

Information for Carers



**DOROTHY
HOUSE**
Hospice Care



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Are you a carer?

If you are close to someone who has a life-threatening illness you may find that you are doing things for him/her or with him/her that are new. This often starts small, such as attending hospital and doctors' appointments together, but can become full-time caring. At first you may not think of yourself as a carer, but providing company and emotional support is as much part of being a carer as looking after physical needs such as helping with medication, washing and dressing and preparing meals and feeding. Being a carer does not change your identity – you are still a wife, husband, daughter, son, parent, friend – but it usually means a change to your lifestyle.

Health and social care services tend to focus on the patient's needs, but you have needs and rights, too. This booklet will tell you about sources of information and support for you as a carer.

Dorothy House provides specialist palliative care services which do not replace, but work alongside, other health and social services. Specialist palliative care is provided for people with life-threatening illnesses who have complex needs and their families. It focuses on quality of life, control of symptoms and helping with emotional, social and spiritual aspects of illness for patients and their families.

Dorothy House Services For Carers

- Dorothy House runs a short course that aims to prepare carers for all aspects of caring for a person with a life threatening illness, including looking after yourself.
- Monthly relaxation class at Dorothy House – you can come on your own or with the person you look after.
- Dorothy House Family Support Team provides chaplaincy, children and young people service, social work and bereavement service.
- Complementary therapies can be offered
- 24 hour phone line for patient care advice 01225 722999

Ask your Dorothy House nurse specialist, day patient leader or other members of staff for details of any of the above services.

How can I get help with caring?

At some point most carers need some practical help so that they can continue in their caring role. As soon as you feel that you need some help contact your local social services department (see numbers on page 4). Help from social services will be means tested. However, when the doctor feels that the life expectancy is about 8 weeks, the health service pay for all care under Continuing Health Care. The district nurse or ward nurse will begin the Continuing Health Care process.

You are entitled to a Carer's Assessment – this will assess *your* needs, not those of the person you look after. You may find it difficult to be completely honest in front of the person you care for. If so, ask for a private meeting with the social worker. The assessment will help you to view your situation clearly and offer guidance on help with caring and breaks from caring.

Contact your local social services department to request a carer's assessment:

BANES: 01225 396201

North and West Wilts: 0845 6031570

Somerset / Care Direct: 0845 3459133

Local carer information and support

Local carer support services offer advice and information on services; signposting to other agencies for help with benefits; opportunities to meet other carers; a home visit; regular newsletters; an information pack and someone to listen to your needs. Their services are free and confidential.

Carers Support West Wilts

01380 871690

admin@csww.freeserve.co.uk

The Care Network (BANES)

01761 431389

carerssupport@thecarenetwork.co.uk

Carers Support North Wilts

01249 444110

carersnw@fish.co.uk

Somerset Carers Project

01749 812841

Help with benefits and coping with debt

Citizens Advice Bureau - will arrange home visits if you cannot get to their office. See telephone directory for your local CAB details www.citizensadvice.org.uk

Macmillan Benefits Helpline 0808 801 0304

National organisations that provide information and helplines for carers

Carers UK • 0808 808 7777

www.carersuk.org and www.carersonline.org.uk

Cancer BACKUP • 0808 800 1234 • www.cancerbackup.org.uk

Macmillan Cancer Relief • 0808 800 2020 • www.macmillan.org.uk

Motor Neurone Disease Association • 08457 626262 •
www.mndassociation.org

Help the Hospices Carers Support Service • 0207 520 8200
www.timetocare.org.uk

Who's who

District nurse

District nurses work in teams attached to GP surgeries. They visit people at home who cannot get to the surgery. They perform nursing procedures such as dressings and injections, taking blood samples, managing catheters. They also advise on personal care such as incontinence, skin care, diet and bowel management. They can order care equipment for the home such as commodes, urinals, pressure

relieving cushions and mattresses. They can be contacted via the GP surgery.

Practice nurse

Practice nurses work within GP surgeries. They run clinics for chronic conditions like high blood pressure, diabetes, heart disease and asthma and undertake nursing procedures like dressings and injections in the surgery.

Dorothy House nurse specialist

Dorothy House nurse specialists work alongside district nurses and GPs but are based at Dorothy House. They visit people with life threatening illnesses at home, in community hospitals and care homes. They provide advice and support to patients, their families and other professionals especially in relation to controlling symptoms and coping and adjusting to the illness. They also work alongside the multi-professional team at Dorothy House and where necessary refer patients to other Dorothy House services, such as complementary therapies, respite services, day patient unit.

