

Response to the All-Party Parliamentary Group review into the lasting impact of Covid-19 on death, dying and bereavement

Introduction

On behalf of the members of the Association of Palliative Care Social Workers (APCSW) we welcome this review. All quotations (shown in italics) are from palliative care social workers who are members of the APCSW.

Our members are specialist palliative care social workers who are part of multi-disciplinary teams, working with people receiving palliative care in hospices, hospitals and the community. We provide a variety of support to the person and those that are important to them. This can include sourcing care at home, accessing other services, help with housing and debt, advocacy, working with schools or employers, or offering psychosocial support. We help people prepare for the end of their lives through advance care planning (ACP) and psychosocial interventions, and provide bereavement care for loved ones and relatives.

The APCSW Response

This response is based on a recent member focus group as well as discussions and written reflections by members throughout the pandemic (please see appendices). These testimonies show the effect of the pandemic and restrictions on palliative and end-of-life care has been profound. Some services have been reduced due to Covid restrictions, financial pressures and staffing problems, and this has impacted heavily and irretrievably on terminally ill people and those close to them. Staff, including social workers, have faced fear for their own safety and that of their families, and in some cases extended illness; witnessed repeated trauma; and worked at a level that has left them chronically exhausted. At the start some social workers found themselves side-lined and also denied access to PPE.

“I can remember being told we couldn’t go onto the inpatient unit to reduce footfall, and one social worker reflected that it was the worst day of her career to be told we couldn’t see clients and patients...and we fought hard to get back on, even though they were terrified, and developed a Dunkirk spirit’... because patients needed us, cos it was impossible to work virtually with people.”

But accounts from our members show that social workers have shown courage, resilience, compassion and creativity. They have demonstrated leadership in developing new ways of working. Barriers to change have been lifted, roles have become more flexible, staff, patients, families and communities have come together in a spirit of shared humanity.

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?

Place of death

Some social workers reported more patients choosing to die at home. People were anxious to avoid hospital for fear of contracting Covid, and being unable to see their loved ones.

“... it was the only way they would get to see spend any time at all with their loved ones or relative some we saw an absolute flip in people wanting to go home, people with much more complex symptoms...were being sent home”.

This was a concern because some of these patients had complex symptoms, and would ordinarily be considered unsafe to discharge. They were going home to die without appropriate equipment or care packages, and sometimes to inadequate housing.

However, some positive learning from some cases was that these higher risk discharges enabled more people to exercise their right to make an informed choice about where they wished to die.

Sadly, other social workers reported a rise in people admitted to nursing homes to die, especially early on, without due consultation. *“There was a directive that anyone who could leave the hospital would leave and would have no choice about the care home they went to where – to free up hospital beds”.* There were more *“fast-tracks into nursing homes for end of life care – either because they couldn’t go home, or didn’t know they could, or weren’t asked.”*

Impact on Hospice Inpatient Care

Some hospices significantly reduced or shut their inpatient services during the pandemic, due to safety issues, staffing, and/or funding pressures.

“We had a number of nurses leave and our in-patient unit has been closed since July this year because we haven't been able to recruit sufficient nurses to operate safely - we are now due to re-open in November but with 2 beds [out of 15] initially. Not having this available has definitively highlighted how essential...hospice care is, especially in supporting the most vulnerable...I worry that the pandemic may have a long-term impact on hospice provision through the lack of fund raising etc.” (Palliative care social worker)

“Our hospice inpatient unit was shut for 8 months, and has only re-opened 4 of its 10 beds so far”. (Palliative care social worker)

However, some hospice inpatient units remained open or even expanded to take patients from local hospitals (more in later section).

Visitors

Visitor rules at hospices have traditionally been very relaxed; but as in other settings, visiting has been severely restricted, with future prospects uncertain. This has had a huge impact, in multiple ways:

“Families are not being allowed to see a loved one, touch a loved one, or give someone a well-needed hug. This has been so missed both with our patients and families, work colleagues and in our own personal lives.” (Palliative care social worker)

“I have heard family members expressing huge guilt that they couldn't cope and allowed their loved one to go to a place where they may be at risk of contracting the virus and wouldn't be able to see loved ones... pre-Covid... the hospice was... a safe haven where the whole family would be supported. (Palliative care social worker)

One social worker spoke of a patient who had three daughters and has to choose which two would be allowed to visit, as it had to be the same nominated relatives each time. (Palliative care social worker)

Curtailed day care and outpatient services

Day care services - where patients could attend groups, therapy and provide respite for carers - were permanently closed in several hospices. Other hospices reduced or closed services.

