

WE PROVIDE HEALTH AND SOCIAL CARE
IN LOCAL COMMUNITIES

Sue Ryder Care 

Coping with caring

Are you taking care of a partner,
family member or friend who has a
serious, palliative illness?



We care for people with end of life
and long-term conditions:

Cancer, Stroke, Brain Injury,
Multiple Sclerosis, Dementia,
Huntington's Disease,
Parkinson's Disease and
Motor Neurone Disease

For more information
about Sue Ryder Care:

visit: www.suerydercare.org
call: 0845 050 1953
email: info@suerydercare.org

Sue Ryder Care is a charity registered
in England and Wales (1052076)
and in Scotland (SC039578).

Introduction

This is not a list of solutions, but just a few ideas from our own experience as carers, of how we manage to cope with the challenging emotional effects of caring for someone close to us with a palliative illness. Everybody is different and we encourage you to choose the help and support that is right for you.

Are you taking care of a partner, family member or friend who has a serious, palliative illness?

Caring includes providing practical help with things like shopping, cooking, finances and personal care.

Don't be afraid to ask for help from family, friends or professionals with practical tasks: you might need to be quite specific about what would help YOU.

Caring also involves providing emotional support, which we have found is often the most demanding and stressful aspect. We sometimes feel like an emotional punch bag, because the person we are caring for takes their frustrations out on us.

It can help to try and take it as a compliment that they can be themselves with us, but it is still hard.

Are you feeling isolated and alone?

Many of us know what it is like to feel alone with our feelings of sadness, guilt, frustration, anger, worry, hurt at feeling 'pushed away' by the person we care for and feeling just plain worn out. We have found we can feel lonely even with lots of people around us, when other people don't connect with how we are feeling.

It can help to ask a family member or friendly neighbour to stay with the person you care for, to give you a short break so that you can meet others, perhaps at a social activity you enjoy or at a carers support group.

Do you feel that you have to put on a brave face?

This may be because the person with the illness does not want to talk about things and you do. Sometimes we feel like the duck that looks calm above the surface of the water, but only because we are paddling madly below the surface to keep afloat. Sometimes the person we care for puts on a brave face themselves for visitors, while expressing their feelings to us, which we tend to keep to ourselves.

We have found that it helps to make time for ourselves, to step back and look for emotional support and/or practical help for ourselves. It also helps to use simple ideas like breathing deeply to help relax for a short time. The main thing is to accept that it is normal and all right to have strong feelings when you care for someone who has a palliative illness, and remember that other carers hold similar feelings. You probably feel that you need to

be strong for the person who is ill, but we would encourage you to have an outlet for yourself too.

Do you feel as if you are on a rollercoaster?

Caring for someone with a palliative condition can involve having to cope with major changes in treatments and medication. These can have a big impact on how both the person and the carer feels. Poor sleep and exhaustion sometimes follow.

We often feel elated one day and down in the depths the next, and have found that we need to take each day as it comes in order to cope with the changes. We have also learned to let people know that as we can't plan too far ahead, we may not be able to confirm social arrangements till the last minute.

Are you feeling things have changed in your relationship?

Some of us find that a lot of stress can undermine our relationship, particularly if some of the following happen:

- The person we care for does not want to talk about the seriousness of the illness and we do
- We are taking on new roles that the other person used to do, such as having to manage the finances or organise lots of appointments
- The cared for person's personality changes due to the illness; they may become less patient and more demanding towards us
- We may find it difficult to talk about our concerns and plans
- We may lose physical intimacy and togetherness

We cope by taking one day at a time, and by talking to other carers at the carers support group, as it can help to know that these feelings are shared by others and to support each other to make some time for ourselves.

Are you facing new challenges because the illness is progressing?

When the illness progresses, particularly if this is sudden, we can find there are not enough hours in the day, that every day is different, and often the person becomes more demanding towards us because we are the one closest to them.

If this happens for you, you can ask for extra help and support from professionals (see contacts list below).

Do you worry about what the future holds?

It can be really hard to face the fact that the cared for person will die in the near future, and especially so if we can't talk openly to the person about this.

We suggest it can help to find someone who will help you to

communicate with the person you care for; someone that will help you talk together about how you feel. Some of us have found it helpful to write a note to the person we care for, to start communicating about what is important to us, such as expressing our feelings or our wish to talk about a particular issue. Macmillan produce a helpful booklet called 'Cancer, you and your partner', or you may want to seek support from a family member, friend or palliative care professional.

