

End of Life Care Strategy

Promoting high quality care for all adults at the end of life.



Equality Impact Assessment

July 2008

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EQUALITY IMPACT ASSESSMENT

1) Aim and purpose of the End of Life Care Strategy

- 1.1 Over 500,000 people die in England each year. Despite this, the Department of Health has never previously formulated a comprehensive end of life care strategy. Although many patients receive excellent care at the end of life, delivered both by the statutory and voluntary sectors, some do not.
- 1.2 The aim of the End of Life Care Strategy is to enable adult patients to have choice about where they live and die and provide them with the support to make this possible.
- 1.3 End of life care is the support given to a person with advanced, progressive, incurable illness to live as well as possible until they die. It includes services that enable the supportive and end of life care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. It is therefore important that we ensure that services are available equitably to all and that they are designed in such a way as to support all people reaching the end of their lives whatever their age, race, faith, gender, sexual orientation, gender identity, level of capacity, disability or preferences.
- 1.4 Patients approaching end of life should reasonably expect that their care will be:
 - Pre-planned wherever possible and based on need (not diagnosis, age, sexual orientation, geography or other factors);
 - Well coordinated and delivered in accordance with best practice to minimise physical, psychological or spiritual suffering;
 - Equitable and delivered in a dignified and respectful way;
 - Ethical with regard to preferences and personal beliefs.
- 1.5 The End of Life Care Strategy encompasses adults with any advanced, progressive, incurable illness and extends to care given in all settings to people reaching the end of their lives. Support for carers, family and friends throughout the process and into bereavement is also included within the strategy.
- 1.6 The Equality Impact Assessment reflects the broad scope of the strategy and focuses on each stage of the person's care pathway. The stages are summarised as, but are not limited to:

1. initiating the discussion about end of life care and dying
2. assessing individuals' and carers' needs
3. care planning (advance care plans)
4. providing care in all settings (hospital, care home, own home, etc)
5. coordination of services
6. reviewing and updating care plans
7. last days of life
8. care after death – viewing the body and returning/handling possessions
9. bereavement support for family and friends
10. carer education and support

1.7 Neither the End of Life Care Strategy or this Equality Impact Assessment will cover the care given at the end of life to children (as work is being taken forward elsewhere) or care given outside the current legal framework (e.g. assisted suicide or voluntary euthanasia). However, the Strategy does include children in so far as they may be carers and they will be experiencing bereavement.

2) Why do we need an Equality Impact Assessment?

2.1 In his BMJ editorial of 15 January 2000, Smith R comments that we have little information about the state of dying in Britain today.¹ Reliable statistics exist on life expectancy, age at death, place and cause of death, but there is little published information about a person's actual experience at the end of their life. Variations in the quality of end of life care exist across the country and there is concern that among certain groups of dying patients such as the old, those with non-cancer diagnoses, people from black and minority ethnic (BME) backgrounds and those in rural areas there is an unacceptable level of variance.²

2.2 Quality of care is also said to vary between each of the different sectors providing end of life care. We know from the literature that many people would prefer to die at home, but we also know that in reality the majority of people die in hospital.³ The End of Life Care Strategy aims to address this and this Equality Impact Assessment helps to reveal some of the issues that need to be tackled before improvements can be made. It also helps to identify some of the different needs of society, suggests how services need to be

¹Smith R. (2000) *A good death*. BMJ

²Payne S. et al (2004) *Community Hospitals: an under-recognised resource for palliative care*. Journal of the Royal Society of Medicine

³WHO Regional Office for Europe. (2004) *Palliative Care – The Solid Facts*

designed in order to meet these needs and ensures that the End of Life Care Strategy does not inadvertently create inequality.

3) The availability and strength of evidence: literature review

- 3.1** The Healthcare Commission's report *Spotlight on Complaints* highlighted that one of the largest areas of concern for patients is poor communication between staff and patients or family, particularly following a death.⁴ This was of particular concern in acute trusts. Many of the complaints related to families receiving contradictory information from the staff who had been caring for their deceased relative. In other cases, relatives felt they were unprepared for the death of their relative and did not have sufficient time to enable other family members to be present. Inconsistent practice in respect of record keeping was also raised as a concern by a number of patients who felt that the lack of recorded clinical observations meant that their relative had not been cared for properly.
- 3.2** The concern that this raises adds weight to the need for an equality impact assessment to be carried out on end of life care to try to understand more about where and why the service is failing to deliver a good quality service in some cases. It will also reveal whether certain groups of society are adversely affected more than others. The equality impact assessment process requires the policy to be assessed against seven equality categories: age, gender, religion and belief, sexual orientation, gender identity, race and disability. However, as other factors (homelessness, refugee, detention in prison, traveller, etc) are also associated with inequity in end of life care, the End of Life Care Strategy has also been assessed against these categories.
- 3.3** A literature review was carried out as the first stage of the process of gathering evidence to inform this Equality Impact Assessment. The results of the literature review are provided below against each of the equality categories.

Age

- 3.4** A number of articles and reports studied in this Equality Impact Assessment (see bibliography) suggest that there is potential for inequality in end of life care in respect of a person's age. Some studies suggest that older people are

⁴Healthcare Commission. (2007) *Spotlight on complaints*

⁵WHO. (2004) *Better palliative care for older people*

less likely to receive end of life care. Estimates suggest that by 2020 the percentage of older people in the general population will rise to 26%, an increase from 21% in 2000⁵ and the Department of Health predict that there will be an increase in the numbers of people living over the age of 80 years by more than 50% and over 90 years by over 100% within the next 20 years.⁶ If older people are a particularly vulnerable group, then within an increasingly ageing population it will be important to ensure that people are treated fairly regardless of their age.

- 3.5** Kalman Kafetz⁷ suggests that in elderly people the process of dying is less clear cut than in younger people in respect of malignant diseases. He suggests the dying trajectory may last longer and that often the individual's awareness may be clouded by cognitive dysfunction. As the death itself may be different, Kafetz suggests that so too may be the process of bereavement. He suggests that when older people die a more complex process goes on in bereavement than when younger people die. He also suggests that when people die of certain diseases, for example cancer, the impact of the death is sometimes lessened by working through a stage of 'anticipated bereavement' which is not always possible to do when elderly people die.
- 3.6** In an exercise undertaken by King's College London to map place of death across the Thames Cancer Registry, older people were shown to be more likely to die in hospital and nursing homes and less likely to die at home or in a hospice.

