



The
British
Psychological
Society

The Role of Psychology in End of Life Care

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British Psychological Society*

Acknowledgements

This document began as part of a deeply held personal belief that Psychologists have a great deal to offer, both to patients who are coming to the end of their lives, and also the relatives and carers who are involved in looking after them. It also derives from an equally deeply held belief that there are too few Psychologists working in the field of specialist palliative care, and other health domains within which people live through the experience of life limiting disease.

This latter belief was borne out when, in late 2004, I was approached to act as a representative for the British Psychological Society on the Select Committee for Lord Joffe's Assisted Dying Bill. It soon became clear that the Society did not have a collective opinion on this important social, medical and psychological issue, and I attended the Select Committee, accompanied by my colleague Elaine McWilliams, as an Expert Witness. Fortunately at the time I was offered support from Ana Padilla, the Society's Parliamentary Officer and the then Chair of the DCP, Professor Peter Kinderman, and this proved invaluable.

Following this I approached the Society with regard to supporting the development of a Working Party to produce a document which demonstrated both the importance of the psychological literature in this field, and also the role of clinical and academic psychologists in promoting dissemination of this literature and also developing excellent evidence based practice.

Fortunately the Society was willing to do this, and in early 2006 the Working Party met for the first time. My gratitude to my colleagues for enabling the production of this document is immense. It has been my great fortune to work with a group of challenging, supportive and ultimately deeply committed individuals, from whom I have learned a great deal, and I thank each of them equally for their contribution.

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I also want to acknowledge the invaluable help that the Society has offered the Working Party in the guise of Nigel Atter. He has provided me personally with a gentle, clear and constructive steer through the process of working with the Society, about which I was a complete novice.

Yours sincerely,

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Executive Summary

1. This Report aims to inform readers of the key issues in end of life care and highlights the role of psychologists within the settings where it takes place. The document is organised around three key domains: Contemporary Issues; Information about Legislation and Policy Issues; Clinical Practice.
2. Contemporary issues include an exploration of the difficulties encountered with minority and disadvantaged groups including people from different cultures and groups who are not traditionally perceived as being valued in society, such as older people, (particularly those with dementia), and people with learning disabilities.
3. Legislation and Policy Issues covers current key legislation that informs not only health and social care professionals but also the general public. The Mental Capacity Act has significant implications for end of life care planning, including drafting Advance Refusals and nominating someone to hold Lasting Power of Attorney should a person be in a situation where he/she is deemed to lack capacity. It also examines the arguments surrounding Euthanasia and Physician Assisted Suicide.
4. The section on Clinical Practice exemplifies the need for clinical psychologists to work as key members of the multi-disciplinary team in end of life care, both within hospice and hospital settings as well as supporting patients, their families and staff in community teams. Working effectively within the community to provide good end of life care will become even more important as the current 'choice agenda' is to prevent emergency admissions to hospital in the final hours of life, and enable more deaths to occur at home with good community primary and specialist care as necessary.
5. It is also important to be aware that in addition to widening choice and access to services there is an equal (and potentially opposite) force to drive down the costs of end of life care, particularly in relation to hospital admission. While reduced hospital admissions in particular may appear to be desirable on a superficial level, it is also the case that there can be very real oncological and other medical 'emergencies' that necessitate good medical care that should properly take place in hospital, and primary care teams need to know when these occur, and how to get the patients needs met.
6. There is also a danger that the voluntary sector, especially hospices, are increasingly disenfranchised from end of life care as the move to more community-based services becomes more prominent. This is neither necessary nor desirable, and both community and specialist services need to continue to liaise closely to continue to provide the best and most comprehensive service to a vulnerable population whose needs are liable to change rapidly.
7. The needs of bereaved people are also highlighted, as they are a group whose mental and physical health is potentially compromised both as the result of long term caring and also of the process of bereavement itself. It is important to offer risk assessment and appropriate intervention as necessary.
8. It is also vital to understand that working with individuals who are coming to the end of their lives, and their families, is inherently emotionally and psychologically demanding on staff. The section on Working in Teams, highlights the importance of recognising signs of stress and burnout, both within ourselves and our colleagues, and promotes good self care.
9. Finally, a Glossary at the end of the document helps those readers not familiar with end of life and palliative care better understand the specific terms used throughout the Report.

Introduction

This document is intended to provide a framework for psychologists who are working with adults who are coming to the end of their lives, their family and others who are involved in the process of care at the end of life. This work may also include offering assessment and intervention to those who are bereaved. The settings within which psychologists work include: specialist palliative care, oncology older persons services, services for people with learning difficulties and other health and social care settings in which end of life issues are faced on a regular basis.

The use of specialist palliative care services is based on an assumption that people share a common understanding of the terminology and purpose of palliative care but most of the evidence indicates that definitions and terminology are poorly understood and not agreed. Terminology relating to end-of-life care has undergone a number of transitions from hospice care and terminal care in the early period of the hospice movement (1960s and 1970s) to palliative care towards the turn of the last century (1980–2000), and since 2000 the term end of life care is increasingly used.

Definitions

The World Health Organisation (WHO) (Sepulveda et al., 2002, p.94) states that:

‘Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’

The WHO goes on to outline the principles as follows:

Palliative Care seeks to:

- Affirm life and regard dying as a normal process;
- Neither hasten nor postpone death;
- Provide relief from pain and other distressing symptoms;
- Integrate the psychological and spiritual aspects of patient care;
- Offer a support system to help patients live as actively as possible until death;
- Offer a support system to help the family cope during the patient’s illness and in their own bereavement;
- Use a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, e.g. chemotherapy and radiotherapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The National Council for Hospices and Specialist Palliative Care Services (2002, p.2) differentiate between:

- *General palliative care* which ‘is provided by the usual professional carers of the patient and family with low to moderate complexity of palliative care need’; and
- *Specialist palliative care services* which ‘are provided for patients and their families with moderate to high complexity of palliative care need. They are defined in terms of their core service components, their functions and the composition of the multi-professional teams that are required to deliver them.’

Over recent years there has been a significant increase in the number of psychologists working in physical health settings, and as a consequence many clinicians are faced with questions from clients, families and colleagues, about the psychological impact of various end-of-life issues. The purpose of this document is to aid psychologists in their understanding and management of these issues.

It is well recognised that clinical depression and/or anxiety are significant features of the disease trajectory for many people diagnosed with life-limiting disease, whether this is cancer or other, more chronic disease states, such as Motor Neurone Disease (MND), Coronary Heart Disease (CHD), or Dementia (which while not life-limiting in itself, is irreversible, and has significant psychological and social impact on individuals and families). It is important to recognise that their carers are also similarly at risk of developing psychological difficulties both in the time they are caring for the ill person, and also in their bereavement (Department of Health, 2000; NICE, 2004; Department of Health, 2005).

Psychologists need to be mindful of potential difficulties in bereavement outcome for surviving relatives and or carers if the health care professionals do not address physical and psychological manifestations of distress prior to the death. Many clinicians can be asked 'difficult' questions that relate to the management of suffering at the end of life, including complex and often frightening symptoms, such as anorexia and breathlessness. There are also issues such as changes in body image, loss of dignity, and requests for assistance to die as a means of stopping the suffering. It is important that these questions are answered sensitively and honestly while bearing in mind the capability of the individual and/or family to understand and manage the information that they are asking for. Psychologists are well placed to help not only the patient and family understand what is happening, but also to support other members of the multi-professional team in their endeavour to manage the often complex situation with which they are involved. It is of equal importance to make clear to clients and others who ask for assistance to die that at the time of writing this document euthanasia, whether passive or active, and Assisted Suicide are illegal in the United Kingdom. This includes the inappropriate administration of medications that might hasten death. For further information on current guidance on end of life care in the UK, the reader is directed to the Weblinks section in this document.

To summarise, the following principles (adapted from Seymour, 2004, p.57) can be seen as underpinning the approach that clinicians, including psychologists, working in end of life care need to take, and it is these principles that this document will endeavour to exemplify.

- Knowing the patient, and offering a holistic approach to care.
- Working together as an effective and efficient multi-disciplinary team.
- Making sure that the clients' *dignity* and *comfort* are paramount in the care that is offered.
- As far as it is possible to work from an *empathic* understanding of the situation of the client and their family.
- The multi-disciplinary team works collectively to offer *support* and '*supportive care*'.
- The multi-disciplinary team offers *hope* to the client and family, whether this relates to management of *suffering* be it physical or psychological, or to the maintenance of *quality of life* for as long as possible.

Part 1. Contemporary Issues

Disadvantaged Dying

The term 'disadvantaged dying' has been coined by Seymour et al. (2005) to apply to groups of people whose physical, social and spiritual care in the latter parts of their lives are at risk of being undermined or neglected because of societal attitude, ignorance or prejudice. In the UK, the people at particular risk of disadvantaged dying include those with learning disabilities, dementia and, most commonly, older people. Members of Black and Minority Ethnic (BME) communities, and lesbian, gay, bisexual or transsexual people may also be at greater risk. However, our modern attitudes to death – as a clinical phenomenon from which we are largely separated – can place any dying person in a situation where their personal needs are overlooked.

