

We need to talk about Palliative Care

British Psychological Society

About the Society

The British Psychological Society, incorporated by Royal Charter, is the learned and professional body for psychologists in the United Kingdom. We are a registered charity with a total membership of 53,000. The Society has over 3,000 members in Scotland.

Under its Royal Charter, the objective of the British Psychological Society is "to promote the advancement and diffusion of the knowledge of psychology pure and applied and especially to promote the efficiency and usefulness of members by setting up a high standard of professional education and knowledge". We are committed to providing and disseminating evidence-based expertise and advice, engaging with policy and decision makers, and promoting the highest standards in learning and teaching, professional practice and research.

The British Psychological Society is an examining body granting certificates and diplomas in specialist areas of professional applied psychology.

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1. What has been your experience in terms of access to palliative and end of life care?

The Society has no comment to make in answer to this question.

2. How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?

Any literature search will demonstrate that the focus on the quality of care is on medical and nursing care, which appears at odds with the whole ethos of palliative care. Palliative and end of life care is promoted as 'holistic' care. However, a survey of GP's in 2012 revealed that 35% had never initiated a conversation about end of life care with one of their patients (National Council for Palliative Care (NCPC) 2014). If we take this last indicator it would appear that care in the community and the understanding of those who commission services has still some way to go to achieve true holistic care. Good palliative and end of life care if everyone's business, though not everyone makes it their business to understand how to do it well.

Together for Short Lives asserts the need for palliative care at the end of life. Emerging evidence (e.g., Temple et al., 2011) demonstrates that patients assigned to early intervention palliative care show higher quality of life scores and lower depression scores and despite this group receiving less aggressive end of life treatments their median survival rates were longer.

Patients and their families must be fully and clearly informed of the palliative and hospice care available to them and should also be explicitly informed of the psychological therapeutic care and interventions that are available and how this can be accessed.

Earlier intervention requires 'awareness' training and assessment, referral and pathway protocols to be updated to ensure the smooth and efficient care of patients and families at an earlier stage in the disease progression.

3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?

Psychologists who work in palliative and end of life care understand that cognitive, emotional and mental health functioning may suffer significantly or be impaired as a result of treatment and/or medication. In these situations, which can in some way be said to have moved beyond the medical, Psychologists are well placed to understand the complexity involved and the fluctuating levels of cognitive functioning.

The range of psychological interventions could be usefully and clearly explained to help providers and others understand that 'one size' does not fit all and that a range of approaches is often required. Often numerous approaches are required at one point or another and at different developmental phases and tailored to specific needs at specific time points.

An emphasis on across-service cooperation and 'non-ownership' approaches of the patient will ease distress. Some patients and families may 'choose' to continue with trusted relationships built up over many years, these attachments and bonds if broken without consent/open discussion with forward planning will also incur unnecessary and avoidable distress. Therefore, increasing collaborative working relationships is essential.

The Society strongly recommends that assessment of capacity must be carried out by appropriately trained and accredited specialists¹ with experience of assessing mental disorder, cognitive and neurological deficits as well as having the skills to intervene where appropriate and understand the difference between clinical depression and personality factors.²

In cases where there are concerns regarding the possible presence of particular forms of mental disorder, such as personality disorder, or learning disabilities and autistic spectrum disorders, a practitioner psychologist may be best placed to provide the relevant expertise. The fluctuating nature of some conditions, such as depression, particularly in palliative care, requires specialist skills above and beyond that of medical practitioners.³

4. When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?

It is important there is sensitivity around timing and permission to discuss options for palliative care with the patient. Patients need to be given the opportunity to explore options for palliative care but it must be patient led. Psychologists can play a key role here, particularly where patients might be struggling to find a voice for the situation in which they find themselves.

5. What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?

Effective communication is essential in palliative and end of life care. For a patient it can have a profound impact on their emotional health and coping, symptom resolution, and function; it may even result in a decrease of reported pain and drug usage. For families, it is essential that they understand what is happening and what to expect, and that they are given space and support in making decisions and saying good bye at the right time. For staff, insufficient training in communication is a major factor contributing to stress and emotional burnout.

Poorly managed 'bad news breaks' can significantly add to the trauma experienced by receiving a life-limiting diagnosis.

¹ Suitably qualified specialists include: registered psychologists, accredited counsellors and psychotherapists and psychiatrists

² McWilliams, E, & Kalus, C., (2004). Evidence to the Select Committee on the Assisted Dying for the Terminally Ill Bill HL Paper 86-II, 2011-2019

³ Petersen, Y. & Koehler, L. (2006) Approaches of Attachment Theory for Psychological Support in Palliative Medicine during the Terminal Phaze *Gerontology* **52**, 111-123

As stated in the Baroness Neuberger report into the Liverpool Care Pathway - "Unless there has been good communication between staff and relatives or carers, unnecessary misunderstandings and distress can arise. Care of the dying requires not only substantial technical knowledge and clinical skill, but above all it needs excellent communication skills. Adequate training and continued support is the key to getting this aspect of care right."⁴

6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?

Anticipatory care planning 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 themselves.

It must be stressed that anticipatory 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.

7. How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?

The Society believes that information giving is not the same as good communication and may sometimes be used as a way of distancing oneself from the emotional impact of this work. It is essential that information on the palliative, hospice care and psychological support available is communicated in the most appropriate way for that person.

8. What training and support is provided to Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?

Psychological input is key in designing and delivering high quality communication courses, which not only help practitioners manage complex conversations but also help them consider how they care for themselves and their colleagues in what is often described as an 'emotionally charged' area of practice.

9. How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?

Decisions around end of life care and preferred place of care are not static and not everyone will find their needs at this time will be met in familiar

⁴ Baroness Neuberger Inquiry 'More Care: Less Pathway: A Review of the Liverpool Care Pathway, 2013 - https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

surroundings. It is necessary to allow for individual choice and the right for individuals to change their minds

Given that decision making in palliative and end of life care is “clinically complex and emotionally distressing”, issues of staff support, supervision and training need to be addressed to enable compassionate care and minimise ‘burn-out’.

10. What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?

The Society has no comment to make in answer to this question.

Are there any additional points you wish to add?

The definitions of ‘Palliative’ and ‘End of Life’ care requires some consideration as they suggest two distinct experiences; though there will be points when these distinctions themselves may become blurred.

The ‘Palliative Phase’ may be seen to begin when the person is no longer being cared for with the expectation that their condition will be cured. Therefore, there will be some groups of people who will be seen to enter this phase from the moment they are diagnosed and from the moment of birth; or even before. This then brings into consideration the issue of ‘life-threatening’ conditions which may quickly escalate into palliative or even straight to end of life and sometimes back again.

The ‘End of Life’ phase may be seen to be the phase that begins when both the speed and extensiveness of the disease process increases observably and inexorably towards rapid and /or certain decline. The expectation then becomes that the person is now living in terms of days (sometimes hours) or weeks rather than months.

However, a further phase may be evidenced. This is when Phase Two no longer applies and the person reverts to Phase One. This constitutes a phase which is extremely challenging for all involved and commonly associated with unpredictable diseases and/or vulnerable groups.

To try and name this third phase, in a way which sufficiently defines it, is a challenge. However, a working definition would be one which encapsulates its main features, particularly around the unexpected and sometimes rapid change involved. The working definition suggested here is the ‘**Uncertain Reprieve**’. This phase may quickly revert back to the ‘Palliative Phase’ and may be seen to have become so once a period of stability ensues or it may just as quickly again move to the ‘End of Life’ phase. Further, this third phase may be experienced many times over for some groups of people and with devastating psychological consequences for all those involved.

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