Disability and long-term conditions

- 3.7** People with a learning disability have poorer health than the general population. In their report *Death by indifference*⁸ Mencap suggest that this is partly due to conditions that can be related to their disability (such as epilepsy, thyroid problems, sight and hearing problems) and socio-economic factors (people with a learning disability are generally poor, living on benefits or low income). As a result they are more likely to have unhealthy lifestyles.
- 3.8** People with a learning disability may find it hard to communicate or to understand what is being told to them. This may lead to people enduring pain for longer than they need to or missing medication because they

⁵Department of Health. (2004) *National Service Framework for Older People*

⁷Kafetz K. (2002) *What happens when elderly people die?* Journal of the Royal Society of Medicine

⁸Mencap. (2007) *Death by indifference*

haven't understood how to take it. In 2006, the Disability Rights Commission (DRC) carried out a formal investigation into the physical health inequalities experienced by people with learning difficulties and mental health problems. The results showed that people with a learning disability receive fewer screening tests and fewer health investigations. It concluded that overall people with a learning disability are less likely to get the healthcare they need.

- 3.9** Mencap's report *Death by indifference* presents the stories of six people they believe died unnecessarily because of failures of medical staff to fully understand the individual's condition. They comment that often medical professionals will assume that a presenting problem is a feature of someone's learning disability and so fail to spot the underlying problem, leading to misdiagnosis, or no diagnosis at all. The report also highlights that professionals are often unaware of issues around capacity and consent to the extent that patients are often denied treatment or treatment is delayed. In end of life care it will be essential to ensure that people's pain is adequately addressed and that professionals are educated to understand the complexities of caring for someone with a learning disability.
- 3.10** There are also inequalities in the way that individuals living with long-term medical conditions are treated and cared for at their end of their lives. Long-term conditions are those conditions that cannot, at present, be cured, but can be controlled by medication and other therapies and over 15 million people in this country report living with a long-term condition. It is suggested anecdotally that people with cancer receive better access to end of life care than people with other long-term conditions. This was confirmed in a study by Grande et al⁹ who found that having cancer was the greatest determinant of palliative care use. Other studies showed similar findings in relation to specific long-term medical conditions.
- 3.11** In a study looking at the palliative care needs of people with chronic obstructive pulmonary disease (COPD)¹⁰ a comparison was made in respect of the services they receive and the services that people with lung cancer receive at the end of their lives. It found that in the last years of life patients with COPD have worse quality of life, greater limitation of activity and higher levels of anxiety and depression than those with lung cancer. In addition, although over 80% are housebound and a third are chair bound,

⁹Grande G., Farquhar M., Barclay S., Todd C. (2006) *The influence of patient and carer age in access to palliative care services*. Age and Ageing

¹⁰Murray S. (2006) *Palliative care for people with COPD: we need to meet the challenge*. Primary Care Respiratory Journal

less than half of them have morbidity aids that might help to reduce social isolation. The report concludes that few people with end-stage COPD are given an opportunity to make decisions about their end of life care and despite the majority saying that they would wish to die at home, the majority are still dying in hospital.

- 3.12** Improvements in end of life care for heart disease patients may also be necessary. A study into the symptoms experienced in the last year of life of a person with heart disease found that pain, dyspnoea, low mood and sleeplessness were reported by more than half the patients studied.¹¹ These symptoms were said to have caused considerable distress to the patients and had troubled them for more than six months. The report highlights the need for better end of life care for people with heart disease and calls for more attention to be paid to dying from causes other than cancer, and specifically from cardiac causes.

Race

- 3.13** Little evidence exists in respect of inequalities in end of life care and race. However, a number of studies have looked at the needs of both BME patients and carers in end of life care and have found that there are factors associated with culture and language which mean that closer attention needs to be paid in order to be able to fully meet their needs.
- 3.14** The first piece of research to be looked at was a study examining the palliative care experience of Bangladeshi patients and carers in Tower Hamlets.¹² It found that family and friends provided the most care and support during the patients' illness. It also noted that there are specific needs in relation to this community based solely on ethnicity. These relate to factors such as when the people migrated to the UK and their religious beliefs. This study showed that few of the Bangladeshi patients and carers were fluent in English and that they experienced difficulties in relation to their Muslim beliefs. In a small number of cases the patients or carers were not able to practice their religious duties or were not given time or privacy to pray.

¹¹McCarthy M., Lay M., Addington-Hall J. (1996) *Dying from Heart Disease*. Journal of the Royal College of Physicians of London.

¹²Spruyt O., MacCallum P. (1999) *Community-based palliative care for Bangladeshi patients in East London. Accounts of bereaved carers*. Palliative Medicine

- 3.15** A further study into the experience of informal carers within the Bangladeshi community found that in addition to the demands and stresses caused by their relative's symptoms and the knowledge that they were dying, the Bangladeshi carers experienced communication barriers, isolation and anxieties regarding visas and housing. It will be important that these additional stresses are noted by healthcare professionals and that practical solutions to help them cope are offered.
- 3.16** A study carried out back in 1995 looking at access to hospice and palliative care for BME communities¹³ found that hospices were not specifically addressing issues of cultural and religious differences and ethnicity. In many instances hospices were uncertain about what they should be doing to meet the needs of different ethnicities and were unclear how they could publicise their services to these groups of people. Another study¹⁴ also found that uptake of palliative care services is lower among black Caribbeans and other ethnic groups. Today, we still see relatively few people from BME communities using care homes or hospices. Language, cultural and religious differences could lead to individuals feeling that their needs could not properly be addressed in a care home or hospice and this theory will be tested further in consultation.
- 3.17** Researchers undertaking the study into access to hospice and palliative care for BME groups questioned hospice workers about the ethnicity of their patients. Two quotes were given in their report:

"It's difficult to say how many black patients we've had, we don't go round saying we've got two Asian patients today or whatever, that's discriminatory, it's something you shouldn't think about, they're just patients" (Hospice Deputy Manager)

¹³Gaffin J., Hill D., Penso D. (1996) *Opening Doors: Improving access to hospice and specialist palliative care services by Members of the Black and Minority Ethnic Communities. Commentary on palliative care.* National Council for Hospice and Specialist Palliative Care Services

¹⁴Koffman J. (2006) *The language of diversity: controversies relevant to palliative care research.* European Journal of Palliative Care