The benefits of living in a prosperous nation in the 21st century means that the vast majority of us can spend most of our lives without having to consider our own mortality. Infant mortality is the lowest in our history, we expect to survive childhood, thrive in adolescence, and remain active and healthy throughout adult life and well into retirement. If we do become unwell, we expect there will be treatments available. Only occasionally do life events jolt us into thinking about our own deaths, and about how and when we might die.

This is a complex issue influenced by physical, family, social and historical beliefs and experiences. For example, a young man in the 21st century, with no particular health problems, may believe with superstitious conviction that he will die at the same age that his father did if his father died young. One hundred years ago a person living in Britain in a low socio-economic group might not expect to live beyond the age of 70. In Africa today, many poor people will not expect to live beyond 40 and in countries such as The Gambia, one quarter will die before reaching their fifth birthday. In Kenya, it is common to hear the expression 'a pregnant woman has one foot in the grave'. Anyone living in an area of armed conflict may consider themselves lucky to reach middle age. The problem is that the rest of us can easily become inclined to share these beliefs. Do we not also console ourselves that the death of an older person in this country is acceptable because they had 'a good innings'? How many years is that? How do we decide when death is 'acceptable'? Of course, we all must die but it is still the case that too many people receive less care and attention than they should.

In Britain today, the most common fear expressed by older people concerning death is that they will be considered a burden by their families and hospital staff. Many fear they will end their days in a hospital ward as a 'bed-blocker', taking the resources of another deemed more worthy to receive them. To be regarded as a nuisance or in the way is hardly a fitting tribute and summary of a long life. In addition, many older people fear that if they are so regarded they will receive less care and treatment than someone younger. They may even believe that certain measures will be taken to facilitate their deaths against their wishes. There is some evidence to support this belief. Older people are often given less aggressive treatment interventions than their younger counterparts, even when there is no medical indication to do so. They are less likely to be offered newer treatments or to be recruited into drug trials that may offer alternatives to existing treatments. Of course, there may be valid medical or research reasons for such exclusion but this evidence tends to contribute to the prevailing view that to be old is to be of reduced value.

Older people with dementia are particularly disadvantaged, being less likely to receive General Practitioner support, specialist palliative care, and access to hospice services than people with any other condition. People with other long term conditions such as chronic obstructive pulmonary (COPD), and cardiac failure are more likely to be disadvantaged than people with terminal cancer (Robinson et al., 2006). Hospices have expertise in providing palliative care and supporting dying people in in-patient, daycare and community settings, but almost exclusively work with people with cancer. In 2005, the Office for National Statistics reported that 95 per cent of people in palliative care units (around 29 per cent of these are NHS managed) had a diagnosis of cancer, 32 per cent were under the age of 65, while only nine per cent were over 84. On the other hand, around 100,000 older people die in care homes each year in England and Wales. While most strive to provide good quality care for their residents they often rely on

high-turnover unqualified staff, and lack the resources and facilities to provide for the dying (Frogatt, 2004). Pain relief, typically rated as the top priority by patients, is often inadequately managed for people with dementia. In part, this is due to the difficulty people with dementia have in communicating that they are in pain when language is impaired and may, due to visuo-spatial difficulties, have problems pointing accurately to the site of pain. However, it is also often due to a failure amongst care staff even to consider pain as a possible explanation for some behaviours.

All too frequently, insufficient time and attention is given to providing information and clear communication to people with dementia, leaving many feeling frightened, confused and alone. Hospital care does not fare well either; busy, noisy and mixed care wards staffed by rushed medical professionals may not have the time to provide good palliative care. Where such care is provided, this often happens at the last minute and focuses on physical care. Good palliative care is a planned, collaborative and holistic programme devised with the client with the maximum amount of time available once the terminal outcome of the condition becomes clear. It focuses on living well, and not just dying well, and takes account of the person's physical, practical, psychological, and spiritual needs. Such care is rarely available for disadvantaged groups.

Evidence from reports produced by the NCPC (Firth, 2001) indicate the under utilisation of palliative care services by black and ethnic minorities. A number of challenges have been highlighted in recent studies (Gunaratnam, 2006). Care staff often, erroneously, feel that it would be intrusive and inappropriate to offer support to patients and their families, believing they lack the cultural competency to do this well. On the contrary, representatives from minority groups stress that there are more commonalities of need for the dying person and their family than there are differences with the majority white population. Frequently, differences occur on the basis of religious practice rather than ethnicity, but this may not be understood by others. Where cultural and other practices differ, most community leaders recommend asking the individual concerned to explain their particular needs, in preference to care staff making broad, homogenous assumptions. Similarly, other needs may be understood in this way. The Alzheimer's Society, for example, formed a lesbian, gay, bisexual and transsexual carer's group a few years ago in order to promote awareness, and to provide a supportive network for people whose needs are often overlooked or misunderstood. A key to eliminating disadvantage in dying must be that staff consider, understand and respond to the multi-factorial elements that construct an individual identity, be they religious, ethnic, cultural, orientation, or cognitive.

In 2005 the charity Help the Aged published a booklet reflecting older people's perspectives on dying. Older people from a variety of backgrounds contributed their views, although a significant number declined on the basis there was too much life to be lived to think about death. A key theme was that of choice and the importance of making decisions. However, they also reflected that health and social care systems, and families do not always recognise or facilitate this right. There was a sense that younger generations tend to regard older people as an homogenous group and, therefore, feel entitled to make assumptions about what they think and feel. The evidence, if anything, suggests the contrary, that heterogeneity increases with age. These writers stressed the need to recognise the multiple world views that are represented as fully amongst older people as any other group.

Older people, along with people from other disadvantaged groups, want to have the same opportunity to discuss their treatment and care options as anyone else. They also want the same access to specialist services, including palliative care. However, the evidence suggests that few people with dementia, for example, receive the support of hospice services in the final phase of the illness. Why should this be when dementia is widely accepted as a terminal illness? One reason may be that people do not generally die *from* dementia but *with* dementia. There will usually be some other condition – pneumonia, heart failure, stroke, etc. – as the cause of death, and frequently an older person will have several concurrent conditions. Many will find themselves in a hospital ward designed to cater only for the most acute condition, for example a person on a surgical ward with a fractured hip who also has dementia and diabetes. Hard-pressed surgical staff rarely have the time or skills to meet the needs of a person who may be dis-orientated or distressed because they don't recall or understand why they are in hospital.

Another problem is that Standard 7 of the National Service Framework for Older People (Department of Health, 2001), fails to provide any guidance on end of life care for people with dementia. However, the NICE Dementia Guidelines (2006) have gone some way to correct this, providing guidance on the provision of information, treatment and care for people and the family carers. There is increasing pressure from a number of sources, including organisations such as the Alzheimer's Society, to end the scandal of 'disadvantaged dying' by providing specialist palliative care. This might be achieved either by supporting the expansion of the work of hospices, or by developing palliative care within dementia services.

Fortunately, we are also in the midst of a cohort change affecting the attitudes and expectations of older generations. A person reaching their 65th birthday in 2007 was 3-years-old when the Second World War ended and 6-years-old when the National Health Service and Welfare state were created. These events were critical in changing social attitudes and were, in part, responsible for raising expectations that the state would support them throughout a long and healthy life. In general, many older people nowadays will report that they have fared better physically and socially than their own parents. Younger older people are less likely to accept inferior treatment than their forebearers and will generally have better access to the knowledge and resources required to secure decent care. However, this will always be dependent on individual difference; not everyone will have such access or confidence to speak out for what they want. Many older people will have no one to speak for them when necessary; one of the drawbacks of a long life is that one may outlive all one's immediate family.

But even if psychological, physical and social care at the end of life have improved, what of spiritual care? Dying well for many is tied up with getting 'one's house in order' and this will include finding a way of making meaning of one's life, acknowledging mistakes, and reconciling oneself to accepting what has not been achieved. The enduring need to achieve these goals towards the end of life embarks the person on a spiritual journey, whether framed within a formal religious context or not. Each journey is different and requires another to bear witness to the search for meaning. We may all ultimately die alone, but the journey to that point requires human contact. For Erikson (1950), the closing stage of life involves the psychosocial crisis of integrity versus despair. Those able to 'die well' achieve, or are helped to achieve a sense of feeling at peace with oneself and the world – 'to be, through having been; to face not being'. He believed that the greatest achievement for a therapist working with older or dying people can be to help someone shift from a state of despair to one of integrity. Psychologists can play an important role, also, in alerting other care providers to the full range of needs of people who are dying and who lack the means or opportunity to express these needs for themselves. Such interventions may then help the person not to fear death but to embrace a life well lived.