However there has been creative development of online options as shown below.

Use of technology

The use of technology has irrevocably changed the way end-of-life care is delivered. Everyone had had experience of delivering care virtually. Assessments, family meetings, advance care planning, advocacy and emotional support have all been conducted online.

“We all learnt how to Zoom, Teams and we made sure that every family could contact their family in this way; with discharge planning meetings, ACP – now we can say to our patients ‘who else would you like to invite’... and if they can't come, then get them on Zoom or Teams...that is the way forward.” (Palliative care social worker)

But this can compromise the delivery of care. There was particular alarm about fast-track/CHC assessments and ACP being done virtually, and that safeguarding issues could be missed.

Impact on team and inter-agency working

The pandemic has afforded social workers an opportunity to integrate more closely with other members of their own organisation, and across agencies. The sense of being ‘in it together’ forged closer bonds and built mutual respect and trust.

“We worked across the hospice; we went in and delivered patient meals, like a HCA role...I also sat on reception ...and the amount of social work I did in that role was astounding. That was really lovely and gave me a much wider view of how other teams worked.” (Palliative care social worker)

However, there were other instances of people working from home feeling isolated. Others spoke of tensions, when certain teams were furloughed, or allowed to work from home, while others were required to work on the ‘frontline’.

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?

Changes in the complexity of need and presentation of conditions

Social workers reported an increase in patients and carers with complex issues and multiple co-morbidities, as well as high levels of anxiety, depression and other mental health conditions. Palliative care social workers found themselves increasingly working outside their usual remit to support these patients, many of whom could not access specialist mental health support due to lack of services and/or long waiting lists.

People are presenting to services later in their illness, due to diagnoses being missed or treatments delayed, so they are less able to benefit from palliative care services such as rehab, emotional support, and advocacy. However, one social worker based in a community team, reports more referrals *earlier* in patients' illnesses due to increased awareness of their service.

The effects of the pandemic have compounded the challenges of living with a terminal illness, with often devastating effects; for example, Covid has made it even more challenging and time-consuming to access housing, benefits and other social services; time and energy that palliative care patients don't have (see 'APPG No Place Like Home' report for detail).

Impact on carers

Grave concerns were expressed for the wellbeing of carers. With health and social care services drastically limited, the burden of care fell increasingly to family and loved ones, and this situation continues.

With hospice services, as well as other community resources, limited or shut, opportunity for carer respite has been drastically reduced. There are many families and carers whose own health is now compromised or who are on the brink of crisis.

Even when help was available, fear of letting carers and professionals into the home and contracting Covid, inhibited many families from accepting support. They were scared to go out, scared to let family or friends visit; many patients did not see loved ones for months on end, sometimes dying before they had opportunity to meet.

"There is a fear of carers, and of people who may not be vaccinated, coming into the house... and for palliative care patients who can't have the vaccine, or for whom it's not effective, that fear is even greater now that social distancing has stopped." (Palliative care social worker).

"...we found many patients reluctant to have visitors and this impacted on being able to offer them the support they needed." (Palliative care social worker)

Carers also faced difficulties such as experiencing their loved one die at home with limited support (especially distressing if this was not by choice).

"...you could see the fear in some people, having someone home who was dying. and the services in primary care were scant and people didn't have as much support." ((Palliative care social worker))

In other cases, social workers spoke of witnessing unbearably painful situations when people were not allowed to visit their loved ones in hospices or other settings and had to say saying goodbye over an iPad.

“I supported a number of carers in crisis who didn't know where to turn. I believe there is a lasting element of post traumatic stress for many people”. (Palliative care social worker)

Impact on safeguarding

A potential for an increase in safeguarding issues was noted; perhaps as a result of families being at home more, under increased pressure, and without support and respite. As families were not accessing other services, it may be that it was falling to palliative care staff to identify these situations.

Others reported that it was significantly more challenging to safeguard without seeing people or visiting the home. Obtaining a Deprivation of Liberty Safeguard order was more arduous than usual, and it was difficult to consult with families, as per good practice.