"I couldn't tell you how many, it's irrelevant, I'm not conscious of people's colour. We reflect the community and our volunteers reflect it too, we have all nationalities, it's not really an issue for us" (Hospice Volunteer Co-ordinator)

- 3.18** The Researchers suggest that these comments show a serious misunderstanding of the purpose of ethnic monitoring and a failure to understand that collecting statistics of this type could help to plan and improve services for all population groups. They also suggest that these comments reflect a denial of people's ethnicity and culture and as a result their needs may not be being met. This is a form of indirect racial discrimination.
- 3.19** For many patients and families from minority ethnic groups, rituals and traditions become more important in advanced illness and at death. A study taken forward in 1997/98 provides an account of the end of life experiences of the black Caribbean population, as reported by close friends, relatives and carers, compared to white patients.¹⁵ The results showed that respondents' ratings of care for black Caribbean patients were inferior across all healthcare settings. Although over half of respondents of black Caribbean patients considered district nurses provided them with enough time, white patients fared better. Respondents of white patients also reported receiving more reassurance and support from district nurses compared to their black Caribbean peers. Of the 42 black Caribbean patients who utilized acute care facilities, 52% of respondents reported that they were given a choice about their treatment. This compared less favourably with white patients (59%). Finally, whilst many respondents representing the views of black Caribbean and white patients rated healthcare as excellent or good, a larger proportion of respondents representing black Caribbean patients expressed dissatisfaction with care than white patients.
- 3.20** These messages were echoed in a later study into the preferred location of death of first-generation black caribbean and native-born white patients in the UK.¹⁶ This study revealed that fewer respondents representing Caribbean than white patients stated that neither they or the deceased patients were given sufficient choice about the location of death.

¹⁵Koffman J., Higginson I. (2001) *Accounts of carers' satisfaction with healthcare at the end of life: a comparison of first generation black Caribbeans and white patients with advanced disease*. Palliative Medicine

¹⁶Koffman J., Higginson I. (2004) *Dying to be Home? Preferred Location of Death of First-Generation Black Caribbean and Native-Born White Patients in the United Kingdom*. Journal of Palliative Medicine

Religion and belief

- 3.21** Little documentary evidence was available to show any inequalities in relation to religion and belief. However, it is clear that different religions have different rituals, requirements and preferences when it comes to end of life care and in handling the body following death.
- 3.22** In some religions the human body, whether dead or alive, is sacred and this makes the practice of post mortem unacceptable to people practising these religions because it violates the sanctity of the human body. In these cases it would be sensitive to the individual practising these religions if post mortems were restricted to cases where MRI scanning cannot achieve the necessary results.
- 3.23** Some religions require the body to be washed in a certain way following death, and some require that the body of the deceased is not left alone. Others require that the body is left alone for a specified number of hours and so it is important that due regard is given to an individual's religion before any action is taken which could be deemed insensitive to their religion. It is also important to treat people within each faith as individuals as they may be practising their religion to different levels and may have beliefs or requirements that are unique to them. One study¹⁷ observes that whilst many patients at end of life may benefit from prayer and religious rituals, equally some may be more selective or choose to ignore them entirely.
- 3.24** Inequality was also revealed in a survey of community hospitals.¹⁸ Although 315 (91%) of hospitals were visited routinely and regularly by Christian ministers, only 2 were visited by ministers of other faiths. To try to identify any further areas of inequality in relation to religion or belief, a workshop on spirituality was held with representatives of a range of religions (including people with no religion). The results of this workshop are provided in section 4.28 below.

¹⁷Koffman J., Higginson I. (2002) *Religious faith and support at the end of life: a comparison of first generation black Caribbean and white populations*. Palliative Medicine

¹⁸Payne S. (2004) *Community hospitals: an under-recognised resource for palliative care*. Journal of The Royal Society of Medicine

Gender

- 3.25** The literature review yielded no areas of discrimination or inequality in respect of end of life care and gender. However, Grande G et al¹⁹ found that women are less likely to die at home than men and men are generally less efficient as carers (which is possibly the reason that less women die at home).
- 3.26** A study carried out by BioMed Central²⁰ into how patients coming to the end of their lives use information to help them cope with their disease found no difference in attitude or behaviour associated with gender.

Sexual orientation and gender identity

- 3.27** Being lesbian, gay, bisexual or transgender/transsexual (LGBT) is about a whole way of life and not just about someone's sexual preferences.²¹ This means that when end of life care is delivered, it must be delivered in a way that embraces the individual's culture and social interests and in a way that does not make assumptions about the individual solely on the basis of their sexual orientation or gender identity. Age Concern's resource pack for professionals working in care homes and extra care housing gives examples of where prejudice has resulted in lesbian, gay or bisexual people or their carer being isolated, excluded and sometimes victimised. It also highlights where problems often occur because assumptions are made that older people are no longer sexual beings. As a result, sexual needs are never mentioned in care plans and even though an individual may no longer be in a sexual relationship, their LGB sexual orientation is overlooked.

*'If I didn't have sex at all with another woman for the rest of my life, I would still be a lesbian. It's as integral to who I am as my identity as a mother, the job that I do and the beliefs I hold dear'*²²

¹⁹Grande G., Addington-Hall J., Todd C. (1998) *Place of death and access to home care services: are certain patient groups at a disadvantage?* Social Science and Medicine

²⁰BioMed Central. (2007) *In the shadow of bad news – views of patients with acute leukaemia, myeloma or lung cancer about information, from diagnosis to cure or death*

²¹Age Concern. (2006) *The whole of me...Meeting the needs of older lesbians, gay men and bisexuals living in care homes and extra care housing*

²²Age Concern. (2006) *The whole of me...Meeting the needs of older lesbians, gay men and bisexuals living in care homes and extra care housing*

3.28 Prejudices still exist in relation to transsexual and transgender people, which sometimes result in people keeping a low profile or concealing their identity. Death of a trans person can bring with it additional anxieties in relation to dealing with appropriate authorities and in keeping the status of the deceased as private. Recent legal changes regarding gender recognition mean that there are requirements in relation to obtaining and security of details of trans people when they have died. These are described in more detail in the Department of Health's publication *Bereavement: A guide for Transsexual, Transgender people and their loved ones*. A number of examples of discrimination in respect of an individual's sexual orientation or gender identity were revealed as part of the consultation process and are set out in paragraph 4.33 below.

