

Looking after a loved one at home with COVID-19 when they may be dying



Information for relatives and friends

By Dr Richard Price, Shropshire GP Trainee, April 2020.

Further ratified by Severn Hospice and the wider Shropshire, Telford & Wrekin end of life group.

Introduction

This leaflet provides simple advice to help both your loved one and yourself in this difficult time.

You will continue to receive the full support of your healthcare team and if you have a particular worry or concern, then please contact your GP, Shropdoc, District Nurse, or Palliative Care team for further advice.

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- ◆ Coronavirus and protecting yourselves
- ◆ Helpful conversations to consider
- ◆ Recognising if someone is becoming more unwell
- ◆ Simple ways to try and help address symptoms
- ◆ Who to contact

COVID-19

Coronavirus is a disease which is spread by cough and fluids from mouth and nose. Coronavirus has also been detected in blood, poo and urine.

Coronavirus causes the disease COVID-19 which is spread very easily. The most common symptoms are a new, persistent cough and/or a high fever.

If you need assistance out of hours, Shropdoc have a dedicated Palliative Care line on **01743 454912** which is open out of normal working hours—between 1800-0800 on weekdays and 24 hours a day at weekends.

Contact numbers

Monday-Friday 0900-1800:

GP practice

District Nurses

Hospice Nurses.....

1800-0800 / Bank Holiday and weekend

Shropdoc : 01743 454912

Keeping yourself safe

It is natural that you will want to do everything you can to look after your loved one during this difficult time.

It is also important that you take steps to reduce your own risk of getting coronavirus, to help you stay well and to reduce the risk of spread to others.

The World Health Organisation has advised that people caring for people with suspected COVID-19 should:

- ◆ Clean hands very often, using soap and water or an alcohol-based hand rub if hands are not visibly dirty. Use soap and water when hands are visibly dirty
- ◆ Keep a distance of at least 1 metre from the affected person when possible;
- ◆ Wear a medical mask when in the same room as the affected person;
- ◆ Dispose of any material (e.g. tissues) in contact with respiratory secretions (phlegm) immediately after use and then clean hands again.
- ◆ Improve airflow in the living space by opening windows as much as possible.

It is also suggested that your loved one wears a medical mask whilst you are providing care for them.

Visitors

This is a difficult time for families with loved ones with coronavirus who are becoming more unwell.

If you have relatives or friends who want to visit, the current advice is that they should not visit if they, or you, have someone in the house with suspected coronavirus.

Other ways of keeping in touch include telephone, video calling or by post.

The latest guidance on social distancing and isolation can be found at www.gov.uk/coronavirus.

Talking to loved ones about their care

Talking about health and care can be a difficult subject, but it will help you and your loved ones. If worries or anxieties are not talked about they can grow.

Ask: What is important to you?

For example:

Where would you like to be cared for?

Do you have anything important to talk about?

Are there any music/books you would like?

What are you worried about?

Don't worry if you don't feel comfortable discussing these things. Your GP, District Nurse, or Palliative Care team can help with this further if this is something you would like to discuss with them.

When someone may be approaching the last days of life

This is something which can be very difficult. People can show different signs as they approach the end of their life and the list below is a guide to help relatives and friends recognise this. These signs include:

- ◆ Becoming more restless / upset / withdrawn
- ◆ Changes in topics they talk about, including talking about death
- ◆ Changes in breathing pattern
- ◆ Fatigue / constant tiredness and becoming drowsy
- ◆ Loss of appetite and reduced ability to swallow
- ◆ Change in skin colour to be more pale
- ◆ Noisy/bubbly breathing
- ◆ Increasing loss of weight

Some of these signs may become more obvious just before someone dies. In particular, the person may stop being able to take food and drink altogether and breathing may become less regular and more noisy.

On the following pages, we will outline some measures which can be taken at home to try to help any troubling symptoms which may arise as someone becomes more unwell.

If these measures are not effective or you have any other worries, please contact your healthcare team for further advice and support.

