Supporting palliative care at home during COVID-19[1]

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Rachel France, Jitka Vseteckova, Susie Lapwood, Nia Roberts, Nicholas Jones and Kate Flemming

At a glance

Some patients with COVID-19 know they are dying and want to die at home, not in hospital.

We wanted to find out how they and their family or friends who care for them can be supported to make this happen well.

We did this by looking at what research other people have done, and any guidance that has been published.

The key things we learned are:

- Some carers can manage the person's medication at home if they are given the right support and information, some carers.
- There is technology that can help, but not all carers have access to the equipment they would need.

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[1] This article has not been peer reviewed. You should check the sources in the full article yourself. The views are those of the authors and not the organisations they work for, the NHS, the NIHR or the Departments of Health and Social Care. This is not a substitute for professional medical advice.
This is a plain English version of the article. The full article with references can be found here [https://www.cebm.net/covid-19/how-can-patients-with-covid-19-and-their-family-or-unpaid-carers-be-enabled-and-supported-to-manage-palliative-care-treatment-safely-and-effectively-at-home/]. An Easyread summary can be found at the same webpage.

- Information and education about their caring role and looking after themselves can help carers. But it is hard to deliver training during the pandemic.

Background

By late September 2020, there had been close to 1,000,000 deaths across the world linked to COVID-19. This includes around 42,000 deaths in the UK.

Many of these people died in hospital. However, some people chose not to go into hospital, but to get end of life care at home. Some people chose to go home from hospital when they knew they were dying.

Choosing to die at home rather than in hospital is nothing new, but during the pandemic, it has happened more often. When community services work well, they can support people who are dying at home by providing responsive care. This stops unwanted or unnecessary hospital admissions.

End of life care at home is provided by ordinary community health services and specialist palliative care services. The pandemic means the services are busier, and the risk of infection makes it harder for staff to work face to face with people who have COVID-19. This has meant informal carers may have to take on more responsibility for providing care.

On the plus side, community services are getting more resources. There are new recommendations for training non-specialists to deliver palliative care. There is more use of digital technology to support patients and carers, for example video consultations.

One challenge is that COVID-19 is unpredictable. Some people suddenly get worse. Some people unexpectedly improve. On average, people without COVID-19 receive palliative care services for five days. For people with COVID-19 this is just two days. That is the average, so for some people it will be longer or shorter.

People with COVID-19 who are dying will have symptoms. The most common are struggling to breathe (69% in one piece of research; 57% in another) and agitation (48% in one piece of research; 57.5% in another). These symptoms can be controlled with medication. People with COVID-19, and their family or friends who care for them, need to be prepared for these symptoms. These symptoms can be distressing for the patient and those around them. This can add to anxieties for the carers and make it harder to cope. In turn, this makes it more likely that people need to go to hospital as an emergency when they had not wanted this to happen.

Past research tells us that carers who provide end of life care feel better able to care when they get effective support. Things that helped most were getting information at the right time, and easy access to healthcare professionals for additional advice and support. We think this will be the same for carers of people with COVID-19. We think prompt, responsive support, along with information and preparation, will make all the difference for carers and the person they are caring for.

What we did

We did not go out and do new research. We looked at all the research we could find that would help us answer the question, ‘How can people with COVID-19 and their carers be supported to get good end of life care at home?’

We looked at research that was about palliative care for people with COVID-19 who were living at home independently or being cared for at home by family, friends or volunteers. We looked for anything about how health professionals and other services can support them, including educating and training a family carer to provide care, support in an emergency and out of hours care.

We did not find any research about people with COVID-19 or their carers and palliative care at home. So we looked at research about palliative care at home for people who did not have COVID-19, and recommendations based on existing guidance or expert opinion.

What we found

We found evidence from studies involving palliative care for people who do not have COVID-19 about:

- Supporting carers to manage medication to ease symptoms when someone is close to the end of their life.