Other at risk groups

Homeless people

3.29 Homeless people are vulnerable and can have a multitude of health problems including physical health, mental health and those related to substance misuse. People who have experienced long-term homelessness (particularly rough sleeping) tend to die younger, whilst having the health problems of much older people. A Canadian study looking into the benefits of providing shelter-based palliative care for the homeless terminally ill reports that often homeless people's behaviour or lifestyle can preclude them from treatment in a hospice environment.²³ Even with terminal illness, some homeless people may prefer to remain in a shelter because it is a familiar environment or because it enables them to continue drug, tobacco or alcohol use. However, without appropriate treatment, a number of homeless people are found dead in public places, residential dwellings, arrive dead at a hospital or die shortly after admission. The costs of hospitalisation of homeless people are high due to the increased length of stay that tends to occur.

3.30 A London-based charity for homeless people is being consulted as part of this Equality Impact Assessment to learn more about any inequalities that homeless people in the UK are likely to experience.

4) The Equality Impact Assessment: consultation

- 4.1 The literature review revealed some important detail about the needs and wishes of different groups of society. It provided insights into some of the differences between people of different ages, races and of differing levels of disability. However, the literature review did not reveal many areas of inequality specifically related to end of life care.
- 4.2 In order to be certain that the End of Life Care Strategy is being developed in an inclusive a way as possible, and to try to identify any potential areas for discrimination, a targeted consultation exercise was also carried out with as many individuals and organisations as possible. All of the organisations consulted in the production of this Equality Impact Assessment are listed at the end of this document and the Department of Health would like to thank all of the organisations and individuals who gave up their time to participate in this very important consultation.
- 4.3 The results of the consultation are summarised under the seven equality headings below.

Age

- 4.4 A number of groups representing older people were consulted to try to determine whether there is actual, or the potential for, discrimination in end of life care towards people who are older. Although respondents were unable to provide specific examples of people being discriminated against on the grounds of their age, there was a perception that older people could be treated differently because they are generally seen to be more vulnerable. Older people said that they wish to be treated as partners in care and stressed a desire for more choice in where, how and by whom they are treated. They also talked about the reassurance that continuity in their care brings them and asked for one point of contact that they can go to for help 24 hours a day.
- 4.5 Older people also felt that they could play an important role in educating their peers, including younger people who they believed should be encouraged to talk about death and dying more often.
- 4.6 A significant number of people consulted (in addition to the direct consultation with users and carers through the Alzheimer's Society) felt that people with dementia are also at risk of unfair treatment, even if this is not deliberate.

Dementia is a widely misunderstood condition and there is a perception that people with dementia receive lower quality care and often do not receive adequate pain relief. As a result, consultees agreed that carers have a vital role to play in looking after and speaking for people with dementia and that advocacy services are crucial. These are all messages that we see echoed in Mencap's report *Death by Indifference*.

Disability and long-term conditions

Disability

4.7 No specific examples of inequality were raised through consultation with a range of charities representing people with disabilities. However, consultees reminded us of the need to ensure that people with disabilities are able to retain the same level of access to specific services at the end of their lives. For example, the home of a blind person might be customised with equipment to make everyday life easier and safer. This could include liquid level indicators, talking clocks and medication alerts. It will be essential for people to continue to have access to these aids if they choose to live in a care home, nursing home or hospice.

Learning disability

4.8 People with a disability, particularly those with learning disabilities or mental health problems, were highlighted as being vulnerable groups who will need greater support and increased advocacy in end of life care. Whilst the older people consulted in the production of this Equality Impact Assessment expressed a desire for a single telephone number to ring for support, it should be noted that this may not be the most appropriate way of supporting someone with a learning disability who may have difficulty dialling the telephone number. Consultees suggested a different approach which involves the individual's phone being programmed to speed dial the helpline number. A photograph of the person that the patient would be contacting is placed next to the speed dial button on the telephone.

4.9 People with, or representing people with, learning disabilities were asked whether they feel inequalities exist in end of life care and how the service could be made fairer. They commented that it is very important to include people with learning disabilities in discussions about their care and suggested the best time to approach a conversation about end of life might be when

someone enters a new care setting. At this stage the person may still be well, which may make it easier to consider what they might want when they are unwell or dying. It is vitally important that the communication needs of the individual are understood and that an environment that is not too distracting is selected carefully to facilitate the conversation. This may include allowing additional time. Consultees also pointed out that the individual may have an existing healthcare plan, link with a healthcare facilitator, person centred plan which details their life wishes and a communication passport which details their communication style and needs. If these exist they will be a vital source of information and support for healthcare professionals.

- 4.10 Consultees also highlighted that there are additional areas of inequality in respect of bereavement support for people with learning disabilities. They felt that mainstream bereavement services are sometimes unable to meet the bereavement needs of people with learning disabilities or to understand the nature of the loss for others who are involved.
- 4.11 Short breaks from caring is an issue which received much comment during the consultation, particularly in relation to people with learning disabilities. Caring for someone with a learning disability can be both rewarding and stressful. There will be times when a person will need an episode of hospital care and consultation respondents pointed out that even during this time the caring parent often gets no rest because they are required to stay with their adult offspring throughout their hospital stay in case they wander, remove 'drips' or become distressed. It is, therefore, important to ensure that carers looking after people with learning disabilities are given as much access to short breaks from caring as those looking after patients with more physical illnesses within their own homes.

Long-term conditions

- 4.12 The literature review revealed that there could be inequalities in the levels of support and care that individuals living with long-term conditions receive at the end of their lives, particularly when a comparison is made against the care that people living with cancer receive, and these messages were reiterated in the consultation. It is often said that cancer patients receive better access to hospice support and palliative care and to test this theory a number of condition-specific organisations were consulted and asked what support and care they feel the patients they represent will need at the end of

their lives. The information provided below relates to COPD, motor neurone disease, multiple sclerosis and renal disease. However, it is important to note that much of the information given in these examples could apply to any medical condition.

