

The Bell Surgery, Henley-on-Thames

End of Life leaflet

Section 1: Practical Issues to Address

- **Writing an Advanced Statement for your Preferred Priorities for Care** - This can cover care preferences towards the end of life including whether a person wishes to be resuscitated or not and where they would choose to die.
- **Arranging Care of Dependents**
- **Considering Organ Donation** – to be added to the register call **03001232323** or complete form online www.organdonation.nhs.uk
- **Choosing Funeral Arrangements and any specific wishes** - there are several local Funeral Directors – details in Henley Standard or local directories
- **Organising Lasting Power of Attorney** for when a person is unable to make their own decisions.
- **Making a Will** - it is always helpful to have arrangements formalised and this can be done by using a Solicitor or Will Writer or obtaining a Will form. These two organisations can help:

Law Society can provide local contacts: **Tel: 020 7242 1222** – www.thelawsociety.org.uk

Society of Will Writers: **Tel: 01522 687888** - www.willwriters.com

The following two organisations both provide useful detailed guidance.

Dying Matters was set up in 2009 by the National Council for Palliative Care. It's a forum which aims to help people talk more openly about bereavement and to make plans for the end of life. It has a very comprehensive website as well as useful leaflets.

www.dyingmatters.org

Freephone 08000 21 44 66.

My Life My Decision can advise you by phone or face-to-face, providing practical support and information. It also has very good guidance leaflets on these matters. To book an appointment call **07800 813305** or see www.ageuk.org.uk/oxfordshire.

Section 2: Getting Care at Home

If you or your loved one can stay at home during their illness, your GP and district nurses will be able to provide care for your symptoms and pain control.

Additionally these are some of the resources that can be drawn upon:

Marie Curie, a free service of specialist nurses for terminally ill patients (any illness). **Tel : 08000902309** (Monday-Friday). Information for someone caring for a friend or family member is on their website: www.mariecurie.org.uk/help/being-there

Macmillan Nurses, for adults and children with cancer. They have specialist advisors: chemotherapy, breast-cancer, palliative and paediatric specialists for instance. They have an End of Life Guide on their website jointly produced by Marie Curie cancer care. www.macmillan.org. **Tel: 0800 808 0000 (Monday-Friday)**.

Sue Ryder, for people with a range of terminal conditions. Their community nurses work 7 days a week to manage fatigue, pain and nausea. In addition, the home at Nettlebed has outpatients' clinics, physiotherapy services and residential respite. They have a befriending service, spiritual and chaplaincy service and family support. **Tel : 01491641384 ext.238**. www.sueryder.org

British Red Cross's programme 'Care and Support at Home' comprises a free confidential service providing low level care at home for 2 weeks, following hospital discharge. **Tel: 01189358259**.

Finding a Carer for your home

My Care My Home is an agency used by South Oxfordshire Social Services. **Freephone 0800 7318470**. www.mycaremyhome.co.uk.

They can advise on employing a carer in your own home. They have lists of local suppliers and can carry out a care assessment.

They also have Reablement Nurses who can help if you have just come out of hospital as part of their 'Hospital to Home' service. They do the same work as carers and also do physiotherapy. My Care My Home will advise on applying for council funding to pay for this care.

Premier Personal Care

PPC is a home care agency based near Henley with services designed for the person who is physically frail or housebound or for those who need help with day-to-day living. They provide care services to both the private and public sectors, locally in conjunction with South Oxfordshire Social Services. Details of their services can be found at: <http://www.premierpersonalcare.co.uk>; **Tel contact details 01491 411144**

Carers Oxfordshire This has free information, advice and support for those providing the care and also has an emergency care service. Tel: **08450507666**.
www.carersoxfordshire@oxfordshire.gov.uk.

Borrowing Equipment

There is an online catalogue of all the items which may be needed to support an elderly person at home. This includes ramps, rails, alarms and frames. Details on www.my-coach.org.uk.

Volunteers who support those with life limiting conditions

Oxfordshire Befriending for Life (OxBEL Volunteers). These visitors give dependable and consistent companionship to help each person they support to live as well and as fully as possible.

Tel: **01235 849427**. www.oxbel.org.uk

Volunteer Drivers

This is a local service for elderly people who need to go to hospital. It is based at 34 Market Place, Henley, **01491 572923** Monday-Friday 10:15 – 12:00. The national helpline is open Monday-Friday, 10-16:00 Tel: **03444111444**.