For further reading, a paper produced by the charity, Help the Hospices is recommended; *Widening Access* (Gunaratnam, 2006). The charity's website also gives details of their Care Beyond Cancer programme, that was launched in 2004. In addition to advocating extending the role of hospices by widening access to people from currently disadvantaged groups, and for a wide range of conditions not traditionally seen in hospice services, they provide useful contact details of other specific organisations committed to these aims.

Treatment and Care

Treatment and care always takes place within the context of place. People die in a wide number of different settings. Sometimes there is no choice of where they are cared for and where they die, but often there is. This choice may be exercised but for others the choice, for a variety of reasons, may not become realised.

Current research suggests that most healthy people would choose to die at home (56 per cent) followed by hospice (24 per cent). Only 11 per cent wanted to die in hospital and four per cent in nursing homes. These figures do not take into account differences caused by age, gender and culture. However, there is a stark contrast between where people would choose to die and where they actually die. Most people still die in hospital. Increasing numbers of older people die in nursing homes which is, in effect, their own home at the time of death (Higginson, 2002).

Although many people have a clear idea of where they might wish to be cared for in their dying, this decision frequently changes as care needs increase and death becomes closer. Difficulties may arise for the carers; the patient might begin to feel the need for the security of a medical setting; sometimes patients' simply adapt to where they are being cared for; and sometimes unforeseen emergencies arise for which carers may feel unprepared. The fluctuations in need can be difficult for the patient, family and professionals to manage. However, being aware of the patient's preferences puts professionals and families in a better place to make such decisions. Palliative care does not only take place in 'specialist palliative care' settings such as hospices, and difficult decisions around treatment and care may arise in any setting.

The decision to stop or limit curative medical treatment is not always clear and may present difficulties for the patient's family and for health professionals. Frequently patients and families, understandably, cling to hope of cure, remission or just keeping decline at bay. However, when medical treatment is no longer serving a purpose it may need to be withdrawn, but withdrawing treatment need not equate to withdrawing hope. One of the difficulties of withdrawing or withholding treatment, because it is deemed futile, is that the term futility itself is loaded with value judgements. What might appear futile to a health practitioner may not seem so to the patient, a relative, or indeed to another health care practitioner. Making decisions about what is in the patient's best interest requires careful consideration and negotiation. In all cases, supportive treatment and nursing care will still be provided for the dying patient.

Medical treatment that might maintain the status quo or offer temporary improvement until the family arrive might confer psychological and social benefit to the family even though medically it might be described as futile. For example, continuing to maintain a life for a few further hours or days to enable an estranged relative to arrive might confer considerable benefit to the patient and/or the family.

Legally physicians are not required to provide treatment they regard as futile and they may, in some situations, choose not to discuss this with the patient or family. However, deciding whether or not to discuss the treatment options remains problematic and is often couched in terms of best interests. This may be justified on all sorts of grounds but there is also a danger of professionals protecting themselves from psychological distress or in some circumstances of practicing therapeutic nihilism, especially in the care of older people.

In addition there is also a danger that withholding treatment may be confused with euthanasia or physician assisted suicide (see section on euthanasia for definitions). It is important that such distinctions are clearly explained to those involved. The former suggests intent to deliberately end the life of a patient whereas the latter is a decision to withhold treatment based on clinical efficacy.

It might be assumed that within palliative care the problem of discontinuing treatment no longer exists. However, there is evidence that a variety of treatments do continue within palliative care. For example palliative radiation for an incurable metastatic disease, that improves the patient's bone pain, would not be regarded as futile even though it would not increase the person's life span and may in some cases reduce it. However, a further round of chemotherapy for a patient whose condition is incurable might seem futile to the physician; but what if the patient and family seek a continuation of treatment? For some patients the discontinuation of treatment is a signal for them to stop living, a turning to the wall as a form of passive suicide. It may also be the physician who might cling to tenuous hopes and attempt to persuade a family to continue treatment when in reality the patient is ready to relinquish further treatment.

Whatever the challenges, poor decision making around issues of treatment and care can leave families feeling disenfranchised and stressed, with the potential for longer term difficulties in bereavement. Helping professionals, patients and families arrive at a shared understanding of the circumstances can help them come to some degree of acceptance and recognise that no further treatment is very different from no further care. It is often at the point where treatment is discontinued that patients and families may seek psychological support and where so much work can be done in helping families begin to tell and explore their own stories; their hopes and their fears. Abiding in this liminal space can be challenging and the psychologist is often in a good place to help the patient, family and staff, stay with uncertainty.

At a time when patients and carers may already feel powerless, not being involved in the decision making process, only serves to compound these feelings. It is important, therefore, that wherever possible there is an open discussion with patients and families. Different perceptions in goals, benefits and harms can be explored, and where possible resolved, or at the very least difficult decisions better understood. Clearly this may be of particular importance where culture, religion and differing value positions are evident. Patients and families often expect 'miracles' to happen and these should not be dismissed as irrelevant. Rather, the health care professionals need to listen and try to understand the reasons for this, which often relate to hope and a desire to find some meaning in what is happening to them.

Part 2. Information about Legislation and Policy Issues

Advance Care Planning

Advance Care Planning (ACP) is an opportunity for patients to consider and discuss a wide range of issues that will help plan for their end-of-life care. The intention is to prepare for end-of-life care in a way that will give health professionals the best opportunity to provide for what the patient wants at a time when they may not be in a position to make those decisions for themselves. An ACP discussion (NHS, 2007) might include:

- the individual's concerns;
- their important values or personal goals of care;
- their understanding about their illness and prognosis;
- their preferences for types of care or treatment that may be beneficial in the future, and the availability of these.

Emergent issues might include preferred place of care, advance refusals and funeral plans. Whilst there is evidence that many people would welcome such a discussion there needs to be sensitivity around timing and permission. Essentially patients need to be given the opportunity to explore ACP but it must be patient led. Consideration should be given to who should conduct the discussion, and to ethnic and cultural differences (Barnes et al., 2007). The discussion should not necessarily be seen as a one off event but a series of discussions with multi-disciplinary team members allowing the patient's wishes to emerge and evolve. The psychologist plays a vital role in this particularly where patients might be struggling to find a voice for the situation in which they find themselves.

The process of ACP usually takes place in the context of an anticipated deterioration in the individual's condition but clearly the process may start earlier. Small beginnings can be very empowering, giving the patient and family permission to talk about their concerns and wishes and may act as a catalyst for constructive dialogue between the patient and carers as the situation changes. An ACP not only provides valuable information for patient choice, once they have lost capacity, but is very helpful in keeping an open dialogue with the patient and family throughout their care.

The issue of Advance Refusals and the Mental Capacity Act (2005) are dealt with elsewhere in the document but an equally important part of ACP is the patient's statement of wishes and preferences. This can provide invaluable information to help guide practitioners in giving the best possible care. A statement of wishes and preferences might include:

- A statement that reflects the patient's individual aspirations and preferences that would help practitioners understand better how the patient would wish to be cared for. This might include sleeping patterns or food preferences or types of music they like.
- A statement that reflects their beliefs and values and provides a biographical portrait. This will help carers see the person rather than the patient and help provide care that is in their best interest.

Such statements might also include the patient's views about treatments they would not wish to receive. Whilst this form of statement is not legally binding in the same way as Advance Refusals they do provide invaluable information when assessing a patient's best interests.

Advance Care Planning is an ongoing process and with the patient's permission all discussions should be documented, regularly reviewed, and communicated to key persons involved in their care.

Case example

Mrs P

Mrs P was a retired teacher of 68. She had been diagnosed with lung cancer 18 months previously, and when she was referred to the palliative care service she had some cognitive difficulties because the disease had spread to her brain. At the time of her admission to the hospice Mrs P clearly had fluctuating capacity, although at certain times of day she appeared to be fully aware of what was happening to her, and able to co-operate with her symptom management. However, following careful assessment it was felt that Mrs P had capacity to make decisions provided she was given sufficient time to consider issues and they were explained carefully. Mrs P's husband was her main carer and advocate. When discussing her preferences it became clear that Mrs P did not want to be given any further active treatment, and she wanted to be cared for and to die at the hospice. She named her husband as the person who would have Enduring Power of Attorney should she become incapacitated and between them they managed to consider some of the funeral arrangements.

Mrs P gradually deteriorated and she lost capacity to make any decisions for herself, leaving the decision making process to be negotiated between her husband and the team caring for her. The staff found this difficult to cope with at times because they felt that his 'demands' on behalf of his wife were unreasonable and interfered with their need to help manage some of her more (apparently) distressing symptoms of breathlessness and agitation.

In the event Mr P was incorporated as part of the 'team' caring for his wife, and he was encouraged to continue to advocate for his wife's needs as he believed they would be if she were able to advocate for herself, while at the same time he began to understand that many of the interventions the team were making were not life-sustaining and 'futile', neither were they aimed at hastening her death, rather they were aimed at helping her feel more comfortable and peaceful through her dying. Mrs P died after three weeks in the hospice, and her husband received minimal bereavement support during the first few months of his bereavement.