- Using digital technology to support carers.
- Providing education for carers.
- Supporting carer well-being.

We found two charities (Help the Aged UK and Hospice UK) had produced guidance for carers, and a group of academics and health professionals had produced a website with videos on supporting people with breathlessness.

We also found a set of recommendations for healthcare professionals on how to support family carers, and a set of advice for healthcare professionals supporting patients with COVID-19 in the community.

Key messages from what we learned

1. Supporting carers to manage medication to ease symptoms when someone is close to the end of their life

Carers may already be used to supporting someone to take routine oral medication. At end of life, patients may need more than this. They may need injections. There may be a lot of different medications, all needing to be taken at different times. There may be difficult decisions about the right dose and timing. It may be emotionally difficult to give medication, knowing how it may affect the person. In normal times a healthcare professional would manage all of this. The pandemic means carers may need to take on some of this role.

We found several things were important if carers are to be supported to provide safe care for someone at home:

- **Address concerns about giving medication.**
  Carers worried about giving too much or too little medication, about not knowing enough about how the drugs work and about getting things wrong. Reasons carers thought they might get things wrong included because they were tired, did not understand the instructions, or things like poor eyesight and difficulties opening medicines. These need to be addressed by healthcare professionals.
- **Help carers to be organised.**
  Carers had concerns about remembering how much of which medication to give when and about keeping records of what they had done. Medication must be stored properly and thrown away when it is out of date. Carers can be supported by being given written instructions, shown how to use a diary, or by being reminded.
- **Empower carers.**
  Carers felt empowered once they were confident giving medication but disempowered if the medication didn't work or if the patient needed to go to hospital.
- **Have good relationships.**
  Carers needed to have good relationships with other carers and healthcare professionals to make sure medication was

given properly. Carers needed to know how to contact professionals for help when they need it. Healthcare professionals need to make sure all communication is clear.

- **Have good support**.
  24 hr telephone and in-person support was essential, along with medication being prepared in advance and troubleshooting guides for equipment.

2. Using digital technology to support carers

Involving carers in meetings with healthcare professionals, using video calls, may be a good way to support carers. It is important to make sure that carers have the right equipment to enable this to happen without hitches.

3. Providing education for carers

There is some evidence that information sessions helped carers to care better and to be happier with the care they give. However, the evidence is from series of sessions over several weeks, and this is unlikely to happen in the final phases of caring for someone with COVID-19.

A review of breathlessness services showed that information sessions with the patient and carer were helpful. However, these were over 4-6 weeks and so may not be helpful for COVID-19 patients.

Using on-line videos to prepare carers for palliative care services at home has been shown to be effective. However, existing videos may not fit with the way services are organised for COVID-19 patients.

4. Supporting carer well-being

A number of studies looking at carer well-being during palliative care were found. These included sessions for psychoeducation (education with added counselling or Cognitive Behaviour Therapy) providing information, stress management and promoting positive emotions. The sessions were seen as beneficial, but there was little evidence provided to back up these claims. It is not clear if the content of the sessions was helpful, or whether simply having regular contact with healthcare professionals was helpful in itself. The length of time for the support was generally greater than available for carers of COVID-19 patients. All studies were in countries with well-developed healthcare systems, so may not help people decide what to do in other countries.

5. Existing guidance for carers during COVID-19

Help the Aged, Hospice UK and the Learning about Breathlessness programme have given advice for carers during COVID-19. The guidance covered subjects like medication, toileting, breathing difficulties, patient anxiety or confusion, eating and drinking, the dying process and what to do after death. The Hospice UK guidance mentions having an Advance Care Plan. The guidance has been developed with carers but does not have sources or references to back up the advice.

6. Guidance for healthcare professionals supporting carers

One article by authors in the field of palliative care gives the following list of priorities:

- Provide personal protective equipment (PPE) and explain its correct use.
- Develop checklists for assessing a person's capacity to provide care, including readiness, burden and distress.
- Develop the capacity to assess and treat patients remotely, whilst including carers in the consultations.
- Encourage Advance Care Plan conversations.
- Thank and reassure carers.
- Encourage carers to use social networks and to help them feel empowered.
- Check guidance being published by relevant organisations.

