
Providing practical end of life and palliative care at home

Summary

- Providing practical care can help someone with a life-limiting illness maintain their independence at home.
 - Knowing how to do practical tasks will help you provide appropriate care as and when required.
 - You can help with tasks such as taking medication, eating and drinking.
 - There are products to assist with daily hygiene care.
 - There is a range of equipment available to assist with practical tasks.
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End of life and palliative care is more than just medical treatment and relief from pain or discomfort. It is care that aims to assist the person to achieve the best quality of life possible.

Depending on their condition, your loved one may be quite independent, may need help with just a few things or they may need a greater level of help with lots of daily tasks. This is likely to change over time.

It helps if you as a carer have some knowledge of how to do these tasks, so you can assist when necessary. Remember, only do things you feel comfortable with. If you are unsure at any time, seek guidance from the palliative care team or other health professionals who know your situation.

No one likes to lose their independence. Helping the person to maintain it as long as they can is best. As much as possible, encourage them to eat a range of healthy foods, be as physically active as possible and get some fresh air.

Maintain good personal hygiene as part of a day-to-day routine. This will help the person feel more positive and have more self-confidence, and will lower the chances of getting any new illnesses or complications.

Practical care – helping with medications

Medication should always be taken as prescribed. Sometimes this may not be easy. For example, if a person has nausea and can't take their pain medicine by mouth, the nurse or doctor may need to visit to give an injection to stop the nausea and to treat the pain. They will then plan with you how to manage this in the future.

Some people with life-limiting illness take strong pain medicines, such as morphine. If a strong pain medicine is required, the doctor, pharmacist or palliative care team can explain why, how and when it should be taken.

Family members and other people providing care sometimes worry about the use of strong pain medicines (opioids such as morphine). They worry that the person may become addicted, or that the prolonged use of these powerful drugs may hasten death.

Be assured that palliative care is based on the latest evidence for administration of medication. Evidence has shown that when given for pain, opioids do not cause addiction and, when used in prescribed doses, do not hasten death.

The following points may guide you in helping the person you are caring for:

- Medicines should only be taken 'as directed' by the person they are prescribed for.
 - Most medications are prescribed to be given at certain times; others are to be given 'as required'. For example, some pain medications should be taken only when the person feels pain.
 - If there are lots of tablets to be taken, consider using a 'dosette box' to make it easier. The pharmacy can also make these up for you in 'sheets' (for an additional small fee).
 - It is common for medicines to be changed for people at end of life. When a medicine is no longer needed, it should be discarded by returning it to the pharmacy.
 - Take note of when medication may run out and another prescription is required. Try not to leave this too late.
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- Not all medicines are taken by mouth; some need to be given by injection or via a skin patch. Often the palliative care team or a district nurse will do this initially and, if you are comfortable, teach you how to give them.
- If swallowing is difficult, some tablets can be crushed in food or drink. Check first with the doctor about which medicines can be crushed – some cannot be.
- Sometimes if medicines are required to be given in the form of injections, the palliative care team may arrange for them to be stored in a safe place.

Practical care – helping with eating and drinking

People with life-limiting illness can lose their appetite or not feel like eating at various times of their illness. This might be due to the side effects of their treatment or medications. They may also just be feeling sick, downhearted, constipated, tired or have a sore or dry mouth.

Depending on the person's illness, often it is more important to eat foods that are enjoyable (even if they are not the healthiest foods). Enjoying food to improve the quality of life is important as a person nears the end of their life. Here are some suggestions you can offer that may help improve someone's ability to eat and drink:

- Serve **smaller meals**, more often, on smaller plates; don't fill drinks to the top of the glass.
- Try new types of foods that your loved one might prefer. People's desire for certain food tastes may change.
- Offer **supplemented drinks** such as Sustagen or Fortisip. These high protein and energy drinks can be bought from chemists and some supermarkets. You can also make your own juices or smoothies.
- **Wine or other alcohol** can help stimulate the appetite. Be aware that alcohol should not be taken with some medicines.
- **Good mouth care** can help, such as keeping the mouth moist by encouraging regular teeth cleaning, drinks and mouth rinses. If poor mouth health is a concern, such as ulcers or whiteness (thrush), let the doctor or palliative care nurse know. Most mouth problems can be treated easily.
- As the illness progresses toward the end of life, you may notice that the person you are caring for is eating less. It may not be so important at this stage to have 'well balanced meals' every day. It is normal for a person not to want to eat in the latter stages as the end of life approaches.
- It can become more important to concentrate on what your loved one enjoys eating and drinking as the end of life approaches.

Practical care – helping with hygiene

Depending on your preference for providing care or not, you may decide to just help with moving in and out of bed or to the bathroom. Or you may offer to wash your relative's face and hands, or you may want to assist with a complete shower or bed bath. If preferred, a visiting service provider can provide the more personal hygiene needs.

Whoever provides this care, the following points need to be considered:

- Safety is important. Consider having rails installed in the bathroom and where there are steps. Consider a hand held shower hose or additional equipment (listed below)
- There are many other devices and products that help people move safely if they are unsteady or frail.
- There are products available to help if incontinence becomes an issue (the loss of control over passing urine or bowel motions).

Care equipment for people at end of life

There is a range of equipment available to help people continue living at home. Equipment can increase your relative's independence and make practical tasks safer and easier for you and them.

If you think you need anything listed below, the palliative care team or a specialised occupational therapist can assist. There may be some safety tips that they will show you. A hire charge usually applies. Talk with the palliative care team if paying a fee is difficult for you.

Management of more complex items, such as various tubes, wounds, drainage systems or injections, can seem daunting and there will be service providers to assist with this. However, many family carers develop significant skills at managing complex care tasks after being shown carefully by specialist staff.

Equipment often used for people at end of life includes:

- shower chair – so the person can sit down in the shower
- commode – a portable toilet that looks like a chair
- bath or shower hand rails – to provide support for standing or sitting
- bath board – to enable a person to safely get in and out of the bath
- slide sheets – slippery sheets that make it easier to move the person
- slipper bed-pan or urinal – devices to enable toileting in bed
- absorbent and plastic sheets – used on a bed or chair where incontinence is an issue
- dosette box – special medicine container that holds pills for each day or dose
- syringe driver – a device used to very slowly deliver medications under the skin
- sharps container – for used syringes or needles
- hospital bed – a bed that can be raised or lowered and has sides for safety
- bed stick – to help the person to sit up and get in or out of bed
- urinary catheter – a tube into the bladder for passing urine
- pressure relieving devices – special mattresses, sheepskins or cushions, to prevent bed sores
- walking frame – to assist independent walking
- wheelchair – to enable a person to be mobile.

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This page has been produced in consultation with and approved by:

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