Troublesome symptoms: how to help

Breathlessness

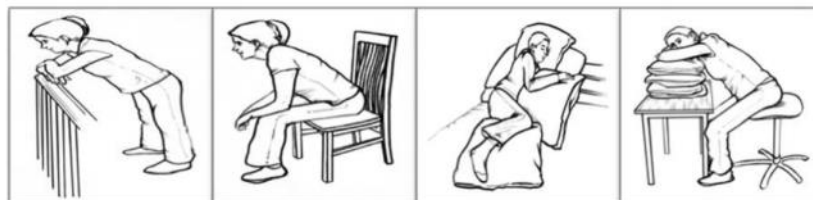
There can be lots of reasons for someone to become breathless, including COVID-19 itself, any underlying chest conditions, pain or anxiety.

As a first step, if the person is able to answer, it may be really helpful to ask them if there is anything worrying them, or if they are in pain.

Some practical things which may be helpful are:

1. Positioning

What may be beneficial will vary from person to person. However, sitting upright, uncrossing legs, letting shoulders droop, keeping the head up, or leaning forward may be helpful. The picture below details some ideas which may be helpful:



Forward lean 1

Forward lean 2

Adapted forward lean for lying

Adapted forward lean for sitting

Source: RCGP Community Palliative, End of Life and Bereavement Care in the COVID-19 pandemic

2. 'Reliever' inhalers (example: Salbutamol / blue inhaler)

These can be helpful if someone usually has an inhaler for asthma or COPD.

3. Reducing the room temperature

4. Cooling the face with a flannel or cough

5. Breathing exercises

There are lots of these available. Pictures of two are outlined below.

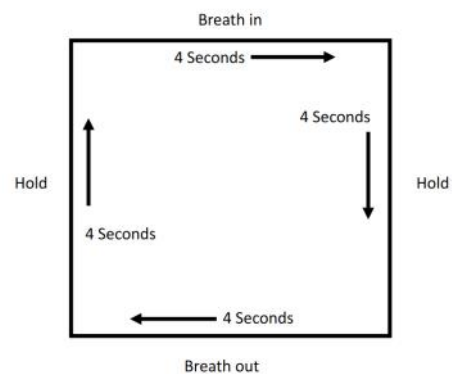
Calming hand exercise



- **Recognition** - Recognise signs of panic early and hold your thumb firmly
- **Sigh out** - Sigh out and remember to relax shoulders and chest ("flop and drop")
- **Inhale and exhale slowly** - Slow breathing helps to reduce the sensation of breathlessness
- **Stretch and relax your hand** Continue to repeat the above steps until feeling calmer

Diagram adapted from Phyllis Tuckwell Hospice 'Calming Hand' leaflet

Square/rectangular breathing



- Breath out
- Hold for a count of 4
- Breath in
- Hold for a count of 4
- Repeat the process

Source: Wessex Palliative Physicians. The Palliative Care Handbook. A Good Practice Guide. 9th ed

There are also some useful video resources to help breathing online at:
<https://www.stchristophers.org.uk/video-breathlessness-breathing/>

Portable Fans are **Not Recommended**

In case of the risk of spreading coronavirus in the air.

Cough

There are various things which can be tried to help cough.

Drinking fluids

If your loved one is able to swallow, this may help improve cough. Some people find that honey and lemon in warm water is effective.

Cough drops/hard sweets

Elevate the head when sleeping

Avoid smoking

Simple linctus

This can be bought in your pharmacy / chemist.

Humidified room air

To minimise the risk of spreading virus:

- ◆ Cover the nose and mouth with a disposable tissue when sneezing, coughing and blowing the nose
- ◆ Dispose of used tissues quickly
- ◆ Clean hands with soap and water, alcohol hand rub or hand wipes after coughing, sneezing, using tissues, or after contact with fluids from the mouth or nose

Fever / sweats / high temperature

This is one of the main symptoms of coronavirus and can leave people feeling tired and unwell.

Symptoms indicating fever include shaking, shivering, chills and aching.