Mental Capacity Act (2005)

The Mental Capacity Act creates new legislation about the way in which decisions are made on behalf of people aged 16 and over and who lack the capacity to make those decisions for themselves. The Act became law on 1st April 2007.

The five Key Underlying Principles

1. A presumption of capacity: Every person has a right to make decisions and it must be presumed they have capacity unless it is established otherwise.
2. Individuals should be supported where possible so that they can make their own decisions: Until all efforts have been made to help a person make a decision for themselves they must not be seen as unable to make a decision.
3. People have a right to make decisions whether or not these decisions may seem eccentric or unwise to other people: and they should not be judged merely because their decision appears unwise to others.
4. Best interests: Any decision made on behalf of another individual who lacks capacity must be done in their best interests.
5. A person's rights and freedoms must be restricted as little as possible: Before carrying out any act or decision on behalf of someone who lacks capacity, regard to how that can be achieved in a way that is least restrictive to their rights and freedoms must be considered.

Some of the issues that emerge from this Act include: advance decisions to refuse treatment; lasting powers of attorney; and research in relation to people who lack capacity. Each of these will need careful consideration by individuals and organisations. However, it is likely that best practice today will meet many of the requirements.

Capacity

Capacity can be assessed based on the person's ability to understand information given to them (this should include all possible steps to assist in this understanding) and the implications of this information for their future. Capacity should be assessed on a 'case by case' basis and it should not be assumed that lack of capacity in one area can be generalised to others.

A person should be able to demonstrate consistency over a period of time in their decision making (even if they need reminding of the decision to be made). As long as their decision is consistent, regardless of the need to prompt or remind them of the necessary information leading to the decision this should be considered to demonstrate capacity.

People with learning disabilities or other cognitive disabilities or difficulties (e.g., people with dementia or neurological damage due to trauma or tumour) should not be assumed to lack capacity. If the person can understand the information given to them and the implications of this information, retain this information and its implications for a sufficient amount of time for them to make a decision (regardless of whether or not we view their decision as unwise or whether they require prompts or reminders) they should be considered to have capacity.

Case examples

Mr B

Mr B was diagnosed with dementia multi-infarct and later with early stage lung cancer. His cancer had an unusually high chance of cure, but, he wished to discontinue his chemotherapy. He was asked if he understood the implications of this decision and gave a clear indication that he did so. However, when asked again he could not remember having made the decision. When reminded of the information and decision to be made he again gave the same decision. He did this again on two further occasions with complete consistency. Assessment for differential diagnosis (clinical neuropsychological assessment) of dementia and depression did not indicate any significant levels of depression. He made it clear on each occasion that he was basing his decision on quality of life considerations. In this case it should be deemed that Mr B has capacity despite his memory difficulties and chemotherapy could be discontinued.

Mrs C

Mrs C was diagnosed as having a neuroblastoma and had increasing cognitive difficulties to such an extent that she no longer understood the consequences of her own behaviour or had control over much of her behaviour. For example, she would become violent with others and put herself in significantly 'at risk' situations but did not appear to have insight into this behaviour or its consequences for herself or others. Clinical neuropsychological assessment demonstrated that Mrs C had severe impairment in her ability to inhibit her behaviour, to plan and execute simple tasks (e.g. making a cup of tea safely) or to solve simple problems. These results strongly suggest 'dysexecutive syndrome'. However, Mrs C was able to make decisions about her social and health care needs with support and was able to give consent to being accommodated in a local care home. She was not, however, able to understand that she was a potential danger to others and in this sphere could not be said to have capacity. This case demonstrates that individuals may demonstrate capacity in one domain but not in another.

In short, people with severe cognitive impairments or disabilities can still make important decisions about their treatment and demonstrate capacity to do so.

Check List

- Can the person understand the information they are being given (with or without appropriate support)?
- Can the person understand the implications of the information they are being given?
- Can the person understand they have a choice to make?

- Can the person retain the information for a sufficient amount of time to make a decision (whether or not they can retain this information over the long-term)?
- Is the person consistent in their decision over a period of time (this may be a brief or extended period of time) regardless of needing prompts or reminders of the salient points involved in making their decision?

If the answer is yes to all of the above then capacity can be assumed.

Voluntary Euthanasia and Physician Assisted Suicide

What is euthanasia and assisted suicide?

Euthanasia is the intentional bringing about of a person's death, by killing them (*active euthanasia*) or letting them die (*passive euthanasia*) and is done so in the person's best interest. Active euthanasia is brought about by an act, for example administration of a lethal drug. Passive euthanasia is brought about by an *omission* usually by withholding or withdrawing treatment.

- Withdrawing treatment: such as switching off a ventilator that is sustaining life.
- Withholding treatment: not starting some treatment that might extend a life for a short period of time.

It has been argued that what is commonly referred to as the 'doctrine of double effect' (see Glossary) is euthanasia by the back door. However, the important distinction here is one of intention in that any prescribed medication is aimed at the symptoms and any unwanted side effect (in this case a hastened death) is not intended.

A further important distinction is between *voluntary euthanasia* where a person requests the termination of their life and *non-voluntary euthanasia* where the person is not in a position to make such a request, for example an infant, someone who is unconscious, or someone with profound learning disability.

Involuntary euthanasia is the killing of someone who wants to live but is killed anyway and this usually amounts to murder or manslaughter.

Although the intentional taking of someone else's life or assisting in the taking of another person's life currently remains illegal, many people are confused by the law, and patients or their families do, from time to time request that a practitioner assists them in ending their life. This is not the place to discuss the moral and ethical issues of ending life but to understand some of the background and terminology thus enabling appropriate discussion with patients. In broad terms those who argue in favour of euthanasia suggest that in a civilised society people should not have to endure pain and suffering and should be allowed to have a say in what happens to their body and their life. As such they should be able to lawfully end their life or be assisted to do so if they are unable to manage it on their own. Those who argue against it often have religious reasons for doing so or fear that if it were legalised it would be abused; the 'slippery slope' argument. Others may have no moral objection to euthanasia but find the law inadequate in legislating for such a complex moral scenario.

The current debate in the UK focuses on whether, in some circumstances, a person should be assisted to end their life (*assisted suicide*). The arguments for and against are well documented by the two main protagonists 'Dignity in Dying' formerly 'The Voluntary Euthanasia Society' who believe in greater patient choice at the end of life and argue that this provides choice and dignity in dying, and 'Care not Killing' who call for the government to reject assisted dying and instead move to better palliative care for all.

Unbearable pain is often cited as the main reason for requesting euthanasia but research on patients and families concerns at the end of life indicate that it is much broader than physical pain. Physical conditions such as incontinence, paralysis, breathlessness that impact on quality of life were cited, but psychological factors including depression, exhaustion, loss of control and dignity, loss of hope and feeling a burden were particularly evident (Hickman, Tilden & Tolle, 2004; Sullivan, Hedberg & Fleming, 2000). Psychologists may find themselves in a position in which clients or families have a need to explore their thoughts and feelings about the ending of life with someone who can listen non-judgementally regardless of the present legal position.

Part 3. Clinical Practice

Psychologists in Palliative Care

In specialist palliative care contexts, the generic skills of the psychologist are applied in a setting where a person has either been given a terminal diagnosis, is a relative or close friend of such a person or has been bereaved as a result of the death of such a person. The ethos of palliative care is that of holistic care, thus palliative care professionals believe working within a Multi-disciplinary Team (MDT) is the right model for management and care of patients. At present psychologists are not 'core' members of this 'team' (National Institute for Clinical Excellence, 2004) though it is widely acknowledged that their membership adds value to patient care and psychological understanding generally within the team.

The following section outlines some important issues around death itself and how an individual, their family and friends may respond and how psychology may play an important role intervening where appropriate.

Finding a way of making meaning in death?

The only universal fact in life is that we will all die. Although we know it, it is not necessarily acknowledged and when it is, it may sometimes result in an existential crisis (e.g. 'what was the point of my life?'). But there comes a time for all of us when death becomes a reality and for some there becomes an awareness of a dying status. The ways in which an individual develops a personal meaning of life and death will include emotion, reason, social and experiential aspects. Thus psychologists are particularly well placed to understand the individual experience of dying and death and to support the individual, the family and others in this and the resultant grief which follows. This may include working with children which requires specialist skills.

Grief itself can begin almost as soon as a terminal diagnosis or impending death has been realised. Such grief is experienced not only by those who are close to the individual who is dying, but also to the dying person, who is, after all, suffering that ultimate loss – that of their life and perhaps their sense of self-hood and agency within the world. For some individuals and their families and friends this realisation and resultant grief will be complicated by life circumstances and past experiences possibly making the pain of death and separation even more complicated. Psychologists with expertise in pre- and post bereavement therapy can play an important role in supporting individuals, family members and friends during the dying phase and in bereavement.