COPD

4.13 The first thing to compare about COPD and cancer is that much more is known about cancer among medical professionals and the general public. This increased awareness, particularly among members of the public, means that people recognise the seriousness of a diagnosis of cancer, whilst they might fail to realise how serious a diagnosis of COPD is. There is great public sympathy towards people living with cancer, whereas COPD still attracts a significant proportion of blame. Consultation with the British Lung Foundation (an organisation with expertise of both lung cancer and COPD) has exposed other areas of inequality. Funding for hospices often comes from donations and much of this will be from cancer charities, and relatives of patients affected by cancer. Targets exist for the treatment of patients who have been diagnosed with cancer, but there are no similar targets for COPD. This has the effect of raising the profile of cancer which effectively leads to cancer patients receiving better pain control, more intense/frequent home nursing, and better access to hospice care. The British Lung Foundation cited an example of a hospice declining to take people with COPD for fear of being 'overwhelmed'. Breaks from care are more readily available for carers of people with cancer and welfare benefits and carers allowances are available for people diagnosed with cancer.

Motor neurone disease

- 4.14** Motor neurone disease is a devastating disease which progressively attacks the body and destroys the ability to walk, talk or feed. Communication will therefore be an issue in end of life care for people with this condition, particularly at certain stages of the care pathway. When initiating the discussion about end of life care it will be important to do this early in the course of the disease to ensure that the patient is still able to speak.
- 4.15** Access to hospice care was raised as an area of inequality as it can vary considerably. A survey carried out in 2000 found that many hospices only provide breaks from care in the terminal stages of an illness and very few provided breaks from care early in the disease's progression. In addition, the

speed of progression of the disease means that symptoms may arise rapidly and services need to react quickly. However, delays in payment for services have prevented this from happening and caused distress and anxiety to patients.

- 4.16 Carers support was highlighted as being an area needing particular attention as many will suffer from ill health, poverty, employment discrimination and isolation. A strong network of support is as important for the carer as it is for the individual with motor neurone disease.
- 4.17 As with the consultation with the British Lung Foundation, hospice funding arrangements were raised again as being an issue as the source of many charitable donations comes from cancer charities and people touched by cancer. There is concern that this could lead to hospices giving preferential access to people with cancer, and people with other conditions may miss out.

Multiple sclerosis

- 4.18 Multiple sclerosis is the most common disabling neurological disorder among young adults and at least 85,000 people in the UK have the condition. Multiple sclerosis is not itself a terminal condition, but its symptoms can cause specific and significant difficulties during the end of life phase, particularly around communication and cognitive function.²⁴ This means that it will be vital for healthcare professionals to ensure people have opportunities to discuss end of life care before their condition reaches end stage and the importance of advance care plans/directives becomes clear. Several interventions may become appropriate for people with severe multiple sclerosis (MS) which require careful explanation or time to improve quality of life. Unless discussed early enough, there may not be time to assess fully the person's choice and wishes.
- 4.19 Consultation revealed that whilst access to end of life services for people with MS have improved, more improvements are necessary to ensure that people with MS have the same opportunities to make choices about their care as others. In particular respondents emphasised the need for professionals to be completely honest when discussing end of life and indicated the best way to discuss death and dying is to take the lead from the individual who has MS. Every person will be different and will wish to have discussions at different times of their disease progression. The need to be treated as an individual is a message being said loudly by all groups.

²⁴Consultation with the Multiple Sclerosis Society, July 2007

- 4.20** As MS is an unpredictable disease, consultation respondents felt that it will be important for care plans to be reviewed regularly and that the care plan should cross both health and social care. Information on all options about where the individual can live should be provided and respondents highlighted the value of being able to visit places such as hospices before the end of life stage is reached.
- 4.21** Inequality was highlighted in respect of access to care homes for people with MS. Few care homes are registered to accept young adults which makes them inaccessible to younger people with MS. This means that staff may have little experience and understanding of MS which could have a bearing on the quality of care they are able to provide. On the plus side, many hospices are now able to provide care to people with MS and active marketing could help to raise awareness of what services are available and how they can be accessed.
- 4.22** A further area of inequality that this consultation uncovered relates to an individual's economic situation. People with a lower income were identified as being vulnerable to gaps in local service provision because they are unable to self-fund additional or high quality care. MS has a significant detrimental effect on people's income as it often prevents them from staying in employment from a young age and incurs additional costs such as adaptations. It is therefore crucial that information is provided to everyone with MS about the support and care available from both health and social care.

Renal disease

- 4.23** Most patients with end stage renal failure usually have co-morbidities and it is possible that they may die of a cardiac event or diabetes complication prior to reaching dialysis. It is important that when a patient begins dialysis they are given supportive care within the community, with appropriate links to specialist knowledge about anaemia, bone disease management, etc. Consultees suggested that all patients with end stage renal failure should be included on an end of life care register.

Race

- 4.24** A number of organisations representing people of different race/ethnicity were consulted to find out whether there are issues specific to their race or culture that need to be represented within the end of life care strategy. Consultees were asked whether there are existing inequalities in the way that end of life care is provided and to think about whether there is potential for inequality or discrimination to occur in the future as a result of the Strategy being developed.
- 4.25** A message occurring consistently across many different races was the importance of offering choices about where people might want to die. In particular, it was thought to be crucial that individuals are given the opportunity to return to their home country to die and that they are told about death at an early stage so that they are able to travel before they become too unwell. Many groups consulted felt that there would be fewer costs and practical difficulties to overcome if family members were able to return home whilst they were alive than there would be if relatives had to arrange for a body to be returned home after somebody has died. Also, some people living in the UK may have the majority of their family living overseas and so the importance of support from health and social care was stressed as was the importance of being given a diagnosis early enough to enable family members to travel to England to 'say goodbye'.
- 4.26** Formal statistics are patchy, but it is suggested anecdotally that residents of care homes and hospices tend to be White British people. It was felt important that this Equality Impact Assessment should try to explore some of the reasons for this as care homes and hospices should be available to everyone. Each group consulted was asked whether they felt that care homes and hospices are available to everyone. There was unison across all the different races consulted that they did not see care homes and hospices as being accessible to them. Reasons centred around issues such as language, cultural differences, availability of familiar foods, and a perception that the staff would not have the skills to be able to support their cultural and religious practices. In addition, the lack of knowledge of the hospice/care home system seemed to feed into a general feeling of mistrust regarding these institutions.

- 4.27 Lack of knowledge about all the services that the NHS and social services are able to provide was widespread across all the races consulted in the production of this Equality Impact Assessment and it is apparent that more needs to be done to provide information locally to different population groups before end of life care can be said to be accessible to all.

