

# Going home near the end of life

This leaflet is to support you as a carer or family member when someone important to you is being discharged from hospital to home, and it is thought that they are likely to die soon. In this leaflet, we refer to that person as s/he.

This information is to help prepare you in a practical way and can be read alongside other information about what to expect when someone is dying.

## Is home the right decision?

It is important to recognise that even with an organised package of care to provide support at home, there will not usually be 24-hour care in your home. Sometimes the reality of caring for someone who is near the end of their life may feel too difficult. If home is not felt to be the best option and 24-hour care is needed, alternatives can be considered such as a care home with nursing, or a hospice for people with more complex needs.

## Who is involved in arranging discharge home?

**An occupational therapist (OT):** They will assess mobility and practical needs. The OT may visit your home to assess what equipment is needed.

**Physiotherapist (PT):** They will assess his/her mobility and liaise with the OT to ensure the correct equipment is in place.

**Discharge coordinator:** They will assess the care needs of the person being discharged home and will involve you in this process. In certain situations, they may also apply for 'Continuing Healthcare NHS Funding' which, if successful, means the package of care is paid for through the NHS.

**Social worker:** Depending on the area you live, a social worker may be allocated to help with arranging the package of care.

**The hospital Specialist Palliative Care Team:** They provide advice for more complex discharges home. They have an additional role in ensuring symptoms are manageable, and additional support networks are set up; (e.g. referring to the community palliative care team), and that the right information is handed over to community healthcare professionals.

**The ward staff:** Doctors and nurses will lead on the discharge.

## How can I prepare practically for discharge home?

You will need to allocate a room that is big enough to hold a hospital bed and commode. Ideally this would be on one level, with no stairs to climb. The OT can support with ensuring there is enough space for equipment and carers. They will assess and order any equipment which may be needed, such as:

- A hospital bed with pressure relieving mattress – some people wish to sleep in their own bed, but a special bed and mattress will protect skin and pressure areas and be more flexible for positioning
- A commode
- A bedpan or urine bottle
- Oxygen
- A noise monitor (e.g. a baby monitor) or bell
- A key safe

## You should also think about:

- A safe place to keep medicines
- Optional extras – such as extra blankets, heater, fan, music or TV.

## How can I prepare myself?

It can be very difficult both physically and emotionally when caring for someone who is dying. We would encourage you to accept help from friends and family, such as prepared meals for you, transport, collecting medicines or someone to sit with your relative/friend. You may wish to consider planning a rota of carers amongst family and friends to ensure you have some time off to rest in between caring if at all possible.

Try to compile a list of questions to ask the hospital team before discharge. Also check that you have all the contact numbers you may need.

## Who will support us once home?

**Carers:** Home carers may be offered 3-4 times a day in a 'package of care'. This will be discussed prior to leaving hospital by the discharge coordinator or social worker to establish what is needed and suitable times. This may include helping with tasks such as washing and changing night clothes or changing the bed sheets. Carers are not usually able to do housework tasks and are not trained nurses.

Some people find it difficult to imagine needing the help of carers at home, but they can provide support and reassurance at an uncertain and unpredictable time. It is helpful to have the package of care set up before leaving hospital, rather than to go home without it, struggle and risk needing to come back to hospital if unable to manage.

**Community nurses:** These are qualified nurses who can give medication, catheter care, and assess general condition. They work closely with the GP.

**GP or out-of-hours doctor:** The hospital team will contact the GP to update them prior to the discharge home. The GP is the doctor in charge in the community, and they will be asked to visit once you are home.

**Community Palliative Care Team:** They are there for medication advice regarding controlling complex symptoms. They normally work in partnership with the Hospice at Home Team. In some instances, the Hospice at Home Team help with hands-on nursing care and psychological support when someone is close to the end of life.

**Chaplaincy:** If there are any particular religious or spiritual beliefs, s/he may want their own faith leader to visit.

## What will I be given at time of discharge?

- Medicines, including 'just-in-case' injectable medicines.  
There will be a leaflet provided specifically with those and you are not to administer these – a qualified health professional will do that if needed.
- List of contact numbers
- Red copy of DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) form.

## Who do I phone if s/he is in pain or distress, or his/her condition changes?

- The Community Palliative Care Team or Hospice at Home Team
- Community nurses would be the first option.

## What do I do if s/he has a fall?

Ensure they are safe and warm. If they are unable to safely get back to bed with your support, call 999 for paramedics and explain they wish to remain at home, but that you need help.

## What do I do when s/he dies?

Phone the community nurses or the Community Palliative Care Team, if they are supporting you. A healthcare professional will come to you at home as soon as possible.

## If I feel I need more help, who do I contact?

- The Community Palliative Care Team for support and discussion
- Your community nurse
- Your own GP.



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**Disclaimer**

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