“You can't explain it the same over the phone – saying that you are putting paperwork in depriving them of their liberty sounds so harsh, it's an awful phrase. It's so much easier to do face to face.” (Palliative care social worker)

Increased demand for bereavement support

Bereavement services were already over-subscribed and under-resourced, and the pandemic exacerbated this. Most social workers reported a significant increase in counselling referrals, and long waiting lists.

“Waiting times have gone from 4-6 months to 8-12 months at our hospice.” (Palliative care social worker)

This is due to a variety of factors; increased demand, closure of other community support services, increased public awareness of grief, readiness to accept face-to-face counselling, and more complex cases requiring greater resource.

The complex nature of grief experienced during the pandemic – including multiple losses, disenfranchised grief, the restrictions on traditional mourning/death rites, not being present when loved ones died - means that there is extraordinary demand for bereavement support which shows no sign of diminishing.

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?

There have been a range of creative and inspiring social work practices developed in response to the pandemic.

Increased powers to commission care and/or direct hospice funding

Some palliative care services found they were given more authority and funding to deliver care. At one hospice social workers were empowered to do their own fast track assessments

and commission care; including organising next day 24-hour care packages for people going home to die. Being able to source care providers while assessments were in progress promoted proactive risk management as well as speedy and effective discharges. (Palliative care social worker)

This hospice was also commissioned (and paid) to undertake carers assessments on behalf of the local authority, and in future may also carry out care act assessments. (Palliative care social worker)

Another hospice set up a care coordination service, employed two additional social workers and was awarded Trusted Assessor relationship with the local authority and the care coordination role, which has improved working relationships between the two organisations. They are able to identify palliative patients more quickly and reduce hand off to different services. (Palliative care social worker)

Other hospices had beds contracted from them by their local hospital for patients meeting certain criteria. This improved links with the hospital and discharge planning team and has resulted in more appropriate referrals. (Palliative care social worker)

More inclusive and efficient ways of working (online and virtual)

The pandemic has galvanised innovative and effective use of online and virtual working.

“It felt like the walls of the hospice were well and truly shaken and we were all inside trying to stand up... but it has dragged the hospice a long way into the future with using Sharepoint and Teams etc.” (Palliative care social worker)

Many hospices successfully developed virtual groups for patients and carers. Some carers found it easier to engage with online support, as they didn't have to arrange care for their loved ones. However, a substantial number don't like, or are unable, to use technology in this way, so traditional forms of support are still vital.

Online working has enabled easier coordination and more inclusive multi-agency, professional and family meetings, saving time and resources.

“We had a complex hospital discharge for a patient who had ignited his oxygen at home; we were able to get the hospital staff, oxygen service, GP, social care, legal team, fire service, human rights advocate, the patient and his relative, all on one video call; that would never have been possible in person”. (Palliative care social worker)

“Rather than driving 45 minutes there and back to a patient's house to call the DWP or housing together, I do a three way call, which can be completed in a fraction of the time! The patient or carer can be part of the call and have more ownership of it with me in the background to support.” (Palliative care social worker)

Social workers have been surprised at their ability to build positive working relationships and work effectively over the phone.

“We also discovered that we could do a lot of social work on the phone, which we were quite resistant to at first...And a lot of our clients have reflected that they quite like it; it aids disclosure and sharing when you aren’t in the same room”. (Palliative care social worker)

However, virtual working clearly has limitations and should not become the default method of working.

“CHC teams do DST meetings virtually and it can work well, but I attended one where daughter was carrying the laptop over to the hospital bed, and the assessor couldn’t see her at all.” (Palliative care social worker)

Increased awareness around death and dying & advanced care planning (ACP)

Some workers felt that the pandemic had increased public engagement with issues of death and dying, bringing opportunities to reduce taboo and stigma.

One example came from a social worker serving a community where discussion of death is traditionally avoided, who reported that people were now more willing to engage in planning their end of life care and wishes for their funerals. (Palliative care social worker)

However, it was apparent that non-palliative care specialists sometimes lack understanding, skills or confidence to handle such conversations with due sensitivity.

“At the beginning they employed nurses to go into care homes and talk to people about ACP out of nowhere, and it kind of felt like, right you’re in a care home we need to think about when you die, really quickly. And I just wonder how that might have felt for patients and families, it was kind of done en masse.... ACP needs to be done in personalised way.” (Palliative care social worker)

APCSW members developed guidance and training to support non-specialist colleagues to talk about Advance Care Planning and death and dying (see appendix 1). Some members were commissioned to deliver training around bereavement to staff working in a high security forensic mental health service.

