



University
Hospitals Sussex

NHS Foundation Trust

**WE ARE
MACMILLAN.**
CANCER SUPPORT

Going home near the end of life

Patient information

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.

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. In this case 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?

The ward staff:

Doctors and nurses will lead on the discharge.

An occupational therapist (OT):

They will assess mobility and practical needs.

Physiotherapist (PT):

They will assess their 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.

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
- 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 the patient and changing night clothes or changing the bed sheets. Carers 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, struggling and risk needing to come back to hospital.

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 ward 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 may 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, they may want their own faith leader to visit.

What will I be given at time of discharge?

- Medicines, including 'just-in-case' injectable medicines. A qualified health professional will administer these injections if / when needed.
- Community prescription charts for the injectable medications.
- Red copy of DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) form and the ReSPECT form if one has been completed.
- Contact numbers for the community nurses and community palliative care team.

Who do I phone if they are in pain or distress, or their condition changes?

- Community nurses would be the first option.
- The community palliative care team or hospice at home team.

What do I do if they have 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 they die?

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.
- The community nurses.
- The GP.

Websites which may provide further information:

Marie Curie

www.mariecurie.org.uk

Whatever your question, Marie Curie is here to help with practical information and support on all aspects of life with terminal illness, dying and bereavement.

Carers UK

Looking after someone can be tough, but you're not on your own. Carers UK is here to listen, to give you expert information and advice that's tailored to your situation, to champion your rights and support you in finding new ways to manage at home, at work, or wherever you are.

Brighton and Hove

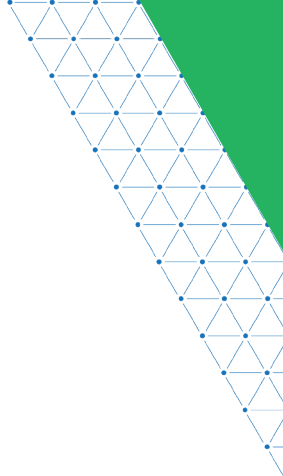
www.thecarerscentre.org

West Sussex

www.carerssupport.org.uk

East Sussex

www.cftc.org.uk



This leaflet is intended for patients receiving care in Brighton & Hove or Haywards Heath

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