Religion and belief

- 4.28 A workshop was held on 14 June 2007 to discuss the role of religion and spirituality in end of life care. Religious leaders from a number of different faiths and members of the Faith Communities Consultative Council attended the event, along with a selection of people representing people with no faith.
- 4.29 The group discussed the importance of ensuring that end of life care addresses an individual's spiritual needs as well as their physical needs. The group agreed that it is important to recognise that where a person does not have a religion or faith it does not mean they do not have spiritual needs. They also stressed the importance of not making assumptions about a person within a certain religion or faith.
- 4.30 Additional consultation events were also held with representatives from a range of different faiths. A number of issues were raised in respect of end of life care and whilst these were not always areas of inequality or discrimination they serve to highlight where difficulty can arise for different faiths. Firstly, it was noted that people working in the area of spiritual care are often excluded from accessing health information about the people they represent. This can sometimes hinder their work as they are not provided with a full account of the individual's condition (even if the individual has given consent for this information to be shared). Another problem was highlighted in respect of the terminology used by medical professionals which may inadvertently cause offence to some religions. For many people with a religious belief, the moment of death is in the hands of God, and consultees felt that medical staff should be cautious about applying actual timeframes for a patient. Pain control was another issue which featured strongly in discussions. Whilst consultees were in agreement that access to adequate pain relief was important for all individuals at the end of their lives, for some religions it was important that the pain relief did not interfere with mental

alertness and clarity. In some religions, people may choose not to accept medical treatment, and may not even register with a doctor. It is important that medical professions are seen to have offered care to an individual even if the individual subsequently refuses to accept it, and it is important that the medical professionals are protected from criticisms of neglect.

- 4.31** Problems were also raised in respect of burial and death certificates, particularly in relation to the Jewish and Islamic faiths. Both faiths require that the deceased be buried as quickly as possible which, in England, requires a death certificate. Access to the registrar is not always possible on bank holidays or at weekends which can cause additional stress for bereaved friends and family members. Issues were also raised in respect of coroners, particularly in relation to individuals who may be practising the religion of Christian Science. If an individual dies and they are not under the care of a GP, the law states that the death is reported to a coroner. Consultees commented that the death can often be considered as suspicious and some had experienced coroners and the police being aggressive in their assertion of foul play based on their belief that it was impossible that someone was not registered with a GP or would choose a form of treatment other than medical. This causes undue distress to family and friends, who may inappropriately be questioned and accused of abuse which may have led to the death. Consultees called for coroners to be given training to increase their awareness of practices of different religions which may mean that they are better able to understand when episodes occur which may otherwise be treated as suspicious.

Gender

- 4.32** Consultation did not reveal any specific areas of inequality or discrimination in respect of gender. However, a number of people commented that they would like to be given the opportunity to choose the gender of the person looking after them (for example hospital staff, home carers).

Sexual orientation and gender identity

- 4.33** The consultation revealed that sexual orientation and gender identity are perhaps the most likely areas for inequality and discrimination to occur in end of life care. Many examples were given of partners being excluded from the care of their loved ones or being prevented from attending funerals by family members. One of the strongest messages coming out of consultation with lesbian, gay, bisexual or transgender/transsexual (LGBT) people was the importance of healthcare professionals not making assumptions about their gender identity, sexual orientation or their lives if they reveal their sexual orientation or transgender identity.
- 4.34** LGBT people said that they may find it hard to talk about their needs and preferences because of the personal, social and historical experiences of discrimination they may have gathered throughout their lives. Older LGBT people in particular may have lived through times when sex between two men was illegal and may have experienced homophobic and hostile reactions from health or social care staff, other service users and the community in general. Many develop the protective strategy of retaining their privacy about their sexual orientation which may affect their ability to effectively engage in discussion about end of life care, as issues could be raised about family, friends, partners or religion which could be difficult to talk about without disclosing their sexual orientation. It is the responsibility of services therefore to take initiatives to make it feel safer to share information about sexual orientation and gender identity, for example by including LGBT people in service design and in publicity.

Other at risk groups

- 4.35** It was crucial from an early stage to ensure that the Strategy was being developed as inclusively as possible and we were keen to identify any additional groups of society, no matter how small, who might be at risk of exclusion. Consultation has been taken forward with a prison, a secure hospital and a charity representing homeless people and the results are included below. Further work may be undertaken in the future to look at how other groups might be affected by the End of Life Care Strategy, e.g. refugees and travellers.

Prisons

- 4.36** People who are detained in prison or under the Mental Health Act in secure hospitals should be treated with dignity and respect and given as much choice as is possible about the care they receive as they approach the end of their lives. This may mean that they will wish to end their days in what has become familiar surroundings and with those who they know. A secure hospital and a prison with a dedicated unit providing end of life care were visited as part of this consultation. They provided useful insights into some of the health needs of their populations. For example, people in prisons are more likely to have mental health problems or learning disabilities, are unlikely to use a dentist, and could have problems relating to substance misuse. Older prisoners experience accelerated ageing, which means that they experience issues associated with older age from 50 onwards.
- 4.37** The visit to Norwich Prison and The Dene secure hospital revealed no specific issues of inequality or discrimination in end of life care. However, all deaths in custody must be reported to the coroner. If a person chooses to be taken from a prison to a hospital or hospice to die it may appear less 'suspicious' than if they were to die in their prison cell. This could create a disincentive for prisons to offer people the option of remaining at the prison to die. In general, however, it is likely that the End of Life Care Strategy will complement the provisions already in place to provide end of life care to people being detained in prison and people being detained under the Mental Health Act.

Homeless people

- 4.38** St Mungo's provides help and support to homeless people in London and was consulted as part of this Equality Impact Assessment. St Mungo's suggests that the average age of death for homeless people is 42 years and consultation with them reaffirmed some of the issues surrounding homeless people that were reported in the Canadian study mentioned above. Often homeless people will have behaviours associated with personality disorders, learning disabilities, poor literacy and offending histories. As a result they are often labelled as difficult and blame is attached to their homeless status. Their treatment at end of life is often undignified and unequal.

4.39 Access to end of life care in hostels is poor and many hospitals are not adequately supported by GPs and primary care teams. Problems identifying homeless people as being at the end of their lives means that they often do not get the opportunity to access hospice care because it is usually not known that they are approaching end of life. Examples were given of hospitals failing to notify St Mungo's that a person is at the end of their life and consequently the individual is found dead in their room some days later. Death in this way is neither dignified for the individual or easy for the member of hostel staff who discovers the body.