Importance of the role of social work in palliative care

There was increased recognition and appreciation of the role social work plays in supporting patients, carers and other staff.

Social workers demonstrated enormous resilience, and flexibility in taking on additional responsibilities and working in new ways to meet changing needs. Social work’s unique skills and qualities proved invaluable; the ability to combine practical expertise such as advocacy, MCA, DoLs, with emotional and psychological support; to use a systems approach to work with the whole family not just the patient, to identify carer needs and to be willing to undertake sensitive and difficult conversations, and to challenge when discriminatory practice adversely affected particular individuals or groups, or perpetuated existing health inequalities.

(See appendix 2 for details of the palliative care social work role in the pandemic).

Other Clinical Practices

One hospice put together packs for people caring for someone at home, containing helpful information...essential items such as aprons and gloves, what to do after a death and a blank chart for important contact details. (Palliative care social worker)

Another hospice is looking at a wellbeing model in place of its day services, which would provide group rehab, gym, exercise and therapy (Palliative care social worker).

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

The pandemic compounded and exacerbated existing shortfalls and gaps in palliative care and other health & public services, including:

- Inadequate provision to die at home, especially with complex needs.
- Shortage of trained palliative care nurses for inpatient and community
- Shortage of paid carers, district nurses, social care staff & palliative care social workers to enable dying people to be cared for safely at home.
- Ongoing high levels of sickness and stress in the workforce
- Inadequate funding for hospices and palliative care. Some services were given extra money at the height of the pandemic which has now been withdrawn, but the increased demand remains.
- A lack of skills and confidence to talk about death, dying and advance care planning amongst generalist staff (GPs, Social Workers, Hospital Nurses, Doctors)
- Overstretched public services are unable to respond to the needs of people with terminal illnesses in a timely manner: *“the DWP and Housing were on hold and people were falling further and further into financial difficulties and living in really unsuitable housing, and it was just a stock phrase ‘we’re not doing anything at the moment’ but unfortunately the people we work with don’t have the luxury of time.”* (Palliative care social worker)

The ramifications of this continue to be felt. (See ‘No Place Like Home’ report).

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?

Practical, emotional and physical challenges of working within COVID-19 restrictions and guidance such as PPE, additional infection control and visitor restrictions

The impact of visiting restrictions on patients, and therefore on staff, was immense. Social workers spoke of carers telling them about loved ones being taken off in an ambulance and saying ‘I never thought that would be the last time I’d see them’.

It made it more challenging to support patients with additional needs.

An autistic man with a terminal illness was taken into hospital; he was scared and anxious, unable to communicate and became aggressive. His family were not with him to explain his

needs. After he died, the family wanted information. The social worker concerned found it incredibly difficult telling the family that he had been so agitated he needed to be sedated prior to his death. (Palliative care social worker)

Social workers have had to contend with the challenge of making an empathic connection with patients when much of their personal identity is concealed by PPE:

On my return back to work for the first time in my career I have been wearing scrubs, full-face shields, gloves, apron or gown and eye protection in the inpatient unit. (Palliative care social worker)

Working with uncertainty and changing conditions

The ongoing uncertainty about how and when the pandemic will end has been punishing. Rapidly changing guidance and clinical practices have contributed to staff exhaustion, confusion and feeling unsafe.

It was extremely distressing and difficult for staff to witness this and manage the constantly changing Government guidelines and people's expectations, anger and distress - as well as fulfilling their responsibilities and managing staff sickness etc. (Palliative care social worker)

"...not knowing when it was going to finish and not being able to put an end date on it; that exhaustion has just continued." (Palliative care social worker)

"It was like walking through treacle sometimes trying to do things for people, due to the uncertainty and upheaval in other organisations' working practices and policies; the local authority wasn't visiting people, but we were." (Palliative care social worker)

Changes to the type of care you are expected to provide & the settings in which you work

As stated, social workers worked dynamically and flexibly across a range of different settings during the pandemic; much of which has continued. Some remained in their usual environments, others were working entirely from home, while some were drafted into other settings.

