

# Living with a life-limiting illness

**Services available for adults in Oxfordshire**



# Introduction

**The diagnosis of a life-limiting illness can raise a number of questions and concerns. This booklet describes the key services in Oxfordshire that support adults approaching end of life.**

# Contents

<b>Who will support me at home?</b>	<b>4</b>
.....	
<b>How do I get equipment?</b>	<b>5</b>
.....	
<b>What financial support is available?</b>	<b>6</b>
.....	
<b>What happens if there is a crisis?</b>	<b>7</b>
.....	
<b>What do Hospices provide?</b>	<b>8</b>
.....	
<b>What support is available for bereaved families?</b>	<b>9</b>
.....	
<b>Things you might want to consider</b>	<b>10</b>
.....	
<b>Useful contacts and resources</b>	<b>11</b>

## Who will support me at home?

**Your GP has overall responsibility for your care at home and can suggest other services or make referrals.**

**He or she can:**

- answer any questions about your illness or symptoms and what will happen as you become less well.
- help you record any wishes you have about your future care.
- provide symptom control, prescribing whatever medications you need.
- arrange for a **District Nurse** to visit to arrange any nursing care that is needed. If overnight nursing care is required, the District Nurse might be able to arrange for a **Marie Curie Nurse** to stay overnight.
- arrange for a **Specialist Palliative Care Nurse** to visit and advise on pain control, symptom management and to provide emotional support and practical advice. These specialist nurses work alongside palliative care **Doctors** and **Occupational Therapists** to support patients at home.

## How do I get equipment?

- Special equipment is available to help you to live at home as independently as possible. This includes stair rails, mobility aids, wheelchairs, riser-recliner chairs, bath aids, commodes, adjustable beds, sliding sheets to help with turning in bed, and special mattresses to help prevent bed sores.
- GPs, District Nurses and Specialist Palliative Care Nurses can refer you to an **Occupational Therapist** (OT) who will assess your needs, explain what equipment can be provided free of charge and order appropriate equipment.
- For people who spend periods of time on their own at home, a 'key safe' can be useful to help people coming to care for you to enter your home. A 'pendant alarm' that is worn around the neck can be a useful way to call for help. There is a small cost for these services, although people who are receiving certain benefits can receive them free of charge. Further information is available from **Social Services** (see page 11).

## What financial support is available?

- People with health problems or who are over the age of 65 might be eligible for financial support. Further information is available from your **District Nurse** or from the helpline 0345 7123456. The **Citizens Advice Bureau** can also provide advice and help with completing the paperwork.
- If you are eligible for free prescriptions, your **GP** or **Pharmacist** will be able to provide you with further information. If you need help with personal care, medication, or have mobility issues, you might be eligible for support through **Social Services**. Your **GP, District Nurse, Specialist Palliative Care Nurse** or **Social Worker** can provide more information about these services and, if you are eligible, can refer you.

## What happens if there is a crisis?

- If there are sudden changes in your symptoms, your District Nurse or GP can seek advice from a Specialist Nurse or Palliative Care Doctor. If your symptoms cannot be managed at home, a bed might be offered in your local hospice for specialist care. Out of hours (evenings, weekends and bank holidays), you can seek urgent help by calling 111 or 999.
- If there are changes in your care needs and you already have home care, then you should speak to your current care provider to tell them of any changes.
- If there are changes in your care needs and you **do not** currently have help with physical care, you can contact Social Services to request assistance. Your District Nurse can refer you to Social Services and might also be able to refer you to the Continuing Health Care service if you are eligible.

## What do Hospices provide?

**It is commonly misunderstood that hospices or specialist palliative care units are places where people go to die. In fact, many people are admitted for a short time for symptom relief before returning home. Hospices provide:**

- staff who are specialists in the control of symptoms, for example pain and nausea. They care for the physical, emotional, social and spiritual concerns of each person as an individual and also provide support and practical advice for families and close friends.
- care for people of all faiths, responding to the differing needs of individuals and their families. Flexibility is offered with meals and visiting times. Interpreting services are available.
- support to people at home through their **Specialist Palliative Care Nurses** who work closely with GPs and District Nurses.
- day services where patients have the opportunity to meet and share their experiences with others in similar situations. The range of activities might include massage, reflexology, music and art therapy, mobility classes and creative activities.

There are four adult hospices in Oxfordshire: Sobell House in Oxford, Katharine House near Banbury, Sue Ryder near Henley and Douglas House in Oxford (for young adults). All services are free and hospices rely on voluntary donations to provide their wide range of support. People can be referred to hospice services by their GP, Hospital Consultant, or another health care professional.

