

# Carers Information



**dovehouse**  
**hospice**

caring for people with a life limiting illness





'People who care do so because they want to help the people they care about, but often it means they end up juggling the support they give with other responsibilities, in a difficult balancing act. For many carers, looking after their own health, combining caring with work, getting access to training or simply having time to take a break and go away for a weekend can be a major challenge.'

(Department of Health, 2008)

## Who is a carer?...

A carer can be anyone who looks after or cares for a partner, relative or friend who may need extra support when they cannot manage on their own. Therefore, everyone is a potential carer. Looking after someone can be rewarding, but it can also be extremely stressful; carers can often feel isolated and feel they have no one to turn to for support.

Caring for someone is difficult, demanding and life changing in many ways and it is important that the support carers provide is recognised. Many people do not see themselves as 'carers', they are just supporting a loved one or friend with things that they are unable to do for themselves. However sometimes recognising yourself as a carer could enable you to access some support for yourself.



## The experience of caring...

There are many emotions associated with caring – love, sadness, frustration, anger, fulfilment, to name just a few and carers can often feel guilty about the way they are feeling. Carers may also think they are alone in feeling the way they do.

The following comments, and others throughout this leaflet come directly from carers and it is hoped that by reading these, this will help normalise some of the variety of thoughts, feelings and worries associated with the experience of being a carer.

**'As a carer you will feel every single emotion possible at one time or another'**

**'If I sit down just to read a book or something, I feel so guilty I am not giving them my full attention'**

**'They get very demanding, possessive and selfish, but don't realise they are doing it and what it is like for you'**

**'You feel as though you lose your "me"'**

**'Their illness is life changing for you too. I feel bereaved because my life and our marriage is not as I knew it'**

**'It is like being in a cage'**

**'Everything in your life is determined by the person you are caring for'**

**'Respite days are sacred. It is the only time I can be me again'**

**'I'm so pleased I was told about the Carers Meetings. I've learnt a lot and I realise I'm not alone'**

**'It's good to meet with other carers and to be looked after. I've made some good friends and we help and support one another'**

**'Finances are such a worry. My partner needs expensive treatment and care which we have been refused through the NHS/Local Authority. Will I have to sell my house, or make the choice to compromise the care they receive?'**

**'I can't even work for a few hours a week, which I really feel would give my life a sense of normality, because it will affect my benefits and mean we cannot afford to live. It's not fair!'**

**'All of the external pressures that exist are stressing the carer, who just simply needs some help and support'**

## Practical/Financial Implications...

The implications of caring for someone with an illness or disability can be far reaching. You may find that you have to reduce or give up work in order to care for someone full-time and that you are not able to do some of the things you have been used to like getting out and about, seeing friends and family and socialising. This is one of the reasons carers may begin to feel very isolated and alone. Being in this situation

may also bring with it other difficulties, such as the financial implications of not being able to work. Moreover, being plunged into the role of managing the day to day welfare of another person may feel like a huge responsibility and navigating your way through what can seem like very complicated healthcare, social services, benefits, housing systems and procedures, can also be extremely daunting and anxiety provoking.

## Young Carers...

A young carer is a person under the age of 18 who is providing substantial care for a friend or relative, the responsibility of which would normally be taken on by an adult.

**Young carers may be carrying out significant or substantial caring tasks and assuming a level of responsibility which is inappropriate to their age. Caring tasks can involve physical or emotional care, or taking responsibility for someone's safety or well-being. The impact of taking on an inappropriate caring role can include underachievement or absenteeism at school, mental or physical ill health. Young carers do not always recognise themselves as being 'carers'. They may see their role as something they should be doing for that family member, or that they really want to be doing. Young carers need to be differentiated from those children and young people who share some of their circumstances but cannot be defined as young carers. Not every child whose parent/sibling is ill or disabled is necessarily a young carer.'** ([www.hullcc.gov.uk](http://www.hullcc.gov.uk))

As the above statement from Hull City Council indicates, whilst all carers face significant pressures in their lives, young carers may particularly need appropriate support. It is the responsibility of the local council to look

out for the well being of young carers and ensure they receive necessary support. There may also be specific support agencies for young carers who can help and advise.

## When caring ends...

For many people who are caring for someone the situation will inevitably change. It may be that you are unable to care for someone at home any longer because their needs have become unmanageable in this situation, or sometimes, very sadly, the person being cared for may die.

The decision to place someone into the care of a residential or nursing home is undoubtedly one of the most difficult anyone may have to make, and you may again feel all sorts of emotions such as guilt that you have not done enough for the person and are letting them down. However, in order for someone to receive the best possible care, it is important to try and be realistic and remember that caring for someone is exhausting in every way and sometimes there is a limit to what you can do without reaching a crisis.

The death of a loved one is naturally one of the most difficult things anyone has to face, and everyone's experience will be very personal and individual to them. For carers, there is the loss not just of the person, but of the caring role, which may have been such a big part of

your life  
for so long...

Dove House Hospice has produced a separate 'Bereavement Information' booklet, which discusses this in further detail. Please ask any member of staff or see the contact details on following page for the Family Support Team if you want to find out more.

It is important to know there is help and support available to those carers facing a bereavement or significant change in their caring role. Details of some of these avenues of support are included in the next section along with details of other support available in your area to support both you as a carer, and the person you care for. There are local as well as national support agencies and organisations.

### Resources...

**Dove House Hospice...  
...recognises the  
support carers provide  
and in turn tries to  
support and work with  
them. Some of the  
ways that we support  
carers are:**

**Carers Room** - A room specifically for carers where they can take a break and meet other carers.

The room can be found just off reception. This room was originally set up following a suggestion from carers themselves at the Service User Forum and is available to anyone who cares about someone using Dove House service.