It is often said that the hope of a life well lived is something we all aspire to and can bring some comfort to us when death is near (this may or may not include spiritual and/or religious beliefs). However, it is likely to include one's life's work and our relationships with others. Thus psychologists have a potentially central role in palliative care as they are trained to help others explore and make sense of their hopes, aspirations, achievements, disappointments and relationships. More specifically they can provide expert intervention where needed (e.g. individual, couple or family work). However, they will have to be open-minded and sensitive to all kinds of interpretations people make about their lives and to none at all. Psychologists must also be aware as Johnson (2002) points out that many people experience 'Biographical Pain' at the end of their lives, which is borne as a result of the dying person recognising that there are some previous 'wrongs which cannot be righted'.

The notion of 'total pain' which is commonly referred to in specialist palliative care is central here. The terms 'total pain' and 'spiritual pain' are also often used. This type of pain is not simply about a physical state, as psychologists working in pain management will be well aware of, it is about much more. A good psychological evidence base is available regarding the psychological management of pain which includes a range of interventions, which can be employed with appropriate modification to palliative care settings (see Melzack & Wall, 2003). Pain itself is known to consist of, physical, emotional, spiritual and cognitive components, but these are not simply the sum of their parts. Thus each individual experiences pain differently and can even experience the same type of pain differently at different times. Psychologists, with their training in pain management and more generalist training in human development and change across the lifespan, are well placed to help people make sense of this complexity and to support other

professionals in developing an awareness of these issues. It is recommended that psychologists working or planning to work in specialist palliative care undertake additional reading and/or training in pain management theory and techniques under supervision.

The above has focussed specifically at making meaning and understanding of 'total pain' in some detail. The following list offers some further examples of 'psychological' practice in end-of-life care:

- Complex grief reactions, such as prolonged grieving;
- Support for families;
- Adjustment difficulties such as coping with a changed body image; changes in cognitive function; loss of role within the family;
- Dependency issues, such as fear of leaving the hospice/hospital, etc.;
- Anxiety and depression as a result of diagnosis/prognosis;
- Relationship and communication difficulties;
- Pain management;
- General symptom management where there is a strong psychological component (e.g. phobias);
- Anxiety management interventions;
- Psychological distress assessment /screening.

Bereavement and Grief

Because of the more specialist nature of bereavement work, the following section will look more closely at bereavement and grief. There are significant individual differences in reactions to bereavement, and in recent years there has been a move away from labelling grief as either 'normal' or 'abnormal' and thus this document will refer to grief as being either 'complicated' or 'uncomplicated'. Archer (1999) has provided a comprehensive review of the literature from an attachment theory and evolutionary perspective which provides a good starting point for psychologists new to this area. Archer argues that grief is not an illness or a disorder but a natural reaction to losses of many kinds.

It is, therefore, important to be aware that the vast majority of bereaved people are likely, while remaining sad about their loss, to incorporate the reality of the loss into their everyday life, and make a perfectly normal adjustment to the fact of the death and the need to make changes in their lives. Nevertheless, those who are finding it difficult to adjust to a death may have these difficulties overlooked or misinterpreted as something other than grief (e.g. depression, anxiety or concerns about their physical health). Psychologists have a central role to play in assessment and intervention in such cases as well as an important strategic role in developing appropriate services, training and supporting others and providing appropriate supervision and consultancy for other professionals.

The focus on a sense of 'letting go' of the deceased has been challenged, as have the interventions that were developed within this framework. A more complex and individually based understanding of the experience of grief is now emerging (Wortman & Silver, 1989; Epstein et al., 2006; Mancini & Bonanno, 2006). Most notably the idea of 'Continuing Bonds', that is, a sustained and sustainable relationship between the bereaved person and the deceased is seen to have positive advantages for many bereaved people in their ability to adapt to their new life. This is particularly evident for young children who are bereaved of a parent, or similarly a parent whose child dies. However, what exactly are 'helpful' bonds is yet to be determined (Klass et al., 1996; Fraley & Shaver, 1999; Epstein et al., 2006).

Another central concept is that of 'resilience' in the bereaved person (Bonanno et al., in press). Factors that may serve to buffer the worst effects of grief include the ability to talk about and remember the deceased, having a good social support network, and appropriate contextual emotional expression. In short the way bereaved individuals cope will be as varied as the individuals themselves, there is no right or wrong. So how do we as psychologists know when and when not to intervene?

A significant difference between uncomplicated and complicated grief is that over a five year period those individuals who are experiencing uncomplicated grief are likely to find that their psychological and physiological reactions diminish to non-clinical levels. The bereaved person is likely to feel able to invest in new relationships, and allow the deceased to take a different role in their life (El-Jawarhi & Prigerson, 2006; Bonanno et al., 2007). In this sense earlier theories of grief which emphasised a re-investment in

new relationships as a healthy progression hold true whilst the emphasis on disinvestment in the relationship does not. Instead holding the relationship within an 'internal working model' (in line with attachment theory) of relationships in general or a continuance through a social group narrative (e.g., with family members or others) can be positively sustaining.

It is important not to routinely offer outreach services to bereaved people as there is little evidence that these services are effective. There are concerns that to offer a service too soon after a bereavement, rather than helping the bereaved person develop their own coping resources, can disable them from making an uncomplicated adjustment to their loss. In-reach services appear to be the most effective; that is those services that people refer themselves into because they recognise that they are having difficulty in coping with their changed circumstances (Schut & Stroebe, 2005).

Measuring complicated grief has been the subject of much theorising, discussion, research and debate and various measures of complicated grief have become available (see Schut & Stroebe, 2005). Important differences between complicated and uncomplicated grief and other psychological phenomena (e.g. Major Depression or Post-Traumatic Disorder) have been observed, though clearly co-morbidity can also be evidenced (e.g. Zisook & Shuchter, 1991; El-Jahwarhi & Prigerson, 2006).

There is little evidence from intervention studies for bereaved people, which offers conclusive guidance on 'What Works for Whom'. Indeed a recent book with this title made no reference to the needs of and interventions for bereaved people (Roth & Fonagay, 2004). A sound individualised approach to assessment, formulation and intervention (the cornerstone of all applied psychologist's training) thus remains the best way forward. Intervention will naturally be dependent upon the individual psychologist's theoretical orientation, bereavement clinical skills and experience.

However, not all bereaved individuals with potentially complicated grief will have the opportunity to be assessed by an appropriately qualified and skilled psychologist. Most bereaved individuals will first come into contact with their general practitioner, who may or may not have the necessary training and skills to help them or know when to appropriately refer on to. The strategic role of the psychologist in terms of supporting other professionals, being engaged in service development, research, training, supervision and consultancy is pivotal here.

Returning now to the clinical role of the psychologist it is important to remember that no one orientation has been shown to be superior to another. What does appear to be important is that the psychologist is aware of the relevant literature and continues to update their knowledge and skills. In this sense this knowledge base should guide but not dictate their assessments, formulations and interventions integrating theoretical approaches where appropriate. An example case study of complicated grief can be found below which helps to demonstrate this 'integrative' approach.

Complicated grief

Case Example

Mr J (38) was referred to the Psychology service for bereavement therapy. His wife of 18 months had died from ovarian cancer eight months previously. The couple had both been married before, and Mr J in particular had been very hurt by the break up of his previous marriage. Mr J disclosed that both had been very wary of new relationships in the beginning and had taken some time to commit to each other. Neither of them had children from their previous marriages. Mrs J had been four months pregnant with a much-wanted baby at the time of her diagnosis, sadly her resultant treatment caused the loss of this baby.

Mrs J had been admitted to her local hospice for rehabilitation but deteriorated rapidly and after five weeks she died there. During this period Mr J was able to have quality time with his wife and was well supported by staff, when Mrs J died he appeared to be calm, accepting and making sensible plans for his future.

At assessment Mr J could not recall the good times they had together, so he tended to visit favourite places in the hope that he would start to remember happier times. This rather 'concrete' way of trying to hold on to what had been lost indicates he had not fully accepted this loss. Mr J was very low in mood, with frequent thoughts of suicide and had been taking anti-depressant medication for three months with no effect (perhaps because he was not depressed but grieving). He had stopped going to work, was avoiding his friends and family, and spending much of the day either at his wife's graveside or visiting places that they enjoyed. He was perhaps avoiding contact with those who might confirm his loss. His thoughts were preoccupied with his wife's diagnosis, surgery and the loss of their baby and he was having flashbacks to her last days, when she became very agitated and distressed (suggesting a traumatic element to his difficulties in line with post traumatic stress disorder).