Help with Pets

Cinnamon Trust is the only specialist national charity to help terminally ill people with their pets: they offer practical help e.g. dog-walking. www.cinnamon.org.uk.

SECTION 3: FINANCE

An Attendance Allowance is available to help pay for personal care. Information on www.gov.uk/attendance-allowance. Also see www.ageuk.org.uk

Sometimes carers have to give up work to look after their loved ones at home. They can claim Carer's Allowance – see websites above or call Ageuk Oxfordshire on **0345 450 1276**.

Guidance on benefits available can also be had from the Citizens' Advice Bureau. They are at 32 Market Place, Henley, open Monday, Tuesday, Thursday and Friday.

SECTION 4: Care in a Hospice

This will be organised by your GP. The two main centres locally are **Sue Ryder** (Nettlebed) for patients over 18 and **Helen and Douglas House** (Oxford) for young people to the age of 35.

Sue Ryder provides support to families and will also arrange for respite stays for the patient, to give the family some rest. Their residential unit has 12 beds with either single rooms or single-sex units of 2-3 beds. They are open 24 hours a day and have a very flexible approach in welcoming families. Tel: **01491 641384**. www.sueryder.org.

Sobell House Hospice is based at Headington and is for adults in Oxfordshire who have an advanced illness. www.sobellhouse.org. Tel: **01865-225860**.

Financial contributions for care in hospices can be arranged through NHS Continuing Healthcare Assessment: see www.nhs.uk for details.

SECTION 5: Going into a Nursing or Care Home

My Care My Home is the agency for South Oxfordshire Social Services. They have a full list of care homes throughout the region. They can also advise on employing a carer in your own home. Freephone **0800 731 8470**. www.mycaremyhome.co.uk.

Nursing homes in Henley-on-Thames, South Oxfordshire is a web site that provides details of nursing homes in the vicinity. There is a free advice line (**08003777070**) regarding this search, please quote reference: 19897303 or search the internet:
<http://www.housingcare.org/nursing-homes/area-3-681-henleyonthames-oxfordshire.aspx>

Care Quality Commission: The independent regulator of health and social care in England. Review recent care and nursing homes inspection reports via <http://www.cqc.org.uk>

SECTION 6: Counselling and Information

Specific Illnesses

There are some very useful websites and leaflets to help you cope with different terminal conditions:

Cancer

www.maggiescentres.org

Tel: **01865 225690**

Maggie's Oxford offers emotional support to people affected by cancer.

Motor Neurone Disease

www.mndassociation.org

Tel: MND Connect **03457 626262** – (national helpline - Monday-Friday); 'End of Life Guide' available online. Local information and support available.

Parkinsons

www.parkinsons.org.uk Tel: 0808 800 0303; 'Preparing for end of life' booklet available, online and in print. Local information and support available.

Dementia

Alheimers Society: www.alheimers.org. Tel: 0300 222 1122 (national helpline). 01189 596482 (Reading).

End of life care booklet available

There are 8000 people with dementia in Oxfordshire. The NHS and Oxfordshire County Council have launched a funded service to help people in all stages (see below). This will include practical help as well as support for carers. The working title is Dementia Oxfordshire. Age UK Oxfordshire is on **0345 450 1276**

Dementia Oxfordshire - new Dementia Support Service from 12 November 2015

Three charities, Age UK Oxfordshire, guideposts and young Dementia UK have brought together their specialist expertise to develop and deliver Dementia Oxfordshire – a new service for all age groups. Their aim is to provide a consistent, high-quality , country wide , integrated service that will ensure that all those diagnosed with dementia and their family have the information , advice and support they need to live as fully and happily as possible in their local community.

Referrals of people newly diagnosed are predominately through GPs and Memory Clinics but people living with dementia and their families can refer themselves to the new service.

Doctors and Memory clinics have a secure referral service. Self-referrals can contact Head of Dementia Oxfordshire

Mandycarey@dementiaoxfordshire.org.uk or Tel **0746467767**

Pre-Bereavement Counselling

Oxfordshire Cruse Bereavement

For carers of dying people who need good support to help them cope with their own emotions.

www.oxfordcruse.co.uk

Tel: **01865 245398**

Oxfordshire Information

There is a new website, COACH (County of Oxfordshire Advice on Care and Health) that has multiple links to source advice on most of the above topics. www.my-coach.org.uk.