The National Institute for Clinical Excellence (NICE) has produced guidance that suggests that carers may have to administer medication but does not say how to support people to do this.

So, how can carers be supported?

Services in hospitals and GP practices and other services in the community are changing and adapting all the time. The risk of passing on COVID-19 means that more services are being delivered remotely than before. This may mean better access for some carers but increased isolation and feeling a lack of support for others.

There is a lack of evidence that is relevant to giving end of life care to COVID-19 patients. This is because COVID-19 is different from other diseases where end of life care has been given. Carers may be afraid of COVID-19. They may catch COVID-19 and therefore be unable to continue giving care. PPE is vital but will affect communication with the patient.

However, this review suggests that some carers can be supported to provide end of life care at home. Healthcare professionals need to take the following steps to make this possible:

- Make sure the carer is willing and able and is not being pushed into providing end of life care at home.
- Give clear written details about the medication and instructions on how to use it.
- Give practical help such as pre-filled syringes or pill boxes to enable correct doses of medication to be given.
- Make sure carers know how to contact their healthcare professional, including out of hours.
- Arrange regular phone or video calls.
- Provide information and support resources as leaflets and on-line.
- Assess the carer’s emotional wellbeing and provide support.
- Signpost carers to bereavement support when appropriate.

Carers should check with their healthcare professionals that these have been considered. There are resources to help healthcare professionals and carers to discuss these issues, such as the Carers Support Needs Assessment Tool [http://csnat.org/].

These steps will need local protocols for healthcare professionals to follow, supported by national guidelines based on evidence.

Conclusions

- Support for carers must be provided when they need it. It must prepare them for what is coming and be tailored to their needs.
- We did not find any relevant evidence about carers giving end of life care to people with COVID-19 at home, or how safe this is for all involved.
- Research evidence indicates that carers can be supported to give medication at home to people who are near the end of life. This depends upon the carer being capable and having the right support and information.
- Digital technology can help provide support, but healthcare professionals should be aware that not all carers have access to suitable equipment.
- Providing information and education for carers that is relevant to their role can be helpful. However, COVID-19 makes it difficult to provide formal, structured sessions.
- Carers’ wellbeing should be supported as much as possible.

- Guidance has been adapted from existing guidelines. It is not based on evidence about supporting people with COVID-19 and has not been checked to see if it is effective during the pandemic.
- There is some advice for healthcare professionals supporting carers giving end of life care at home.

The authors

Rachel France is a Research Fellow at UCL looking at the social impacts of the pandemic. She has extensive experience as a systematic reviewer.

Jitka Vseteckova is Senior Lecturer in Health and Social Care at the Faculty of Wellbeing, Educations and Language Studies at The Open University. She regularly leads and contributes to systematic, narrative and rapid reviews. Her specialism is around ageing, care and caring, exercise, people living with dementia and people with learning difficulties.

Susie Lapwood is Emerita Senior Associate Specialist in paediatric and young adult palliative care at Helen and Douglas House Hospices, Oxford UK. She is a member of the Together for Short Lives / Association for Paediatric Palliative Medicine research group. She has worked as a general practitioner and is a GP appraiser.

Nia Roberts is an outreach librarian and information specialist at Bodleian Health Care Libraries. She regularly contributes to systematic reviews in population health and primary care.

Nicholas Jones is a GP and Wellcome Trust Doctoral Research Fellow at the University of Oxford, Nuffield Department of Primary Care Health Sciences.

Kate Flemming is Professor of Hospice Practice and Evidence Synthesis at the University of York, Head of Research and Clinical Innovation at Hospice UK and a Registered Nurse.

To contact the authors, email Kate Flemming at kate.flemming@york.ac.uk

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