Mr J engaged well in therapy for several months. He described the first 12 months of his marriage as being the 'best' year of his life. Shortly after their first anniversary Mrs J lost their first baby but became pregnant again soon after. When she started to lose this second baby her doctor undertook some tests which revealed her ovarian cancer. This devastated both of them. Mr J described how his wife 'shut down' after her surgery. They were never really able to talk about the impact of what was happening to them after that. In this sense there was 'unfinished' business in the relationship which again would have made it difficult for him to cope with.

Since his wife's death Mr J had begun to ruminate over her illness, and the 'unfairness' of life. Bereavement therapy focussed on allowing Mr J to tell his story and help him incorporate the devastation of his double loss into the broader context of the positive aspects of his marriage. He was encouraged to gradually introduce new behaviours into his life and to develop new ways of living, including a phased return to work. At the end of the therapy Mr J had fewer intrusive images (the traumatic element of his grief was subsiding). He reduced his visits to his wife's grave and was began seeing friends and family again. The idea of meeting new people remained difficult for him, he still had days when his mood was very low but he was able to cease his anti-depressant medication and therapy. His grief remained but could now be said to be 'uncomplicated'.

Core Competencies

The professional practice of applied psychologists is underpinned by five core competences (BPS, 2007):

- Assessment;
- Formulation;
- Intervention or Implementation;
- Evaluation and Research;
- Communication.

The additional benefits which a psychologist can offer in physical health settings, including end of life care are persuasive and clearly demonstrate that psychosocial interventions are not only effective, but also economical (see Carlson & Bultz, 2004, Efficacy and medical cost offset of psychosocial interventions in cancer care: Making the case for economic analysis, *Psycho-Oncology*, 13, 837–849).

The added value which a psychologist can bring to areas such as end of life care is unquestionable and supported by research (e.g. Carlson & Bultz, op cit). However, it is not simply related to the roles psychologists perform or even the above stated core competencies, as many other professions could lay equal claim to these and do. The added value of a psychologist in end of life care (as well as other areas) lays in the discipline of psychology itself. It is from this discipline, which is firmly rooted in research and theoretical understanding, that psychologists approach each unique human being and each individual situation. It is also from a detailed understanding of human development across the lifespan, cognitive functioning, personality development, group dynamics and much more, that psychologists bring a particular unique perspective. The knowledge and skills base which a psychologist brings to end of life care is both broad (for example, an ability to understand and apply several different models and approaches) and deep (for example, an ability to be expert in specific models of therapy, research and clinical areas). Thus it is not simply a question of what a psychologist does or how they do it but what they *bring* to their 'doing' as psychologists.

Additional training may, however, be required to build on the above generic skills. This additional training will ensure that a good understanding of the nature of bereavement, grief and working with severe and life limiting illness and disease is obtained. Some working knowledge of medical treatment and surgery will also be necessary. Psychologists have an obligation not to practice outside the limits of their particular skills and knowledge base. The intensely emotional nature of much of the work in palliative care is likely to have a marked effect on the psychologist's own emotional and physical health and good mentoring and supervision will be required. Psychologists working in this field without prior placement experience will need to ensure that they access the most appropriate additional training and are given time to engage with and consolidate new learning prior to taking on any 'lone' or senior practice position. It is recommended that external assessors be involved in all appointments.

Role of Consultancy

Apart from the more direct clinical interventions that psychologists may be able to provide when working in palliative care there are many other areas where our skills and expertise will be of use. In following sections of this document some of the following suggested areas of work will be addressed either more specifically or in general terms. These are briefly outlined as follows:

- Staff supervision;
- Reflective practice;
- Research;
- Service development;
- Managing change;
- Consultancy;
- Training.

Team Functioning in End of Life Care [drawn from Brennan, 2004¹]

Groups of people are powerful at influencing the individuals within them so one approach to staff stress is to consider how the health care team functions as a whole. All health care teams are bound by the tasks and rules of the institution, and structured around hierarchies created by those in authority (Obholzer & Roberts, 1994). Leadership ensures that institutional systems enable members of the health care team to deliver their work effectively, efficiently and to a high standard. But 'authority' in health care settings can sometimes be ambiguous, leading to potential conflict. Is it with the clinical team leader (frequently a senior doctor), one's professional head, or the institution's management team?

End of life care is undoubtedly a mixture of triumphs and losses. The 'contagion' of distress from patient to professional is probably intrinsic to the work. Cancer care touches the professional's underlying fears, beliefs and behaviour and probably their relationships with *their* loved ones. These powerful feelings (anxiety, loss, conflict) can be 'acted out' in the dynamics of working relationships (Hinshelwood & Skogstad, 2000). For example, an observational study of a hospice (Ramsay, 2000) noted how dying patients were essentially isolated in single rooms behind closed doors while the communal areas of the hospice were empty. The emotional distress of dying was 'shuttered off' by the staff who, feeling helpless to prevent the inevitable, maintained a 'stoical brightness'. In other words, the distress of health care staff can be unconsciously expressed through 'blocking' practices that soon become institutionalised. Such team dynamics are usually hard to perceive from within the team itself but can often be unearthed by a skilled external team facilitator.

Team working is based on the idea that by collaborating, team members with different professional skills are able to provide comprehensive and seamless care. The reality invariably drifts from this simple ideal. A diversity of perspectives within the team inevitably leads to some degree of conflict; team members not only have allegiances to the team but to their professional standpoint too (Firth-Cozens, 2001). For example, in the past nurses have complained that doctors leave them to care for patients in pain without adequate analgesia (Wilkinson, 1995). Their more continuous contact with patients meant that this was a significant source of stress for nurses. In fact, these previous conflicts between nurses and doctors seem to have decreased, perhaps as a result of doctors' improved knowledge and prescribing of palliative interventions for pain and symptom control (Wilkinson, 1995).

Of course, different perspectives also offer the potential for more creative discussions and decision-making. Team collaboration implies a common understanding of health care goals, a common language, and a mutual understanding and respect between professionals regarding each other's roles and areas of expertise. In other words, a well-functioning team develops a 'shared model' of its resources and purpose. In reality, though, every team is active, fluid and constantly changing so if it is to maintain a shared model, it must be able to reflect upon and review the assumptions upon which the shared model is based. Teams therefore need to be self-reflective and adaptive about the ways they are functioning – constantly exploring different approaches to patient care (Firth-Cozens, 2001).

A successful and well-functioning team demonstrates:

A clear sense of leadership

The aim of team leadership is to help the team to function effectively and supportively. It is not primarily one of control; authoritarian leaders only betray their anxiety. The style of the clinical or management team leader sets the tone for the rest of the team so all leaders should try to model what they expect from the rest of the team.

Contact and communication

If there is limited contact between team members they will feel less comfortable communicating with one another. Frequent formal and informal contact helps to break down barriers and enables team members to support one another.

¹ OUP Material, Chapter 7, 'Strategies to Prevent Stress in Health care and Team Functioning', pp.381–385 from *Cancer in context – a practical guide to supportive care* by Brennan (2004) Not to be published elsewhere without permission.

Opportunities to review its objectives, aims and means of functioning

Does the team have opportunities to consider its core goals and principles and the ethical principles guiding them? How does the team handle complicated issues of confidentiality? Is the team organised appropriately? Are members clear about one another's roles? Without clear role boundaries, there is scope for confusion, duplication and omission. For example, one study revealed that the specialist breast care nurse was playing an 'unseen' role of having significant discussions of diagnosis and treatments with patients, while others in the team assumed her contact was more focused on psychosocial concerns (Jenkins et al., 2001).

Respect for different perspectives

Do team members really work together as a multidisciplinary team in which all perspectives are valued and respected, or is only lip-service paid to this ideal, with one or two people's views dominating and intimidating others? Does conflict between people within the team feel dangerous or is there a willingness to entertain a diversity of opinions?

Self-Care In End of Life Working [drawn from Brennan, 2004³]

Introduction

Despite a number of difficulties with the concept of stress, a consensus has emerged that the amount of stress people experience in relation to their work is related to three primary factors (Linzer et al., 2002):

- the demands of the work;
- the degree of control they have over it;
- the amount of support they feel they receive in their personal and professional lives.

The negative effects of stress are well-documented although fairly non-specific (NASS, 1992). Some of the many effects of stress include behavioural and social outcomes (e.g. increased use of alcohol and drugs, relationship problems and social withdrawal), physical outcomes (insomnia, hypertension, headaches etc.), cognitive outcomes (poor concentration and memory, etc.) and organisational outcomes (higher absenteeism and sick leave, poor productivity and decision-making, etc.). In short, the effects of stress are widespread and damaging (see Brennan, 2004).

Sustained or chronic stress leads to a phenomenon called 'burnout', a term first applied to the work setting in 1974 (Freudenberger, 1974). Since then, burnout has been widely investigated, particularly among human service occupations such as health care in which sustained stress is thought to be largely due to the emotional nature of the relationship between staff and patients (Maslach, 1997). Burnout refers to the end result of chronic stress though it is often used as if it were a direct measure of stress, perhaps because there is a widely used psychometric tool for measuring it among groups of people (Maslach & Jackson, 1986). Yet despite its usefulness in describing particular work environments or staff groups, one should be wary about applying the term to an individual because no reliable method exists for 'diagnosing' burnout in individuals (Maslach, 1997).