## What support is available for bereaved families?

- **GPs** are often the first point of contact for bereaved people. They can answer any questions about the nursing or medical care that was given and can provide support themselves or suggest other services or information that might be helpful.
- **Hospices** are able to provide bereavement support for families of people who have used their services.
- **Cruse Bereavement Care** provides individual support and counselling to bereaved adults. The national **Cruse** website also provides practical information about what to do after a death, links to useful organisations, information about adult and children's grief and hosts a dedicated website for young people (Hope Again). Their contact details are provided on page 11.
- Some services specifically support young people who are bereaved. **SeeSaw** is an Oxford-based charity whose details are also provided on page 11.

## Things you might want to consider

### Advance Care Planning offers you an opportunity to voice your wishes and preferences about your future care.

You might choose to do this so that your views can be taken into account if you were unable to make your own decisions at any point. Examples of things you might want to consider include:

- the name of someone that you want to be consulted on your behalf at a later time.
- how you might want your religious or spiritual beliefs to be respected.
- your wishes about where you would like to be cared for at the end of your life and who you would like with you.
- your views on different treatments or types of care that might be offered.

If you would like to talk about this further, your GP, District Nurse or Specialist Palliative Care Nurse could arrange this. More information is available from the Dying Matters website (see opposite page). Their booklet *'Planning for your Future Care'* provides further explanation and useful information.

## Useful contacts and resources

**Bereavement Advice Centre** provides a national helpline and information service offering support, information and advice about what to do after a death and the practical issues and procedures that people may face.

**Web:** [www.bereavementadvice.org](http://www.bereavementadvice.org)

**Helpline:** 0800 634 9494  
open 9am-5pm Monday-Friday

**Email:** [info@bereavementadvice.org](mailto:info@bereavementadvice.org)

**Cruse Bereavement Care** provides individual support and counselling for bereaved adults.

**Web:** [www.cruse.org.uk](http://www.cruse.org.uk)

**National helpline:** 0844 477 9400

**Email:** [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

**Oxford helpline:** 01865 245398

**Email:** [oxfordshire@cruse.org.uk](mailto:oxfordshire@cruse.org.uk)

**Dying Matters** provides information on dying, death and bereavement. Many of their leaflets can be downloaded from their website in a range of languages.

**Web:** [www.dyingmatters.org](http://www.dyingmatters.org)

Their booklet *'Planning for your Future Care'* suggests things people with a life-limiting illness might want to consider in planning their care.

**Healthtalk.org** provides video and audio clips, as well as written transcripts, of patients' and carers' experiences of a variety of health-related conditions and illnesses. These include people's experiences of dying and bereavement.

**Web:** [www.healthtalk.org](http://www.healthtalk.org)

**Marie Curie** provides a range of publications and guides for people with life-limiting illnesses and their families.

**Web:** [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

**Macmillan Cancer Support** provides practical, medical and financial support for people with cancer. Their website has information on a range of topics including living with cancer, support for carers, and facing the end of life. Many of their leaflets can be downloaded.

**Web:** [www.macmillan.org.uk](http://www.macmillan.org.uk)

**Maggie's Oxford** offers emotional support to people affected by cancer. The Maggie's national website hosts an online facilitated bereavement support group.

**Web:** [www.maggiescentres.org](http://www.maggiescentres.org)

**Telephone:** 01865 751882

**Email:** [oxford@maggiescentres.org](mailto:oxford@maggiescentres.org)

**OxBEL** (Oxfordshire Befriending for Life) is a befriending service for people with life-limiting illnesses and their carers.

**Email:** [enquiries@oxbel.org.uk](mailto:enquiries@oxbel.org.uk)

**Telephone:** 01235 849427

### Oxfordshire County Council

provides details of a range of private and voluntary services which support people in their own homes.

**Web:** [www.oxfordshire.gov.uk](http://www.oxfordshire.gov.uk)

**SeeSaw** is an Oxfordshire charity that helps children and their families before and after a major bereavement. Their website provides information for young people, parents and teachers, as well as details of further sources of support.

**Web:** [www.seesaw.org.uk](http://www.seesaw.org.uk)

**Enquiries and advice line:** 01865 744768

**Email:** [info@seesaw.org.uk](mailto:info@seesaw.org.uk)

**Social Services** can provide financial and practical support.

**Telephone:** 0845 0507666



**NHS**  
*Oxfordshire*  
**Clinical Commissioning Group**



This booklet was produced by Sobell House in collaboration with the Health Advocates for Oxfordshire (Public Health) and was funded by Oxfordshire Clinical Commissioning Group

Further copies of this booklet are available from Sobell House Study Centre,  
Churchill Hospital, Headington, Oxford OX3 7LE **email** [ssc@ouh.nhs.uk](mailto:ssc@ouh.nhs.uk)