Are you feeling guilty?

We know what it is like to feel guilty about many things as a carer, especially that we are going to survive and that we have a future that the other person does not have.

We have realised that we are able to cope better if we face up to it being normal and OK to admit that it is very difficult to cope with the emotional aspects of caring for someone who is seriously ill, particularly feeling guilty at times. The illness is not our fault! We try to give ourselves credit for what we are doing well in providing care.

Family and friends sometimes give us a lot of support but we have found they can only do so much. They may find it hard to show their feelings and we may find it hard to show ours, as we do not want to burden those close to us. If this is the case for you too, we suggest it can really help to find other carers to talk to who will understand what you are going through.

Sources of help for carers in Gloucestershire

Carers Support Groups for palliative carers in Gloucester

Sue Ryder Care – Leckhampton Court Hospice, Cheltenham
Tel: 01242 246298

Wheatstone, 2 North Upton Lane,
Gloucester GL4 3TA
Tel: 01452 371022

Your health and social care professionals

e.g GP, District Nurse, community palliative care nurse ('Macmillan nurse'), social worker

Hospices across Gloucestershire

Sue Ryder Care – Leckhampton Court Hospice, Leckhampton
GL53 0QJ
Tel: 01242 230199
www.suerydercare.org

Cotswold Care Hospice, Minchinhampton GL5 2PQ
Tel: 01453 886868
www.cotswoldcare.co.uk

Great Oaks Dean Forest Hospice, Coleford GL16 8QE
Tel: 01594 811910
www.great-oaks.org.uk

Palliative Care Teams

Cheltenham General Hospital
Tel: 08454 223447

Gloucestershire Royal Hospital
Tel: 08454 225179

Community Palliative Care Team (for whole county)
Tel: 01452 371022

Crossroads Care

Providing the carer with a much needed break of a few hours

Cheltenham and Tewkesbury
Tel: 01242 584844

Stroud and Gloucester
Tel: 01453 755999

Forest of Dean
Tel: 01594 823414

Careshare (Cotswolds)
Tel: 01285 650168

Carers Gloucestershire

For information, advice, support and advocacy on a wide range of carers issues

Tel: 01452 386283
www.gloscarers.org.uk

Cancer Information Centre

A wide range of leaflets and helpful information for carers as well as patients – situated in Oncology Centre, Cheltenham General Hospital
Tel: 08454 224414

GUiDE and PALS

Health, social care and disability information for Gloucestershire, including health conditions other than cancer
Tel: 08000 151 548
www.guide-information.org.uk

Maggies Centre Cotswolds

Due to open during summer 2010, situated next to Cheltenham General Hospital. Will offer information and psychological support to anyone affected by cancer, including carers
Tel: 01242 250611
www.maggiescentres.org.uk

National organisations for different health conditions

Macmillan Cancer Support

Produce a wide range of publications, all available free of charge, including:

'Hello and how are you?' (a guide for carers, by carers)

'Emotional Support in advanced cancer'

'Cancer, you and your partner'

www.be.macmillan.org.uk

Helpline: 0808 808 0000

Parkinson's Disease Society

www.parkinsons.org.uk

Helpline: 0808 800 0303

Multiple Sclerosis Society

www.mssociety.org.uk

Helpline: 0808 800 8000

Motor Neurone Disease Association

www.mnda.org

Helpline: 08457 626262

British Heart Foundation

www.bhf.org.uk

Helpline: 0300 330 3311

Huntington's Disease Association

www.hda.org.uk

tel 0151 298 3298

This leaflet was written by:

The Carers Support Group, Sue Ryder Care – Leckhampton Court Hospice

Church Road, Leckhampton, Cheltenham,
Gloucestershire GL53 0QJ

This is a small, friendly group of carers who meet monthly in a group facilitated by the Head of Family Support and Complementary Therapist based at the hospice. You are welcome to contact us for more information.

Contact: Head of Family Support

Tel: 01242 246298

Email: felicity.hearn@suerydercare.org

**This document is available in
alternative formats on request.**

Sue Ryder Care
114 -118 Southampton Row
London, WC1B 5AA

This document will be reviewed in June 2011.
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