Burnout has three primary features:

(i) Emotional exhaustion

A depletion of emotional resources whereby people feel they have little more to give. Patient contact may be experienced as oppressive and burdensome. There is a loss of energy for the work and a general sense of fatigue.

(ii) Depersonalisation

A negative, callous or excessively detached attitude towards patients or colleagues. Individuals with burnout may appear irritable or distant, and there is often cynicism or lack of idealism.

(iii) Loss of personal accomplishment and job satisfaction

A loss of confidence in one's competence and achievements, involving a loss of productivity, creativity and motivation. Burnout leads to low morale, withdrawal and an inability to cope.

Burnout is ultimately a way of coping with sustained stress, rather than a failure to be professional. End-of-life care is an intrinsically emotive area of work, assuming professionals allow themselves to be touched by their patients' experience. There are many moving and rewarding moments in working with people facing adversity, but the highs are more than balanced by the lows.

Most health care professionals have not had training or preparation for the emotional impact of their clinical role and there is little formal recognition of the emotional strain of the work. There are many clinical situations, however, when the most appropriate course of action for the professional is to do little other than 'stay with' the patient's distress and offer their emotional support. Without training and support, this important act is seen as 'doing nothing', often leaving professionals feeling helpless and a failure. However professionals can reduce the emotional distress such situations bring about by learning how to manage their feelings of helplessness and appreciate the therapeutic value of support and clinical supervision.

Health care managers need to encourage their staff to develop ways of sustaining their ability to care, rather than becoming burned out – in other words, using emotional detachment and distance as a way of coping. They should also ensure that professionals have sufficient opportunities to 'off-load' their stress while in the workplace rather than allow it to accumulate or be taken home. For example, they should provide new staff working in end-of-life care settings with an induction training that emphasises self-care and the responsibility of individual staff member to raise concerns about their own levels of stress. They should also ensure that all staff have received training in the psychosocial aspects of palliative care. By developing expertise in communication skills, professionals feel more confident and competent at handling difficult emotional situations (Maguire, 1985). Where volunteers are deployed, managers should ensure that they are vetted, trained and supported. Volunteers usually work for short periods with often limited contact with professional staff. They may be motivated by their own personal experiences of illness or health care and consequently may be confronted by issues that remain powerfully salient to them. It is therefore essential that volunteers are not only carefully vetted for their readiness to volunteer, but are provided with both clinical supervision and regular support.

A work environment that does not acknowledge the implicit stress of end-of-life care is more likely to promote a culture of emotional detachment, distance and lack of support between staff. If emotional distress is not expressed it is likely to go underground. By contrast, a workplace culture that encourages staff to talk through difficult clinical experiences and mutually support one another is one which enables professionals to remain emotionally involved in their work, while continuing with other fulfilling areas of their lives (Figley, 1998).

Individual strategies to reduce stress in health care

Like burnout, it is far better to reduce stress in the workplace by anticipating and preventing it, than by having to react to a crisis. The following are suggestions for health care workers to consider when addressing their own levels of stress.

(i) Be aware of your own feelings

It is hard to predict when patients or family members will trigger powerful emotional reactions. You may find yourself identifying with a particular patient because they remind you of an important figure from your past, someone currently important to you or even an aspect of yourself. Such feelings can be difficult to understand because they are implicitly or unconsciously known. You may feel angry towards a patient for no apparent reason, upset by them, or wanting to rescue them, or find yourself feeling over-involved, bored or coldly detached. The point to note is whether you can explain these feelings in light of what has occurred between you or whether they have arrived 'out of the blue', or are out of proportion to the situation. Clinical supervision is an ideal forum in which to unearth and understand these feelings (see below), often to the benefit of patient care.

(ii) Be aware of your stress level

Keep a mental tally of how your work pressures rise and fall. Consider typical symptoms of stress with a view to becoming aware of when you are becoming generally overstressed. Some sources of stress are obvious and inevitable, such as when a ward team has to manage a number of deaths over a short period. Others may be more obscure, such as when a patient is angry and hostile, or when on top

of work pressures your own children are unwell. How do you feel at the end of the day? How much time do you think about your work when you are not there? How much time do you think about particular patients when you are not at work? If demands are becoming intolerable, it is essential that you speak to supervisors and colleagues. Maintaining a macho image of unyielding vigour and determination is ultimately self-defeating and potentially damaging to patients.

At an organisational level, it may be helpful to conduct a stress audit of a particular staff group to determine the levels and sources of stress. A number of paper and pencil tests are available to measure both stress (Cooper et al., 1988; Tattersall et al., 1999) and burnout (Maslach & Jackson, 1986). Engaging all parties to discuss the findings and to suggest solutions can promote a sense of team cohesion and participation.

(iii) Be aware of stress in other members of the team

Support among professional colleagues needs to be reciprocal. When health care staff show concern for their colleagues and the stresses they have been dealing with in their professional and personal lives, everyone benefits. Furthermore, while no one is exempt from stress, some people are more isolated from support than others. Senior members of the medical team, hospital managers, secretaries and porters may all experience stress in their workplace yet may feel inhibited about asking for support. A little extra concern for your colleagues reaps long-term rewards in the form of a more supportive workplace.

(iv) Maintain the boundary between work and home life

To be involved with end-of-life care involves a level of personal commitment to the intrinsic value of the work. Patients' needs are important and, while professionals are at work, they become their pre-eminent concern. However, the pressures of work can easily assume an almost moral imperative that edges out the 'selfish' needs of the individual professional. But to care for others effectively, health care professionals need to be sufficiently cared for themselves; maintaining a loving, happy and stimulating home life is therefore as important as having a fulfilling and successful career. Try to prevent 'spillage' between personal and professional life by sticking to clear boundaries between the two (taking a proper lunch break, going home on time as much as possible, not taking work home, and so on).

(v) Be aware of your sources of support

Ideally, access to support should be a continuous feature of everyone's working life but, at stressful times, it is particularly helpful to be aware of your main sources of support. Talking about your experiences is a powerful way of integrating them with your own mental assumptions about the world (Brennan, 2004) while at the same time dissipating their emotional impact. However, be aware of the difference between talk that relieves stress and complaining that reinforces it.

Be clear who you feel comfortable talking with on an informal basis and seek them out at moments of high stress, while not forgetting to reciprocate at other times. If possible, formalise this contact into regular meetings to discuss issues arising from your caseload and other work pressures.

Staff support groups are an option for teams who have the time but they need to meet sufficiently frequently to feel relevant, and generally work best when led by someone external to the team who can provide the safety of structure and boundaries. However, a team leader can show concern for staff by arranging an impromptu meeting in response to an especially distressing incident or series of incidents.

An accessible option is to incorporate a supportive element into frequent team meetings. In the context of discussing clinical material, the team leader can introduce more general topics of relevance to everyone: how was the incident handled, how could care have been improved, how did it leave people feeling (especially those most involved), and are there ethical questions to be considered? By encouraging people to support one another in this way, the team leader promotes a non-blaming team culture in which mistakes can be openly discussed and rectified.

(vi) Clinical supervision

Clinical supervision is a particular form of staff support that also fulfils another important aim of professional health care: ensuring that the individual is practicing at an appropriate level of expertise. It is therefore best done by someone within your own profession, though other professionals can sometimes be excellent substitutes. Staff of the same or a different grade can give supervision, provided the supervisor is clear as to the purpose of their role, and provided the person being supervised (and their patients) remains the central focus of attention (Hawkins & Shohet, 1989).

Clinical supervision is not management supervision but an opportunity for any professional to reflect on their primary skills as well as the broader pressures they are facing. It focuses on helping the receiver reflect on their clinical practice and explore alternative decision options, while receiving acknowledgement for tasks well done. It can involve learning to recognise blind spots and areas of difficulty, identifying unexamined assumptions brought to the work, discussing ethical doubts, or strong feelings about particular patients. At a more sophisticated level, clinical supervision can help health care staff use their emotional reactions to patients as a valuable additional source of information. Not surprisingly, this opportunity to talk through and integrate recent experiences is not only validating and supportive, but time well spent. Such reflective practice promotes self-regulation or corrective feedback. Yet although clinical supervision offers advantages in both quality control and staff support, it is still quite rare in many areas of health care.

(vii) Staff appraisals and professional development

Formal appraisals by managers are valuable opportunities to identify sources of stress, provide feedback and consider remedial action. They also enable staff to clarify ambiguous elements of their role and to set achievable targets to aim for. Managers can use this opportunity to acknowledge and praise the individual's work while helping to develop their range of skills through suggesting new initiatives: training courses, taking on different clinical roles, teaching, research and management. Continuing professional development not only enables professional staff to stay up-to-date with clinical and academic knowledge, it also breathes the energy of fresh ideas into clinical practice that may have become tired and stale.