Social workers supported their MDT colleagues. For example doing basic medical assessments to report back to nursing colleagues, working on reception or as an HCA, carrying out local authority carers assessments; one social worker was even asked to train to verify deaths (they rightly declined)! A social worker in a senior management role took on responsibility for managing their hospice's single point of access for all new referrals.

There were mixed opinions about the effects of this; it encouraged development of new skills and knowledge, as well as cross-organisational working, but in other cases it created unhelpful divisions.

"Everyone in the hospice was doing something different, front line staff were in every day, some working from home, some furloughed and it almost created a bit of a divide, and we are trying to build up those relationships again". (Palliative care social worker)

Impacts of the pressure of the pandemic, and caring for people who have died during this time, on your mental health and any support you have received

Staff stated unequivocally that the pandemic has had a profound and long-lasting emotional and psychological impact.

“The thing that stays with me is how brutal it all was to begin with. It was absolutely brutal – it was no visitors and no choice about where you were ‘decanted’ to certainly from acute trusts.” (Palliative care social worker)

“It felt like the walls of the hospice were well and truly shaken and we were all inside trying to stand up.” (Palliative care social worker)

Social workers talked about the fear and anxiety they experienced, especially when the pandemic first hit.

“At the beginning we were terrified of Covid, of walking out of our office into a cloud of Covid and contracting a horrendous disease that potentially would kill us, but still balancing that with the needs of the people we were working with...” (Palliative care social worker)

‘I caught Covid and didn’t work for 3.5 months...and it was scary, and scary to think that having a plastic apron and a mask was really going to stop you from getting this...You look back on some of the things you were doing, and they do haunt you...it was frightening, as much for staff as patients.’ (Palliative care social worker)

Witnessing so much death and dying in such harrowing circumstances will have lasting effects. Being unable to help and support people according to social work values and ethics lead to moral injury; for example, not being able to bring relatives together, or providing substandard care due to restrictions or lack of resources.

I was working with a young Mum, who was not able to see her son and she knew she wouldn’t see him before she died. (Palliative care social worker)

One social worker was asked to make bereavement calls on behalf of the local hospital who couldn’t keep up with demand. She describes feeling “haunted” by the memory of sitting at her kitchen table making “bereavement call after bereavement call” (Palliative care social worker).

Bearing witness to trauma, highly charged emotions and an increased workload which show no signs of diminishing has taken a heavy toll on staff.

Support Received

This issue was not discussed at length. Some social workers described receiving informal peer support from colleagues, and from family and friends.

Within weeks some hospices began providing online Schwartz Rounds and Team Time a new scaled down version for individual teams (<https://www.pointofcarefoundation.org.uk/our-programmes/schwartz-rounds>); this enabled people to connect and share experiences and support one another across sites (Palliative care social worker).

New positive work habits or ways or working

Working from home significantly improved work-life balance for some, although others find it harder to maintain boundaries between home and work as a result.

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 your staff?

During the pandemic some social workers in management roles stepped up into more senior positions with more inclusive responsibilities for staff and services. This development reflected recognition of the increased relevance of their skills in staff support and of the transferability of core social work skills of holistic assessment, strategic thinking and tactical agility, in a situation of crisis and rapid change.

Financial sustainability of your service

Many hospices experienced financial hardship; as charity shops closed and fundraising events were cancelled, cutting off a major source of regular income.

“The immediate adverse financial impact of this could be approximately a loss of £1 million per quarter. (Palliative care social worker)

Impact on Volunteers

Hospices are heavily reliant on volunteers to run many of their services; staffing shops, helping with administrative and caring duties, befriending etc. These volunteers largely fall into the demographic of older people, many of whom were instructed to shield and who continue to need to self-isolate.

Conclusion

We would like to conclude with a few quotes from a reflective diary written at the height of the pandemic by one of our members that remain relevant now:

“Death in the time of COVID -19 is lonely and silent”.

“The new challenges that will be faced in the NHS and Social Care, care homes, prisons and the impact on the voluntary and charity sector will now change forever.

There is so much uncertainty about the virus and how long it might take before life begins to return to normal and how the provision of health and social care can come out the other side of this pandemic stronger and better prepared to face future challenges. It will need an urgent review.” (Palliative care social worker).

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Appendix One

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We need to talk about dying!