Social Worker

Social workers work in many different areas including hospitals and social services departments. They assess patients' and carers' needs and offer advice and practical and emotional support. This can involve helping to arrange practical help at home and undertaking carer's assessments. Social workers can be contacted through local social services or hospital social work departments. There are specialist social workers at Dorothy House.

Children and Young People Service

Dorothy House provides a support service for children and young people who are affected by a parent's / carer's illness or death. It also provides advice and resources for them and their families, supports young carers and provides information about other services in the community.

Occupational therapist

Occupational therapists (OT) work in hospitals where they ensure that each patient has the aids and equipment they need for discharge home and they work in Social Services departments where they assess people at home and order aids, equipment and adaptations to help them to cope with illness or disability. For a home assessment the OT can be contacted via the GP, district nurse or directly through the local social services office.

Physiotherapist

Physiotherapists work in hospitals and in the community. They help patients with life threatening illnesses to manage problems such as mobility, pain and breathlessness. Physiotherapists are normally arranged through the GP or consultant. There are

specialist physiotherapists at Dorothy House who see patients and their carers at Dorothy House or at home.

Lymphoedema nurse

Lymphoedema nurses specialise in the management of swelling caused by the build up of lymph fluid in the tissues of the body. This can be a side effect of some cancers. These nurses see patients in clinics, hospitals and at home and referrals to them are normally arranged through the GP, consultant, district nurse or nurse specialist.

Care Agencies

Care agencies employ carers who provide personal care and domestic help for people in their own homes. Some social services departments also provide home care. There is a charge for these services and depending on financial circumstances you may have to contribute to the costs.

Hospice at home

Hospice at home is based at Dorothy House and provides trained auxiliary nurse care for periods of time at home for people with life threatening illnesses. Typically this would be overnight care to allow the regular carers to get a night's sleep. But

daytime care is also provided sometimes especially in the final stages of the illness. Hospice at home is organised by the district nurse and/or Dorothy House nurse specialist or Continuing health care co-ordinator.

Marie Curie nurses

Marie Curie nurses are trained nurses who provide nursing care for periods of time in the home for people with cancer. They also typically provide overnight care and are organised through the district nurse. There are a few Marie Curie nurses available in our areas.

Hospital-based nurses

There are Specialist Nurses working as part of Specialist Palliative Care Teams at the Royal United Hospital and in all the other hospitals in the area - Bristol, Salisbury and Yeovil. They visit people with life threatening illnesses in the wards, or in outpatient clinics. They provide advice and support to patients, families and other health care professionals, particularly in relation to control of physical symptoms and coping with the illness.

They liaise closely with the Dorothy House Nurse Specialists when patients go home and when they are readmitted to hospital.

A number of other nurses working in the hospital specialise in cancers in different sites of the body. For instance people with lung, head and neck area, urological (e.g. bladder, kidney), gynaecological, stomach and bowel or breast cancer would always be able to see a Specialist Nurse who has extensive knowledge about that type of cancer and its treatments.

There are also Specialist Nurses who concentrate on other life threatening conditions such as neurological illnesses, heart failure, and lung diseases. They also give information, support and advice from diagnosis onwards.

Dorothy House Hospice Care 12/06

Comments, Concerns and Complaints

Dorothy House Hospice Care always welcomes feedback, whether this is comments or suggestions for improvement. We strive to give the best possible quality of care but should you wish to make a complaint please contact our Chief Executive. Your complaint will be responded to within two working days of us receiving it and we would begin the process of investigation as soon as we have knowledge of the complaint. You will receive a full reply within 20 working

days. If however, for any reason this is not possible, we would inform you of this and the reason why. At their two monthly meetings, our Board of Trustees receive a report of complaints that we have received. A copy of the report shall also be forwarded to the Healthcare Commission. Further information about our complaints policy and procedure can be found in the 'Making A Complaint' leaflet which is available to all patients.

Please contact 01225 721480 if you require a large-print version of this booklet



Registered Charity No: 275745

Dorothy House Hospice Care
Winsley, Bradford on Avon
Wiltshire BA15 2LE

Tel: 01225 722988 • Fax: 01225 721478