(viii) Learn to dissipate the effects of stress

The option of relaxation may sound absurd as an antidote to stress when it merely constitutes the polar opposite. It is like saying that the best cure for being ill is to get well. Happily, there's more to it than this. Learning to relax may be a largely symptomatic response to stress but few people are aware of the ambient physical tension they carry with them from one situation to the next. It is the chronic nature of stored physical tension that seems to lead to many illnesses, so mastering the skills of releasing stored muscle tension can bring wide-ranging health benefits. Of course people can spontaneously release their bottled-up stress through talking, laughter, crying and anger, while sport and physical exercise also carry additional health benefits (Blair et al., 1992).

Forms of relaxation (meditation, yoga, etc) have been used within a number of cultures for thousands of years, yet only relatively recently (Jacobson, 1929) has Western medicine made scientific use of relaxation exercises as a natural antidote to stress. A number of different relaxation techniques exist (progressive muscle relaxation, autogenic training, biofeedback, meditational techniques such as mindfulness – Bruch, 1997) but their essence involves the subject learning how to release muscle tension and breathe more calmly so as to reduce autonomic arousal, while finding some 'psychological peace' through focusing on particular words or scenes. Cognitive techniques provide a more complete picture by focusing on the many ways people mentally amplify the pressures they face and their behavioural responses to them².

² OUP Material, Chapter 7, 'Strategies to Prevent Stress in Health care and Team Functioning', pp.381–385 from *Cancer in context – a practical guide to supportive care* by Brennan (2004) Not to be published elsewhere without permission.

Conclusion

This Report has set out the current issues that are facing both Commissioners and Providers of services for people who are coming to the end of their lives, In particular it aims to inform psychologists about the key areas that they need to be aware of when working with patients and families who are in receipt of end of life care.

Good general palliative care and specialist palliative care have been highlighted in a number of National Service Frameworks that have been produced in recent years. Recently the Government has made End of Life Care one of its eight priorities for commissioning authorities, with a report due out in 2008. This will include Baseline Reviews of current service provision across England Wales and Northern Ireland.

The drivers for this report are diverse and include:

- Greater choice for patients in where they wish to live and die.
- Decrease in the number of emergency admissions of patients who wish to die at home.
- Decrease in the number of older people transferred from a care home to a DGH in the last week of life.
- An overall reduction in the cost of end of life care, through appropriate and timely community services to help support patients and families to stay at home as far as possible.

This challenging agenda has created an opportunity to look carefully at the way in which services are currently provided and for Commissioners and Providers to work closely together to develop services that meet the needs of their local population.

There is a clear role for psychologists to help meet this agenda. The recent DoH Cancer Reform Strategy (DoH, 2007) makes it clear that good psychological care is a vital component of cancer care throughout the course of the disease:

‘Cancer patients and their families and carers may need psychological support. Commissioners should work collaboratively to ensure that good psychological support services are available throughout the cancer journey’ (DoH, 2007, p.14).

However it is disappointing that this Strategy has failed to be specific in both the way in which ‘psychological care’ is provided, and also in defining the psychological practitioners who are best qualified to both design and develop the services necessary

NICE Guidance for Supportive and Specialist Palliative Care (2004) describes four levels of psychological intervention that are necessary and appropriate within supportive and palliative care services for cancer. Clinical Psychologists are able to offer support, in the form of training and supervision for staff working through levels one to three, and are trained to offer assessment and interventions at levels three to four, and thus it is essential that psychologists ensure that they are part of this collaboration *at all levels* of service provision, from planning of new services through to direct face-to-face assessments and interventions.

All recent documents attest to the need for appropriate communication with patients and families throughout their illness and when they are dying. In addition it is vital that there is well co-ordinated and clear communication between professionals, particularly in the patients’ last few weeks and days of life. The Gold Standards Framework and the Liverpool Care Pathway are two tools that endeavour to meet this need. Inherent within these tools is the need for a good understanding of the changing preferences of the dying person in terms of their preferred place of care when they are dying.

It is apparent that people’s choices about care and preferred place of death often change as they become more unwell, and staff need to take account of these changes. They also need to be sensitive to the motivations of individuals and families, which are likely to be very different as the dying person becomes more debilitated as a result of their illness and/or disability. These are difficult issues for staff to address with patients and families, and here again psychologists are well placed to help staff ask potentially difficult questions, and support them in difficult family situations.

It is also important to remain mindful of the issue of Assisted Dying, whether this is in the form of Physician Assisted Suicide, or allowing patients and families to explore other ways in which a life can be ended. While all forms of Euthanasia remain illegal in the UK, there is every likelihood that the debate will continue. Psychologists are well placed both to help interpret the complex psychological literature to facilitate others' understanding of the issues, and also to help individuals and families discuss their thoughts and feelings in relation to decision-making.

Finally, this document is inevitably 'work in progress' because dying is the business of all of us, not simply the policy makers and health care professionals. As the impact of legislation such as the Mental Capacity Act and linked documents that encourage individuals to make advanced decisions about their care (e.g. *Advanced Care Planning: A guide for health and social care staff*, DoH, 2006) begins to influence the general population, and as the population ages, we will be constantly encouraged to consider how we want to look after ourselves and be looked after, in the final stage of our life.

Weblinks

The following links will provide more information about many of the issues raised in the Document.

End of Life Care

Advanced Care Planning

www.endoflifecare.nhs.uk/eolc/acp

Cancer Reform Strategy

www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/CancerReformStraegy

Liverpool care of the dying pathway

www.mcpcil.org.uk/liverpool_care_pathway

Gold Standards Framework

www.goldstandardsframework.nhs.uk

NICE Guidance

www.nice.org.uk/nicemedia/pdf/csgspinfofpublicenglish

Mental Capacity Act

www.dca.gov.uk/menincap

Organisations

National Council for Palliative Care

www.ncpc.org.uk

Help the Hospices

www.helpthehospices.org.uk

Age Concern

www.ageconcern.org.uk

Macmillan/Cancer Backup

www.macmillan.org.uk

Pressure Groups

Dignity in Dying

www.dignityindying.org.uk

Care not Killing

www.carenotkilling.org.uk

Bereavement

Children's grief

Winston's Wish

www.winstonswish.org.uk

Rip Rap

www.riprap.org.uk

Childhood Bereavement Network

www.childhoodbereavementnetwork.org.uk

Adult grief

CRUSE UK

www.crusebereavementcare.org.uk

Bereavement Research Forum

www.brforum.org.uk

Glossary

Autonomy

Autonomy is self-rule or self-determination. It involves the capacity, rationally, reflectively and freely to think about, decide and act upon what one desires, though not to the detriment of others.

Bereavement

Describes the experiences of loss when someone close to him or her dies or when they lose something that is important to them.

Capacity

This is essentially a legal term and refers to a person's ability to make decisions. The Mental Capacity Act defines it as '... a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.'

Consciousness and Sentience

Is the most obvious and the most mysterious feature of our minds. In palliative care whether someone is conscious or not and able to make reasonable decisions matters. Levels of consciousness may fluctuate depending on drug regimes and disease progression and cannot be seen as static.

Dignity

The quality of being worthy or honourable; worthiness, worth, nobleness, excellence. Dignity tells us that the value of a person's life is not solely dependent on her view of it. Even if an individual does not value her own dignity, it should still be respected by society

Double Effect

For the Double Effect (DE) principle to be applicable, four criteria have to be met:

- The intended outcome is good in itself;
- The intention of the action is solely to produce the good effect;
- The good effect is not achieved through the bad effect;
- There is sufficient justification to permit the bad effect

Euthanasia

Euthanasia is an active intentional act to end a person's life. The word 'euthanasia' literally means 'good death' (Greek origin).

- **Voluntary Euthanasia** is death brought about by an agent at the request of the person who dies.
- **Non-Voluntary Euthanasia** is the killing of someone who lacks the capacity for consent.
- **Involuntary Euthanasia** is the killing of someone who could consent but does not.
- Voluntary Euthanasia at the time of writing is illegal in this country but under certain circumstances legal in others.

Futility

This term is used in the evaluation of treatment options. Medical futility cannot be defined with precision but is based on outcome probabilities in terms of survival and quality of life

Grief

Describes the emotions that people experience as a result of the loss of someone (or something) that is important or close to them.

Mourning

Describes the behaviour that people demonstrate when they are grieving. It is very difficult to put a timescale on mourning, and current research suggests that the time that many bereaved people take to grieve the loss of a significant person is variable, and relates to a number of factors.

Sentient & Sentience (also see Consciousness)

That which feels or is capable of feeling; having the power or function of sensation or of perception by the senses. Conscious or percipient of something. Responsive to sensory stimuli. One who or something which has sensation.

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