Respect, dignity and choice at the end of life are fundamental human rights. The opportunity to talk about death and dying is crucial, especially in this time of COVID-19. Social workers have the skills but often lack confidence. We offer some brief guidance based on our experience as palliative care social workers.

Prepare yourself:

- It is normal to feel daunted, overwhelmed, or unsure of yourself, especially if you are new to doing this. It may help to start by thinking and talking to someone you trust about your own end of life wishes.

Opening the conversation:

- Try to find a time when the person is comfortable and alert, maybe after they have taken pain medication or had a rest. Does a family member or carer need to be present? Try to ensure that you won't be interrupted.
- A good starting point can be to ask what they know about their condition or illness. What do they think is happening? Or refer to a recent conversation: "I understand that the doctor has given you some news about your condition"
- Sometimes the issue can arise organically, via a cue from the person. They might say something like 'I am not sure I'll live to see Christmas', or 'When the inevitable happens...' You could say, "Tell me more about what 'inevitable' means to you? or "What would that mean for you if you weren't here for Christmas?"
- Sometimes people find it easier to begin by talking about practicalities. You can ask "Is there anything you are worried about?" "What keeps you awake at night?"

Managing the conversation - communication skills:

- Try to sit alongside them – so you are at the same level, and maintain open body posture, return eye contact, and show you are listening.
- Use simple direct language and avoid euphemisms.
- Allow silences and pauses – these give the person time to think and process.
- Use techniques of active listening: pick up cues, paraphrase, summarise.
- Leave space for questions.
- Encourage the person to talk; they should be saying more than you!
- Some people may respond with jokes or 'gallows humour' – take your cue from them but give them chance to talk more seriously as well.
- It can be tempting to jump into problem solving and finding solutions; sometimes this is a way of coping with your own feelings of pain and helplessness. Resist!

- Empathy is crucial. Show someone you have heard their story and acknowledge how it feels. Phrases such as “I can see how very painful/upsetting this is to think about”, “It is entirely normal to feel overwhelmed/full of grief/frightened.” “This has been so challenging for you all”. “It must be so hard to live with this uncertainty”.
- The process can be extremely tiring, especially for someone who is ill. You may have to take breaks. You may need more than one conversation; go at their pace, do what you feel comfortable doing or have time to do.

Things to discuss:

- What are their main worries or concerns; what would help them feel more in control or reduce anxiety and worry. Do they want help to talk to their families or loved ones?
- Advance care planning: “How/Where would you like to be cared for?”, ‘Who do you want to be involved?’ “What would you not want to happen?”
- Recording and formalising their choices and decisions: Information and support with Care Plans, Advance Decisions, Lasting Power of Attorney, wills, funeral plans.

Closing the conversation

- Summarise what you have talked about, including any plans made and actions required by them and you. It may be useful to write these down.
- Do they have unanswered questions?
- Check out how they are feeling now and thank them for sharing with you.
- With consent from the person, inform family members and other professionals of the discussion, and that the person may need some extra TLC / support or care at this time.

Self-care

- These conversations are emotionally demanding. Take time to ‘decompress’ afterwards.
- They may elicit powerful emotions or trigger painful memories of your own. It is important to acknowledge this and perhaps get support from a supervisor colleague or other trusted person.

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More information: <https://www.apcsw.org.uk/wp-content/uploads/sp-client-document-manager/1/palliative-care-social-work-for-covid-19-version-of-8-april-2020.pdf>

Appendix 2

Printed in BASW Magazine, 'Professional Social Work', December 2020

A Reflection of the challenges faced in a hospice as a Palliative Care Social Worker during the COVID – 19 pandemic by Stella Murray

As a social worker of 30 years, working in a hospice during Covid-19 has been the most challenging experience in my social work career.

The hospice covers two boroughs in London and is five minutes away from a hospital recording the highest death rates during this pandemic.

At the end of February, I met a gentleman with cancer who was referred to the hospice for physiotherapy and emotional support. A few days later I was informed that he had died in hospital after testing positive for Covid. Because I had been in contact with him, I had to go into isolation for a week.

On my return to work, for the first time in my career I was wearing scrubs, full-face shields, gloves, apron or gown and eye protection in the inpatient unit.

The hospice had to make an appeal for personal protective equipment (PPE), as supplies had run low.