Some things which can be done at home which may help:

Reduce the room temperature

But not to the point where it causes shivering

Wear loose fitting clothes / pyjamas

Cool the face with a cool flannel or cloth

Avoid alcohol

Paracetamol regularly

Please follow the packet instructions.

Ibuprofen

If you are able to take this, Ibuprofen can be taken for symptoms of COVID-19 such as fever and headache (information correct as of 14th April 2020). Please follow the packet instructions.

If all the above measures have been tried and your loved one is still distressed due to a high temperature, please speak to your GP, Shropdoc, District Nurse or Palliative Care team for advice.

Confusion

We know that infections can cause people to become muddled or confused. This can come and go and there may be times where someone is not confused at all.

After assessment by your healthcare team, some things you can do at home which may help confusion are:

Familiar objects around the person

Having things such as photos of family, or familiar places, can help people feel safe and provide reassurance. A large, visible clock and good lighting (with a low light overnight) may be helpful.

Explain everything you are doing

Some of the things we do while looking after someone, such as applying cool flannels to the face, can cause upset in people who are confused. Talk to the person in a calm voice and explain what you are doing and why.

Pain

As well as pain killers, there are some simple things which can help with pain.

Relaxation techniques

May include listening to music, or breathing exercises.

Distraction

Can include talking, watching TV, listening to music, drawing/painting or reading a book.

Heat pads or ice packs

Appetite

It is common for appetite to decrease as people become less active and more unwell; simple suggestions to help:

If your loved one feels sick / has vomited:

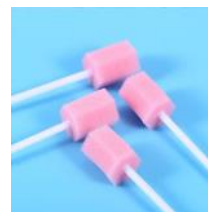
- ◆ Relaxation techniques, such as listening to music, watching TV, breathing exercises
- ◆ Ginger biscuits or tea
- ◆ 'Seabands', which provide pressure on wrists
- ◆ Talk to your healthcare team to review medications and discuss whether any medications may help
- ◆ Try small amounts of food, more often
- ◆ It is more important that your loved one tries to drink sips of fluids than have food. Do not worry too much about trying to increase the amount they eat if they are struggling with this

Mouth care

Ensuring good mouth care can improve someone's appetite and comfort.

Some things which may help with this are:

- ◆ Ensuring the mouth is kept clean and moist, with a choice of drink, or use sponge sticks soaked in water / drink
- ◆ Teeth cleaning (use a soft, children's brush)
- ◆ Good denture care



Anxiety

Asking about any worries your loved one may have

This may be difficult, however knowing about specific worries, concerns or anxieties can help your healthcare team.

Relaxation techniques

As discussed previously, these will be different from person to person but can be really helpful

Mindfulness

This is therapy focused on 'being in the moment' and can be effective in helping stress and anxiety.

There are various online or CD resources for this, one of which is:

Headspace app — www.headspace.com

This therapy may be more difficult for your loved one as they become more sleepy. At this time, other relaxation techniques such as playing music that they like may be more helpful.

Sometimes, family members and friends also try mindfulness as they care for a loved one and you may feel that this would also be helpful for you.

Spiritual Care

Spirituality is whatever is important to a person, and will mean different things to different people, including:

- ◆ The need for meaning and purpose
- ◆ The need to love and feel loved
- ◆ Religion
- ◆ The need to feel a sense of belonging
- ◆ The need to feel hope, peace and gratitude

Social distancing and self-isolation are changing the way we do things. Technology such as telephone and video calling may help.

Please speak to your healthcare team to see if there is anything we can do.



<https://www.silvercentury.org/2019/02/spiritual-support-at-the-end-of-life/>

Support for you as a carer

Looking after a loved one who is approaching the end of life is tiring, especially with coronavirus changing the way things work at the moment.

It is important that you think about your own health, both physical and mental.

If you, or another family member or friend is struggling at this time, speak to your GP, hospital team, or the Palliative Care team.

Marie Curie also have a support phone line which can be reached on: [0800 0902309](tel:08000902309).

In addition, Marie Curie also operate and email and webchat service for support.

See <https://www.mariecurie.org.uk/help/support/marie-curie-support-line> for further details.