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## GUIDANCE

# The End of Life Care pathway during the Coronavirus pandemic

This is a guide for psychologists working in palliative care, who need to think about the End of Life Care pathway for patients, relatives and healthcare staff during Covid-19. It offers considerations and recommendations for new ways of working to help keep a clear End of Life pathway for patients.

Under normal circumstances, psychologists in palliative care services will work directly with patients and their loved ones and other healthcare professionals to provide a 'holistic' and coordinated approach to care<sup>1</sup>. However, the profound effects of Covid-19 can drastically impact on the traditional End of Life Care pathway.

### The different ways Covid-19 can impact of the End of Life Care pathway

The speed at which patients go from 'being well' to their death

Important decisions that will need to be made more quickly

Patient's end of life care preferences may not be possible

People will be unable to see loved ones prior to their death or afterwards

The 'breaking of bad news' to loved ones will take place differently

Government restrictions may disturb the funeral planning and attendance – impacting on the loved ones grieving process

Loved ones' grieving process may also be affected, as they too continue to live with the realistic threat to their own health.

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As a result, the End of Life Care pathway will need some necessary adaptations and modifications to the usual process and the role that psychologists play within this. Delivering good end of life psychological care will still include following the [NICE Quality Standards](#) with the central pillar still to reduce or lessen psychological distress, which in turn will later reduce trauma and unresolved/complicated grief for loved ones<sup>2</sup>.

Since Covid-19 is caused by a novel virus, there is limited information and data available on the extent to which this will impact on the traditional End of Life Care pathway. However, this guide is based on the emerging knowledge and experiences during the current pandemic, as well as published guidelines and studies on best end of life care practices<sup>3,4</sup>.

## CONSIDERATIONS AND RECOMMENDATIONS

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### DECISION-MAKING

The time for difficult, end of life conversations which are normally spaced out over days or hours may no longer be possible. Decisions will need to be made at pace, whilst addressing potentially practical and communication barriers related to Covid-19 conditions (e.g. the availability of personal protective equipment (PPE), social distancing measures).

Whilst this presents challenges, the important point is that good end of life care continues, and decision-making should include:

Supporting the patient, their loved ones, staff and others in beginning difficult conversations early and to consider the patient's preferred (perhaps very near future) care preferences.

Having early discussions with patients whilst they are conscious (not ventilated or sedated), about their preferences for care.

While decisions will, of course, be difficult for patients and loved ones to make, the circumstances due to Covid-19 may prevent loved ones being involved in those decisions. At some point in the pathway, the decision to stop active treatment may be made by the treating clinicians, in the patient's best interest. We may thus expect an emergence of feelings of failure at this point in the pathway which will need to be addressed early if at all possible.

### COMMUNICATION

While time pressures may impact on the pace of decision-making, everything that can be done to allow the patient and others to express their concerns, and hopes with the time left to them, should be done. Decisions made about patients will have to be communicated to their loved ones at a distance, and may need to be done by non-specialist health workers. Allowing patients' and their loved ones' alternative ways of staying connected and then saying goodbye will be required.

Try to make time for conversations (even brief), even though not everyone that should be involved can be.

Utilise technology, creative and therapeutic methods to help bridge the communication gap between patients and loved ones, for example, the use of tablets to record poems, messages, audio or video messages and other. In many care settings staff are already using such methods. Many have set up central 'mailbox' email addresses where loved ones can forward letters, pictures, photographs, poems etc. which are then delivered by staff to the patient.

The use of narrative can help loved ones understand that whilst there may be physical distance there can still be emotional closeness. For example, a script along the following lines... 'Beyond that door, not too far away, I am here, thinking about you, sending you all my/our love. Just beyond that door, you should be able to feel it from where you are, you are not alone.

I want you to remember that if you feel worried or lonely later, you are not alone'.

Winston's wish provide many other creative suggestions, including preparing a memory box, which could be explored and supported.

## PROVIDING SUPPORT

During these unprecedented times, the role of psychology will be to support everyone through this 'different' End of Life Care pathway and to help people process the emotions involved.