Death in a time of Covid-19 is lonely and silent

Dealing with the death of a loved one is one of the most difficult things we have to go through. Covid-19 has made it even harder for people to say goodbye.

Mourning in coronavirus means something unimaginable for the relatives and for the dying - they are not allowed to be together or say their final farewell.

The wife of the gentleman who died of cancer told me she had been unable to visit him in hospital and instead had a daily call from the doctor. She said that her husband was a practicing Hindu and religious rituals would have been very important for him.

The pandemic impacted on people practicing their religion with worship and services cancelled. Our local faith leaders continued to come into the hospice to meet the spiritual needs of our patients and families. Social distancing rules applied and they were issued gloves, masks and aprons.

The man's wife was grateful that the hospital chaplain said prayers for her husband and found this comforting. She said not being able to say goodbye was a harrowing experience when he died. She was also not allowed to see her husband in the funeral parlour due to restrictions.

At his funeral, four weeks later, only five visitors were allowed. In the early days of the pandemic, no family members were allowed to attend.

Some of our patients have no next of kin or families who can afford a funeral. During the pandemic I have had two cases I had to refer to the local authority due to no money for a funeral.

In another case, I was dealing with a patient who came to us from hospital for end of life care who had two cats that needed looking after. Her property had been burgled while she was in the hospice.

At the height of the pandemic the local hospital mortuary became full and extra space had to be provided in another borough. Funeral parlours also became full due to the delay in cremations and burials. A family member informed me that the parlour their deceased relative was in was charging £200 a week for storage.

I remember travelling to work in March and April past the local ambulance station and seeing the ambulances lined up on both sides of the street ready to be called. At work and at home I could hear their sirens in the background going to the local hospital day and night.

People cannot grieve together properly as a family

Hospitals and nursing homes have either not allowed visitors or where visitors have been allowed it has been limited to one visitor if they wear PPE.

Touch is so important for everyone's wellbeing. How we feel about others and how we use verbal communication is so important.

During the pandemic it's been so sad that families have not being allowed to see a loved one, touch a loved one, or give someone a much-needed hug. This has been so missed both with our patients and families, work colleagues and in our own personal lives.

A simple touch or touching an arm or shoulder, giving somebody a hug, shows that we really care.

The emotional impact of social touch triggers the release of oxytocin, a hormone that decreases responses to stress. It could be a nurse holding a hand to reassure a patient before surgery, a carer supporting somebody with eating or a nurse supporting someone who is distressed.

Non-verbal communication - body language and tone - is important in exchanging information and building trust.

But during Covid, the use of the mobile phone, FaceTime, Zoom, Teams, Google Translate and video calls have taken over our daily lives and in our workplaces.

We had a young male patient from Europe who had cancer and was admitted to the hospice for symptom control/terminal care. His wife and young child were living overseas.

His family were unaware of his disease progression. He suddenly died and his phone was ringing on his bed table with a picture of his wife and son. His wife and son were on Facetime and the unit sister, a nurse and I were present when the news was told to his wife and child that he had died.

His wife wanted to see her husband and she was shown on Facetime that he died. It was very daunting and very emotional because it was a sudden death.

English was not the family's first language and the discussion was difficult. The grief was unbearable. I was involved in supporting family and friends to repatriate the body back overseas by land.

Facilitating family visits is a challenge

Some of our patients in the hospice had been transferred from hospital. Some family members were unable to see their loved ones during the pandemic for several weeks. I have had to facilitate family visits, farewell visits and final visits. We had discussions with the multi-disciplinary team on how to coordinate these visits through the hospice gate, patient's room window and the garden.

All visits have to be planned in advance. Children under 16 were allowed to visit at the discretion of the clinical services manager or the inpatient manager. No pets have been allowed.

If a patient is expected to die imminently two family members will be called and this may be extended to other key family members. PPE and social distancing rules apply.

It has been so heartfelt and humbling to watch families being reunited with their loved ones.

I supported a lady who was in the end stages of life and we were able to celebrate Mother's Day. The patient's daughter asked if her own daughter was allowed to see her grandmother in the garden and she would take responsibility for social distancing and the visit.

Access was given through the garden gate and watching the grandmother and granddaughter meet was truly moving. The laughter, smiles and emotions were so powerful and it was obvious how important this was for all of them. There was peace, tranquillity and watching the expressions of love and calmness within the family was so touching. The sun was shining and the garden was peaceful and looking beautiful.

