

British Geriatrics Society
Improving healthcare for older people

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Jack Dromey MP and Baroness Finlay of Llandaff
Co-Chairs
All Party Parliamentary Group on Hospice and End of Life Care
C/o Hospice UK
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Dear Mr Dromey and Baroness Finlay,

Review into the lasting impact of COVID-19 on death, dying and bereavement – evidence from the British Geriatrics Society

The British Geriatrics Society (BGS) welcomes the opportunity to contribute to this review into the impact of the COVID-19 pandemic on death, dying and bereavement.

The BGS is the membership association for healthcare professionals working with older people. Founded in 1947, we have over 4,500 members and we are the only society in the UK offering specialist expertise in the wide range of healthcare needs of older people. Geriatricians, nurses, GPs, care home staff, old age psychiatrists, allied healthcare professionals, pharmacists and researchers provide high quality care for older people as part of a multidisciplinary team at all stages of illness, including at end of life, both in hospital and community settings. The BGS has a number of Special Interest Groups (SIGs) concentrating on various issues of interest to our members. This submission has been drafted with input from our End of Life Care SIG.

1. What significant changes have you seen in how palliative and end of life care is being delivered as a result of the pandemic that you expect to last into the long-term?

Members identified that during the pandemic there was an increased prominence of the palliative and end of life care needs of people with multi-morbidities and particularly those with dementia and frailty. There has also been better recognition of severe frailty and dementia as conditions with a significant impact on survival from acute illness. In addition, there has been an increase in discussions about the benefits and burdens of aggressive hospital treatment. While members acknowledged that this has at times been poor (eg, blanket application of DNACPR orders in care homes), it was felt that overall the increase in conversations about how and where older people want to spend their last days has had a positive impact on planning for better, individualised end of life care for older people.

The integration of services was identified as a positive development during the pandemic with services working better together across health and social care and across a range of settings. Members also identified that the pandemic has encouraged rapid sharing of palliative and symptom control guidance internationally which is crucial to sustain the sharing of knowledge and best practice. There has also been rapid upskilling and innovation, particularly regarding the use of technology, eg, telemedicine, education and connections. It will be important to retain the lessons learnt from this, especially to ensure that in person activity is targeted towards those who need it most.

2. What significant changes have you seen in palliative and end of life care needs as a result of the pandemic that you expect to last into the long-term?

Members identified that the pandemic has given the public wider exposure to death, dying and bereavement and expressed a hope that this would result in a better understanding among the general public of the process of death, dying and bereavement. Bereavement support is however still necessary and it was identified that the support available during the pandemic has not been adequate for some people including some older people, people who are digitally excluded, have sensory impairment or otherwise experience difficulty with remote technology.

3. What positive ways of working and innovative approaches to delivering palliative and end of life care have been rolled out during the pandemic that should be supported to grow?

Members highlighted that the pandemic brought enhanced cooperation and integration between palliative care, emergency departments, acute medical specialities and geriatric medicine. During the pandemic, palliative care nurses have worked alongside ward nurses, helping with symptom control and communication with relatives. This was vital to ensure the provision of good end of life care in a crisis when resources were stretched and families unable to come into hospital. While this has been identified as a positive development, it has been identified that additional resources would be required to continue this in the long term as this work was conducted at a cost to the palliative care nurses' regular workload.

It was also identified that additional funding and steps taken to reduce paperwork during the pandemic improved patient care.

'Faster and better access to NHS funded care.' - member of the BGS End of Life Care SIG

'Ability to sort out discharge first and then decide who was paying speeded up processes to the benefit of patients.' - member of the BGS End of Life Care SIG

'Staff had more time to care with less paperwork.' - member of the BGS End of Life Care SIG

4. What shortfalls in the provision of palliative and end of life care have been exposed by the pandemic?

Several members of the BGS End of Life Care SIG identified the experience of older people living in care homes during the pandemic and the lack of palliative care available to those who died in care homes as a shortfall. Some identified this as exposing how underfunded and under-resourced the social care sector continues to be.

'During the pandemic many older people died in care homes with very little access to palliative care.' - member of the BGS End of Life Care SIG

'Community social care completely overwhelmed by the pandemic, the lack of capacity in community health care. This has prevented many dying in their preferred place of death.' - member of the BGS End of Life Care SIG

Some members also stated that the pandemic exposed a lack of availability of equipment in different settings. This included social care settings experiencing difficulty in accessing personal protective equipment (PPE) and infection control resources as well as people at home not being able to access hospital beds and lifting equipment. This has a fundamental impact on the care that can be provided in those settings and on the experience of the patient.

It was also identified that the pandemic exposed a lack of support services available to staff, both in terms of their professional development and their own wellbeing.