5) Proposals

Age

Issue

5.1 It is clear from both the literature review and consultation that there is potential for inequality against older people. Older people in particular will need information and support to help them make choices and be fully involved in planning their care. It will be important to provide comprehensive packs of information about the support that is available because if people don't know what there is they don't know what to ask for or what they are entitled to. This information needs to be provided at an early enough stage to ensure that the individual has the best chance of being able to participate in planning their care before their condition deteriorates.

Action

5.2 Advance care planning is a useful way of ensuring that individuals can be involved in planning their care before their condition worsens to the extent that they are no longer able to communicate their wishes.

Issue

5.3 There is a need for increased awareness of dementia. Carers can play a crucial role in the care of people with dementia and medical professionals will benefit from their expertise in identifying when the person is in pain, distress or discomfort.

Action

- 5.4 The strong messages about the role of carers and the value they have in supporting patients to live in a place of their choice must not be ignored. The End of Life Care Strategy incorporates the needs of carers and devotes a chapter to this area.

Disability and long-term conditions**Issue**

- 5.5 The results of both the literature review and consultation have clearly identified that there is potential for inequality to occur in respect of people with a learning disability or severe mental illness. These people will require skilled professional care from people who understand the complexities of learning disabilities and mental illness. Healthcare professionals should also recognise the importance of the role the family or carer can play in helping to identify when a person with a learning difficulty is showing a difference in their behaviour and could be experiencing pain.

Action

- 5.6 More training is needed for those who work with people with a learning disability. In addition, the Books Beyond Words project, supported by the Department of Health through Section 64 funding, should help to ensure that people with a learning disability have access to information about end of life issues. Books Beyond Words will develop a full-colour picture book in the Books Beyond Words series that provides accessible information and is a communication tool for people with learning disabilities who are terminally ill. The book will include guidelines for carers, supporters, health professionals and voluntary organisations who work with people with learning disabilities. The strategy also includes examples of good practice when caring for those with learning disabilities who are approaching the end of life.

Issue

5.7 To have any chance of closing the inequalities gap between the end of life care that cancer patients receive and that which those living with other long-term conditions receive, it will be necessary to raise the profile of other long-term conditions. The workforce will need to be equipped with the right skills to be able to provide advice and support and to recognise the limits to their knowledge so that they can seek further help from other care workers.

Action

5.8 The End of Life Care Strategy will address workforce issues.

Race

Issue

5.9 It is clear from a number of studies and the consultation that staff education in multicultural health could play a large role in helping end of life care to embrace society's diversity and changing needs. Language has the potential to be a barrier to good quality end of life care for some BME groups, particularly those who have migrated to the UK recently and are not fluent in English. In one report, children had missed school to stay at home and act as an interpreter when a medical professional or community support team was visiting the dying relative. This was deemed to be unacceptable and has the added disadvantage of information possibly being misinterpreted or withheld.

Action

5.10 The use of formal interpreters could be encouraged to prevent a large burden being placed on children and younger generations who often have to act as interpreters. This will help to create a more standard quality of service for people across the country and across difference ethnicities.

Issue

5.11 Communication skills are important and it will be essential that all professionals providing end of life care are trained in effective communication.

Action

5.12 Communication skills will be part of all under- and post-graduate training.

Issue

5.13 Other issues relating to race and culture apply to the choices people are given about where they would like to die and in handling of the body after death. It should be recognised that some patients, particularly those of recent migration, will either wish to return to their 'home' country to die or will wish to be buried in their country of origin after they have died. Where possible these wishes should be elicited by the professional responsible for the individual's care at the time of care planning and while the patient is still well enough to travel. In a study of Bangladeshi carers, four patients had travelled to Bangladesh to die. In the carers' view this had led to a more peaceful death for them, despite the lack of medical resources.

Action

5.14 Assessment and care planning should include a prompt by the healthcare professional about the option of returning to another country to die. Having a discussion about end of life care and drawing up a care plan at an early stage within a person's illness could also help family/friends living abroad to have sufficient time to make arrangements to travel to England to visit the individual or for the person to return to their country of origin.

Issue

5.15 Information is also key to ensuring equity of access to end of life care. The consultation revealed a widespread lack of knowledge across all races about the services provided by health and social care. Formal statistical collection by care homes, hospices, extra care housing, etc, about the ethnicities of residents would be a useful way of monitoring whether uptake to these services increases over time.

Action

5.16 Primary Care Trusts (PCTs) and Local Authorities (LAs) should make information widely available. In addition, to assist with service planning and design, care homes, hospices, extra care housing, etc, should consider collecting information about a resident's ethnicity, religion, language and culture to ensure that they are able to meet the needs of people from BME communities. Appropriate consents to record, store and share this information must be obtained and compliance with the Data Protection Act

1998 (and NHS code of practice 2003) ensured. Residents will need to be given clear instruction about why the information is being collected, how it will be stored, how it can be accessed and who it will be shared with.

Religion and belief

Issue

5.17 This consultation has demonstrated that there is potential for discrimination if assumptions are made about whether or not someone has a religion or belief, and also if assumptions are made about all people of a particular religion. Clear messages came out of a number of focus groups and the faith communities workshop that assumptions can lead to unfair treatment and people being stereotyped. It will be important for healthcare professionals to have a basic knowledge of the differences between different religions and to be aware of the limits to their knowledge.

Action

5.18 Spiritual care should be coordinated across the care pathway and those caring for the dying and bereaved should have a reasonable knowledge of various faiths and practices.

Issue

5.19 It is clear that different races will have different languages, cultures and religious practices. As previously discussed, few BME people use care homes or hospices and some of the reasons for this were explored above. Religious practice is an area where discrimination could occur, even if this is indirect. Consultees suggested that one of the reasons could be that it is felt that these two settings are unable to meet their needs. This is backed up by the findings of one of the studies looked at as part of the literature review where only Christian chaplains visited the patients taking part in the study and no other faith leaders made visits. In another study, the fact that there was a cross on the wall made the room inaccessible for prayer by a Muslim carer.

Action

5.20 PCTs and LAs should ensure that there is space and time for religious practices to be carried out by both the individual and their visitors, family or carers regardless of the setting. This could be as simple as reminding professionals that areas designated for prayer need to have neutral furnishing and décor to enable individuals of any faith to be able to use the facility.