A few days later we were able to celebrate the patient's 49th wedding anniversary. We decorated her room and the patio area with balloons, cards and banners. Her room was full of family photos that were done in a collage. Her daughter had arranged for hand statues to be done by an artist and when the moulds were finished the artist brought these to the hospice.

The daughter and her mum were clasping hands and the granddaughter and the patient had clasping hands. The artist was allowed to come to the hospice and took some photos.

The cook made 25 cup cakes and the celebrations touched the patient, her husband and her family. It made her feel very special.

In the last week of the patient's life her husband was allowed to come in to see his wife, wearing full PPE with masks and gloves. Only one visitor was allowed in the room.

On her final day, the patient's husband and daughter were able to be with her as she took her last breath and died in their arms surrounded by love.

The patient's son travelled from outer London and was allowed to say goodbye to his mum in a special room at the hospice. It was so important for him to do this.

One of our volunteers knitted pairs of hearts for the patient with the other being for their family. This has been used a lot and families love the connection they bring to their loved ones.

An extreme time for families and practice

This pandemic this is an unparalleled and extra ordinary public health emergency. The changes made in the last few months have been to protect our vulnerable patients, as well as our nurses, doctors, domestic staff and the wider health care team.

To those of us working in the hospice the outpouring of love from individuals and businesses in our community has blown us away.

The hospice's online resources have helped carers supporting people at home. It has produced information resources including moving and handling techniques and administering medication through a line and needle.

As social workers we have the knowledge and skills to support patients and families by reassuring, informing and supporting communities who are frightened, worried and wanting to stay well and have dignity in their end of life care.

It is clear that this pandemic will not affect everyone in the same way. The message from the government has been to stay home and stay safe within that home, in the assumption that everyone has a home that is safe and with which they have some autonomy.

With this pandemic there is a fear of the unknown and concern for what lies ahead, for us as social workers, our patients, clients and their families, our colleagues and their own families and friends. There are uncertain times ahead.

The mental health and wellbeing of families and professionals

Bereavement which is a difficult experience under any situation is taking place under very challenging circumstances during the coronavirus pandemic. How will we know who the bereaved families are? How they cope and are supported is a challenge.

Several UK bereavement charities and organisations offer guidance, advice and support to deal with bereavement during the pandemic; both the practical and psychological aspects. The hospice has made applications for bereavement grants.

Concerns have been raised about our responses to the increased anxiety and mental health needs of the population.

The mental wellbeing of all the staff working directly in the pandemic will have a huge impact on us and affect us physically and emotionally. The mental health of the nation is another concern.

The way this crisis has unfolded has meant that we have all sorts of new challenges in seeking to meet the health needs of our populations.

The new challenges that will be faced in the NHS and social care, care homes, prisons and the impact on the voluntary and charity sector will now change forever.

There is so much uncertainty about the virus and how long it might take before life begins to return to normal and how the provision of health and social care can come out the other side of this pandemic stronger and better prepared to face future challenges. It will need an urgent review.

When lockdown happened on the 23 March the government guidelines said that everyone must stay at home except to obtain food or medical supplies, take daily exercise or travel to and from essential work.

Emotions around the country have been expressed in different ways from scenes of panic buying to selfless acts of kindness where more than 600,000 people volunteered to help the NHS or vulnerable and older people in their communities.

During this pandemic I have felt stress, anxiety, grief and worry. Recording these experiences has helped me to keep track of my own feelings and views of what has happened and it has helped me reflect on my experiences the last few months.

When I look back on working during this pandemic there is a reasonable chance that I will have forgotten quite a lot of what has happened. I want to be able to read it and feel good about the things I have achieved.

Some lessons learned

Staff need to be given time/support to be able to reflect on what has happened during this pandemic.

I am so proud of everyone in the hospice for the way they have accepted the situation and just got on with it.

It has been important to take care of my family and myself and to try to eat healthy, exercise regularly and get plenty of sleep.

It is important to build a strong peer/support system using technology.

It is important to unwind and be kind to yourself. It is still hard to keep social distancing and not to have a hug.

Try to take deep breaths and do activities you usually enjoy if you can.

Stay informed of what is going on, but be aware there may be rumours during a crisis, especially on social media.

Seek help when needed if distress impacts activities of your daily life.