**END OF LIFE: CHANGES TO EXPECT**

*Acknowledgement: the below section is based on information sheets developed for families from, from Stepping Stone Hospice and Care Services and can be found in more detail at [https://www.steppingstonehospice.co.za/](https://www.steppingstonehospice.co.za/)*

When patients near the end of life, there are some normal signs and symptoms that show that their body is getting weaker and death is near. It is helpful to know what these are to reduce anxiety around the normal process of dying. The table below details the normal signs and symptoms to expect and what can be done to manage them in the home environment.

<table>
<thead>
<tr>
<th><strong>Decrease in appetite and fluid intake</strong></th>
<th>Offer softer foods and sips of water. If jaw is closed and clenched the patient is indicating that they do not want food. Use a syringe/teaspoon to provide drops of water into the side of the mouth to keep the mouth moist. A spray bottle filled with water can be used to spray water onto the inside of the mouth from time to time to keep the mouth moist. Ice-chips can be used to keep the mouth moist. <strong>DO NOT FORCE FOOD AND WATER IN TO THE MOUTH, THE PATIENT COULD CHOKE AND VOMIT.</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><em>If a patient is in the dying phase it is NORMAL that their food and fluid intake will decrease until it stops altogether. This is a very normal part of the dying process as the body weakens. Food and fluid should not be forced. Offer fluids but let the patient tell you what they want. NEVER give food/ fluids to a patient who is unresponsive in the dying phase, they will not be able to swallow and could choke.</em></td>
<td></td>
</tr>
<tr>
<td><strong>Urine output and bowels decrease</strong></td>
<td>It is normal for the patient to have less urine output and less frequent bowel movements. No intervention required unless there is severe amounts of abdominal pain and an urge to pass urine. (retention of urine-call for advice in this case.)</td>
</tr>
<tr>
<td><strong>Increased sleep</strong></td>
<td>Patients will sleep more and more and seem to withdrawal from the world around them. Let them sleep. Spend time with them.</td>
</tr>
<tr>
<td><strong>Increased confusion</strong></td>
<td>When they wake reassure them and remind them the day, time and where they are. Allow them to talk, even if what they say makes no sense to you at that moment.</td>
</tr>
<tr>
<td><strong>Increased secretions</strong></td>
<td>Speak slowly and clearly. Use yes/no questions. Keep the room calm and quiet. Patients can hear us, talk as if they can still hear you even if not responsive.</td>
</tr>
<tr>
<td><em>There may be a build-up of secretions in the back of the throat that may rattle/gurgle when the patient breathes.</em></td>
<td>If loud, keep the patient on their side so the secretions can come out. Treat the patient’s anxiety if there is, ask for advice re: medications to use. Small sips of water can help with phlegm build-up.</td>
</tr>
<tr>
<td><strong>Breathing changes</strong></td>
<td>Prop the patient up in bed slightly, to make breathing easier. The moaning and sounds are normal, it is families who become distressed rather than the patients, who are usually unaware at this point.</td>
</tr>
<tr>
<td><strong>Breathing may become irregular, with long gaps between, or speed up faster. It may seem like hard work for the patient. There may be some normal moaning and groaning at this time.</strong></td>
<td></td>
</tr>
</tbody>
</table>
### Restlessness

**Decreased oxygen the brain can cause restlessness.** Patients may try to get up out of bed, and may pull bedclothes on and off repeatedly, or “pick” in the air with their hands.

- Reassure the patient in a calm voice.
- Use chairs next to the bed to prevent them falling out, or cushions on the floor.
- Use anti-anxiety medication to help relax and calm the patient during this time, ask Dr or hospice sister for advice on this.
- Soft music/back rub can help settle them.
- Limit visitors into the room, this can cause agitation (IN COVID-19 VISITORS WILL NOT BE ALLOWED).

### Temperature changes

**As the circulation slows people will get hot and cold.** They may also present with blue/cold hands, feet, elbows and knees, known as “mottling.” This is not reversible.

- Use blankets, warm bean bags and beanies to keep patient warm if cold.
- Massage the hands and feet to promote circulation and heat.
- Sponge bath using luke-warm water if patient sweating.
- Keep linen dry and clean.

### Symbolic language/visions

- Sometimes as people near death they will see people that have passed before them or have visits from loved ones who are dead.
- They may also talk about packing their bags, catching a train, taxi or aeroplane etc.
- Take note of this, it can indicate that they are getting ready to ‘depart’ from this life.
- No intervention is necessary unless the visions cause the patient extreme distress, contact your clinic for advice on sedating the patient.

### At death

**The patient is unresponsive.** Bowels and urine may release. Eyes will become fixed (not moving) and stare. Breathing will cease. No pulse will be felt. Jaw may relax and drop open.

- Remember if the patient is COVID-19 positive the body must not be touched or washed, refer to the section on death at home during COVID-19 for more information on how to proceed.

- Put a plastic bag under/on top of the sheet beforehand to prevent mattress and linen being soiled.
- If open, gently push the eyelids down and hold them for a few seconds, to close them.
- A towel can be placed under the jaw, around the neck to close the mouth.
- Lay their legs out straight and arms down by the sides or across the chest.
- Cover them with a sheet.

**ALWAYS REMEMBER TO WASH YOUR HANDS AND SANITIZE AFTER TOUCHING THE PATIENT.**

The focus as patients enter this terminal phase of life is comfort care. All actions taken at this point are to minimize discomfort and promote comfort for the patient. Remember, at this point it is important to “just be there” and reassure the patient, by doing and gently saying, that you are fulfilling all their needs at this point. There are 6 important things to say to someone at this time, which can make it easier for them to gently “let go”[^2022]:

- I’m sorry
- I forgive you
- Thank you
- I love you
- It’s ok to die, we will be ok
- Goodbye

[^2022]: www.ambient.com/articles/6-things-to-say-when-someone-is-dying