**For the patient.** There is a high chance in this Covid-19 context, that patients will receive care without their loved ones being present. Therefore, when the pathway diverts from one of intent to cure to one of dying, comfort for the patient is needed, especially when they may have very limited physical contact.

**For the loved ones.** There can still be an opportunity to say what needs to be said. Each person, family, community and a particular culture will have their own ways and rituals they will wish to follow, when it is clear life is nearing the end. Wherever possible, these should be followed, supported and reviewed. This begins with a conversation between loved ones and the patient's care team to see explore the art of the possible.

**For the staff.** It will be important to provide additional team support and supervision during these times. Staff members may need support to work differently and to see this different way of working is not a failure, as well as help staff experiencing emotional exhaustion and possible future burnout.

Find some time and space for staff to acknowledge their feelings.

Helping staff to recognise that they have done their best may avoid possible negative feelings and a 'sense of failure'.

Staff who have been very closely involved with many deaths require additional psychological support so they do not become overburdened with the loss and grief. The wider community of supportive care outside of the acute setting should also be considered and their needs addressed. They too may bear the brunt of excess death experiences and suffer burnout or traumatisation.

The aim is to address short-term, medium-term and long-term grief in a responsive way, not prematurely or pre-emptively.

## CONTRIBUTORS

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### BPS Covid-19 Bereavement Workstream

This document has been generated as a cross-divisional, multidisciplinary effort. The contributors were as follows:

**Professor Nichola Rooney PhD FBPsS CPsychol (COVID-19 Bereavement Workstream Lead)**

Consultant Clinical Psychologist; Queen's University Belfast Chair DCP NI; Vice Chair BPS NI.

**Dr Angel Chater**

Registered Health Psychologist, Chair of the Division of Health Psychology and Member of Division of Sport and Exercise Psychology. Reader in Health Psychology and Behaviour Change, University of Bedfordshire.

**Dr Becci Dow**

Consultant Clinical Psychologist, Vice-Chair of the Faculty of the Psychology of Older People (FPOP), Oxford Health NHS Trust.

**Dr Frances Duffy**

Consultant Clinical Psychologist, Division of Clinical Psychology, Faculty for the Psychology of Older People. Psychology for Older People Services, Northern Health and Social Care Trust.

**Dr Theresa Jones**

Registered Clinical Psychologist, Senior Research Associate for Anthrologica and the Social Science in Humanitarian Action Platform.

**Dr Elaine Johnston**

Lead Adult Intensive Care Clinical Psychologist, Chelsea & Westminster Hospital. British Psychological Society (BPS) Crisis Disaster & Trauma (CDT) Section Committee Member.

**Polly Kaiser**

Consultant Clinical Psychologist and Clinical Lead for older peoples' psychological therapy Pennine Care NHS Foundation Trust. Psychological therapies workstream lead Division of Clinical Psychology, Faculty for the Psychology of Older People. Honorary lecturer University of Manchester.

**Dr Elaine Kasket**

Registered Counselling Psychologist. Member of Division of Counselling Psychology and Cyberpsychology Section. Independent Practice, London.

**Dr Sarah Meekin**

Consultant Clinical Psychologist, Head of Psychological Services Belfast Health & Social Care Trust, DCPNI Policy Lead.

**Dr Benna Waites**

Benna Waites, Consultant Clinical Psychologist, Co-chair of Division of Clinical Psychology Leadership and Management Faculty, DCP Wales Committee, BPS Psychologists in Social Care Committee, BPS Safeguarding Committee.

**Dr Elaine McWilliams**

Consultant Clinical Psychologist in End-of-Life Care, Previous Chair of the BPS End-of-Life Working Party. Member of the Division of Clinical Psychology and Faculty of Oncology and Palliative Care.

## REFERENCES

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psychological society  
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St Andrews House,  
48 Princess Road East,  
Leicester LE1 7DR, UK

☎ 0116 254 9568 🌐 [www.bps.org.uk](http://www.bps.org.uk) ✉ [info@bps.org.uk](mailto:info@bps.org.uk)