'The continued paucity of seeing reflective practice, clinical supervision, mental wellbeing, coaching and counselling as a fundamental part of practice rather than an add on. The abundant need for them has been exposed by the pandemic.' - member of the BGS End of Life Care SIG

5. If you are a frontline worker, what has been your experience of working within the field of palliative and end of life care during the pandemic? What were the key challenges? How might these experiences shape future care you provide and impact your professional and personal life?

All of the members of the BGS's End of Life Care SIG are frontline healthcare professionals – for this question, we have chosen to share their verbatim comments, rather than paraphrasing.

'Heartbreaking. In the field of geriatric medicine death is a normal part of our practice. We do our best to help people and their families prepare for their death and to ensure it is as comfortable and distress free as possible.'

'During COVID people died alone, without family to comfort them and often with no one by their side due to the pressure of work. If someone was there, they were behind a mask and gloves.'

'On non-COVID wards patients continue to die and their carers' access to them in their dying days is very limited by COVID visiting, use of gowns and gloves. Heartbreaking to see carers' holding their loves ones' hands in dying moments with gloves on or people not able to see each other's faces properly for the last time.'

'For patients with sensory impairment and delirium it was even more distressing because they could not understand where they were or what was happening.'

'Giving families terrible news on the phone and hearing their distress but not being able to give proper comfort was awful for everyone. Breaking bad news over the telephone is really hard, and the toll of doing so several times a day for weeks on end is soul destroying.'

'Geriatricians often had to choose between supporting their community teams or stepping back into the hospital completely. This was hard to do as either way feelings of guilt about not doing enough or not supporting other team members enough.'

'That care is delivered and experienced at micro level – but what happens at meso and macro level influences what we can do – and in the pandemic it exposed how powerless we were at micro level to be able to care in the way we wanted. Huge experience of

moral injury and subsequent consequences on staff as individuals as well as health care workers.'

'How important senior, local, regional and national leadership and management is to adjust and adapt immediately to meet the constantly changing and exhausting challenges of care. Where leadership and management is in tune with the 'coal face' it can make a huge difference.'

'I think we should also remember all the hidden heroes of the pandemic – the less visible workforce that keep the hospitals running and the logistics going. It is a timely reminder that it's not just the health and social care workforce that enable care to be delivered.'

'On the positive side, everyone really pulled together, we implemented change rapidly and managers were very supportive. Bureaucracy melted away for a few weeks.'

6. If you are a manager or leader within an organisation that provides palliative and end of life care, what impact has the pandemic had on the operation of your services and staff?

Members identified that services were redesigned to give more responsibility to advanced nurse and clinical practitioners and non-medical prescribers. People were also empowered to work in a more integrated way with less silo working and more respect for different roles and services.

The significant impact on staff wellbeing was also identified with members saying that staff have significant levels of emotional fatigue and moral injury meaning that they cannot work at normal capacity and tempers are frayed.

7. If you are an informal carer of someone currently living with a life limiting illness, what was your experience of providing care during the pandemic? What were the key challenges and what, if any, support did you receive?

Care home visiting was identified as the biggest challenge in this area:

'Care home visiting – completely changed our lives in a bad way and showed how person-centred, relationship, family care is hijacked by biomedical safety as well as what support care homes could access during the pandemic.'

8. If you are a bereaved family member or friend of someone who died during the pandemic, did your loved one receive good palliative and end of life care? What kind of support did you receive as a result of your bereavement?

While most of our members responded in a professional capacity, one member did comment on this question:

'As a family carer working in palliative care at a senior level – I was unable to ensure my mother received the right palliative and end of life care because of care home visiting restrictions. She suffered for some of her end of life/actively dying period. There was no systematic way to identify that I may have bereavement support needs.'

9. If you are a non-medical organisation, how have you supported people who have been bereaved during the pandemic?

Not applicable

10.If you are a representative organisation of a group known to have had poor access to palliative care, how has the pandemic impacted access to care and are there any specific impacts of the pandemic on the experience people have had of death, dying and bereavement that are disproportionately or solely felt by members of the group you represent?

BGS members are primarily concerned with older people, a group that fared particularly badly during the pandemic. Members identified the significant impact of visiting restrictions on older people living in care homes and the detrimental effect this had on the mental and emotional health of many residents. It was also identified that medical care for residents in care homes deteriorated at the beginning of the pandemic as healthcare professionals were unable to visit. The BGS sought to fill this gap with guidance on the delivery of medical care in care homes and while there has been some improvement, members feel there is still a significant unmet need.

Older people often struggle to access health services using digital technology which means that the lack of face-to-face appointments to access medical care has impacted significantly on this group.

Thank you for the opportunity to contribute to this review into the impact of COVID-19 on death, dying and bereavement. If you would like to discuss our comments further or to further involve our End of Life Care SIG in your review, please contact our Policy Manager Sally Greenbrook on s.greenbrook@bgs.org.uk and she will be happy to make the necessary arrangements.

Yours sincerely,

Dr Premila Fade
Co-Chair
End of Life Care SIG