5. BANES PCT and BANES Council to identifying a role of advocate, navigator or broker is required to help service users and carers navigate the complex care pathway of palliative care into end of life.**
- 6. BANES PCT and BANES Council should ensure the health and social care workforce including doctors, nurses, home care staff and allied professionals receive training in a person centred approach to ensure they have the ability to engage in sensitive discussion about end of life care.**
- 7. The PCT should consider the appointment of specialist staff in roles such as a palliative care nurse and/or MS and MND nurse to:**
 - Be a specialist resource for service users and carers**
 - Provide pain and symptom management**
 - Influence palliative care management at all levels**
 - Provide palliative care and end of life training to staff.**
- 8. The PCT needs to ensure:**
 - Carers are identified and receive appropriate support.**
 - Voluntary sector and carers' projects also focus on the needs of carers of people with long term neurological conditions who may be receiving palliative or end of life care.**
 - Continued training for health professionals in awareness of the needs of carers.**
- 9. BANES PCT should consider palliative and end of life audits on practice which would contribute to any work on equity and the reduction of all forms of health and health care inequalities.**
- 10. The PCT's ambition to adopt The Gold Standards Framework and the Liverpool Care Pathway (Appendix 1) for the dying should be progressed in primary/community and secondary care settings respectively, as service users need to access consistent pain and symptom control whether cared for at home, in a care or hospital setting.**

11. BANES PCT, working with partners, promotes the awareness and profile of ACP through the use of various communication channels and the production of guidance/information for all involved.

12. BANES PCT should ensure there is a protocol in place for how the ACP will be delivered; where the document is to be kept and how it will be shared by professionals involved in the care of the individual at different stages along the care pathway.

The Gold Standards Framework (GSF)

The main aim of this scheme is to translate hospice care into the community. Seven main areas are targeted for improvement:

- Communication between professionals involved with the patient
- Coordination of care
- Control of symptoms
- Continuity of care around- the- clock
- Continued education of staff
- Carer support
- Care of the dying in the last few days of life.

Evaluations to date have shown that the GSF improves standards of care, reduces practice and District Nurse workload, and minimises out of hours calls and unnecessary admissions.

The Liverpool Care Pathway for the Dying (LCP)

The LCP was developed to take the best of hospice care into care for people in hospital and other settings, including care homes. It is used to care for residents in the last days or hours of life once it is known they are dying. The LCP involves promoting good communication with residents and family, anticipatory planning, including psychological and spiritual needs, symptom control (pain, agitation and respiratory tract secretions) and care after death. The LCP has accompanying symptom control guidelines and information leaflets for relatives.