Issue

5.21 Respect and forethought needs to be given to whether certain medical practices are acceptable to certain religions. This Equality Impact Assessment revealed at least one example of a Muslim patient being given an injection just before he died. The patient's carer said that injections are forbidden within her Muslim faith and she cited this as an example of dissatisfaction with the end of life care given to her husband.

Action

5.22 Assumptions should not be made about the treatment or care in individual may wish to receive. Healthcare professionals should seek individuals' views about whether any aspect of their religion would make certain medical practices inappropriate.

Sexual orientation and gender identity**Issue**

5.23 Ensuring that inequality or discrimination does not happen in end of life care is not just as simple as treating everyone equal. Both the literature and consultation have confirmed the need for people's differences to be recognised and actively addressed, including LGBT people. This will mean that healthcare professionals should be careful not to make assumptions that people are heterosexual and if an individual reveals they are lesbian or gay, stereotypical assumptions should not be made about what type of person they are. The language that healthcare professionals use should be selected carefully so as not to inadvertently make someone feel that they have to reveal their sexual orientation or transgender identity. Words such as 'important people in your life' should be used instead of 'spouse', 'next of kin' or 'family' and LGBT people should be given the opportunity to say who they would like to be involved in planning their care.

Actions

- 5.24 Care homes, hospices and extra care housing should be encouraged to positively market themselves as being gay friendly places so that positive messages are given out and also that LGBT people feel that they will be welcomed into these environments. This could include the production of welcome packs which contain contact details of local lesbian and gay organisations. Staff need to be trained to understand LGBT issues and policies should be developed to require staff to report any incidences of discrimination by staff or other residents.
- 5.25 Given that the consultation found LGBT people to be the most at risk of discrimination of all the groups considered within this Equality Impact Assessment, it should be a requirement, as part of continuing professional development, that staff attend relevant courses on LGBT issues, equality and diversity and keep themselves up to date on current equality legislation.
- 5.26 Healthcare providers also need to have in place a clear policy on confidentiality. This should contain details about how a situation should be handled if an individual decides to 'come out', for example finding out whether the person is happy for the information to be included in their care plan and whether or not they are comfortable with other people knowing they are 'out' and having access to the care plan.

Homeless people

Issue

- 5.27 Whilst some homeless people will want their families to know they are dying, others may not. Many homeless people will have lost contact with family or even made a choice to remain estranged. This means that for many, it will be important to have advocates (which could be staff from charities and organisations such as St Mungo's) to help in the care planning process. The fact that some homeless people may not wish for their family to know they are homeless strengthens the necessity for healthcare professionals to ask the individual if there is anyone else they would like to be involved in their care and to refrain from making assumptions about the individual's relationship with family members.

5.28 The consultation highlighted problems that currently exist when homeless people are discharged from a hospital into hostel care and no notification is given that they are approaching end of life. Part of the reason for this could simply be that healthcare providers lack the understanding of the complex end of life needs of homeless people. For example, it will be important for hospital discharge teams to understand the history of the homeless person (for example that because of their background they are unlikely to be able to take regular medicine and they are unlikely to attend follow up appointments unless they are assisted with transport) and to work with organisations supporting homeless people to plan the discharge and produce an appropriate care plan.

Action

5.29 The care planning process should help to ensure that hospital discharge teams identify when a homeless person might be at the end of their life and work with other organisations to put in place an appropriate package of care.

5.30 PCTs and LAs may wish to take note of the Canadian study into the benefits of shelter-based palliative care. The homeless people taking part in this study were able to remain in the familiar surroundings of their shelter, and received palliative care from registered nurses employed by the programme. The study found that shelter-based palliative care was cost effective. Further work may be needed in the UK to ascertain whether the same benefits (both for the residents and in respect of cost savings) could be realised here.

Carers

Issue

5.31 Participants taking part in our consultation commented that there can be guilt and embarrassment associated with having to ask for help and suggested that regular support should be provided, which can be turned down if not needed. It is easier to turn down an offer of help than it is to ask for it. Breaks from care should also be considered as a means to support people to continue living at home and to support carers to enable this to happen and in fact Nikki Rousseau et al²⁵ refers to a study which found that a support unit incorporating residential respite and day care did prolong life at home and could be considered cost effective.

²⁵Rousseau N., Smith M., Corner L. (1996) *Evidence based purchasing – continuing care*. Centre for Health Services Research

Action

5.32 The service should recognise the vital role carers play in enabling someone to die in the place of their choice and acknowledge that they are central to the caring team. Carers have a right to an assessment of their own needs and systems should be in place to ensure that in addition to supporting carers in a planned way, they are also able to provide support to carers who, because of a crisis or emergency, are temporarily unable to care.

Issue

5.33 A number of groups indicated that it would make the death of a loved one easier for them to experience if visiting hours (in hospitals, care homes and hospices) could be more flexible.

Action

5.34 Visiting times for patients at the end of their lives should be flexible where possible and dedicated family rooms for relatives and friends to sleep the night when a loved one is very close to death should be made available.

6) Monitoring

6.1 NHS and social care bodies will wish to ensure that when implementing this strategy they bear in mind their responsibilities towards ensuring that end of life care is available equitably, and with due regard to the differing needs and wishes of different members of society. To this end they will wish to put in place suitable ways of monitoring end of life care to provide assurance.

7) Publication of the Equality Impact Assessment

7.1 This Equality Impact Assessment is being published alongside the End of Life Care Strategy.

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CONSULTATION LIST

MAY – JULY 2007

Help the Aged user group

Stonewall written consultation response

Social Action for Health written consultation response

Alzheimer's Society user groups

Terence Higgins Trust written consultation response

The Dene, secure hospital

National Council for Palliative Care carers workshop

S.A. Albin, Funeral Director

Faith Communities workshop

Positively Women focus group

Norwich Prison

British Lung Foundation

Princess Royal Trust for Carers workshop

Polari focus group

National Council for Palliative Care written consultation response

St Christopher's Hospice written consultation response

Motor Neurone Disease Association written consultation response

Chinese Mental Health Association focus group

Royal National Institute of Blind People telephone conversation

The National Network for Palliative Care of People with Learning Disabilities

St Mungo's

Multiple Sclerosis Society written consultation response

Christian Scientists written consultation response

Confederation of Indian Organisations, report of five focus group meetings.

Questionnaire responses from transgender/transsexual people

Telephone interviews with two bereaved people from Cruse Bereavement Care

National Centre for Independent Living



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