**Carers Meeting** - Every month a meeting is held at Dove House where carers are able to raise issues and share or be provided with information. An extra bonus is that refreshments and lunch are always provided. Above all, this is an opportunity to meet in a friendly and supportive group. If you require any more information, please feel free to call Bill Chappell or Janet Dean on (01482) 784343, and they will be more than happy to help.

**Service User Forum**  
- Every two months Dove House has a Service User Forum which has been set up for the use of patients and carers. It is an ideal opportunity for everyone to get involved in helping Dove House review and develop its services whilst at the same time share ideas on how our

services can be improved. For more information, please speak to Janet Dean or Bill Chappell on (01482) 784343.

### **Family Support Team**

- Can provide emotional, practical and spiritual support not only to patients who come into contact with Dove House services, but also to their family and friends. The team can also provide support to the bereaved and has produced a 'Bereavement Information' booklet. To find out more information about the help we offer please contact (01482) 784343. Messages can be left for the team with the Medical Secretaries.

**Respite Care** - Dove House recognises the importance of respite care for carers and the people they care for. We may be able to provide someone with a life limiting illness a short break of up to 7 days in our Inpatient Unit or 1 day per week respite care in our Day Therapy Unit. To enquire about respite care, please contact our medical secretaries on (01482) 785721.



**Timber Lodge** - Timber Lodge is a fantastic respite facility that we are pleased to be able to offer to patients and their families.

The Lodge is located in Burton Constable Holiday Park at Burton Constable Hall. It is independent of and quite separate from other services offered by Dove House Hospice. The hospice is not able to offer care in this facility and service users and carers must be satisfied that their medical and nursing needs are able to be met independently of the hospice.

For more information, please see our website [www.dovehouse.org.uk](http://www.dovehouse.org.uk), pick up a booklet at the hospice or contact Jo Longden on (01482) 784343.

**Complementary Therapy** - Dove House provides a range of these supportive treatments which aim to ease symptoms of

illness and enhance the person's feelings of physical, emotional and spiritual wellbeing. Carers may receive these treatments after appropriate referral. For more information, please speak to Caty Wood on (01482) 784343.

**Music Therapy** - Carers, as well as patients, can benefit from the music therapy we offer at Dove House. Music Therapy can help with both pain and symptoms and emotional issues. Music Therapy is a way of expressing yourself when words are hard to find. Music Therapy is not a music lesson and no previous experience of singing or playing instruments is necessary. For more information, please speak to Briony Ming on (01482) 784343.

**Website** - Information for carers is available on our website at [www.dovehouse.org.uk/forcarers](http://www.dovehouse.org.uk/forcarers)

**Hull & East Riding Local Community...**

**Social Services**

**Assessments** - As a carer you are entitled by law to an

assessment of your needs. A carer's assessment assesses whether you need any support and is an opportunity to discuss the things that could make caring easier for you.

The person you care for can also have an assessment of their needs and may be eligible for care services, or in some cases direct payments so that you can arrange your own care services.

Social services are also the lead agency in making assessments of the need for residential or nursing care.

To arrange either of these assessments or ask for more information, you will need to contact your local Social Services department. If you are a young carer, or have concerns about a young carer you should ask the advice of social services for children and families, rather than adults.

**East Riding of Yorkshire Council** - (01482) 393939

**Hull City Council** - (01482) 300300

**NCH Hull and East**

**Riding Young Carers Project** - The Young Carers Project offers support to children and young people across Hull and East Riding who have a parent who is severely disabled – this includes parents who may have alcohol or drug addiction or mental health problems. The project is managed by NCH and funded jointly by Hull City Council and East Riding of Yorkshire Council.

46 Middle Street North  
Drifffield, YO25 6SS  
Tel: (01377) 272 774  
Fax: (01377) 254 010  
Email: [nesdc@nch.org.uk](mailto:nesdc@nch.org.uk)

## Carers Support Scheme

- The Carers Support Scheme is a joint partnership between the Hull Primary Care Trust (NHS Hull) and Hull Churches Home from Hospital. Initial funding came from Macmillan Cancer Support when the scheme was established in 2004.

The scheme recruits and trains volunteers who give their time to help someone who is caring for someone with a life limiting illness.

The Carers Support Scheme can offer support to carers by providing:

- A break on a regular weekly basis or for a 'one off' social event
- Telephone support
- Help to access a welfare benefits assessment
- Transport for carers to and from appointments or hospital visits
- Outings or shopping trips for the carer as needed
- Light domestic duties within the home

They cannot however, administer medication or provide personal care

The Carers Support Scheme offers a free 8-week service and at approximately week 4 the support will be reviewed and adjusted if needed. At the end of the 8-week service and a further 4-week interval, carers can be referred again for support.

1st Floor, 82 Princes Avenue  
Hull, HU5 3QJ  
Tel: (01482) 475265  
(Referrals can be made Monday - Friday 10 am - 4 pm)  
Email: [carerssupport@hfhpkaroo.co.uk](mailto:carerssupport@hfhpkaroo.co.uk)  
Web: [www.hchfh.org.uk](http://www.hchfh.org.uk)

**Carers Centre Hull** - The Carers Centre is a charity dedicated to supporting carers and is an information point and support structure for carers and former carers living in Hull. You can drop in to the centre for information and advice, or call.

Carers Centre Hull  
Unit 5, The Shirethorn Centre  
37-42 Prospect Street  
Hull, HU2 8PX  
Tel: (01482) 225078  
Email: [information@carerscentrehull.org.uk](mailto:information@carerscentrehull.org.uk)



**East Riding Carers Support Service** - The East Riding Carers Support Service is run by the local authority and offers the following information and advice to all carers:

Activities and training courses designed to support carers in their caring role.

Benefit information relevant to carers.

Access to other organisation and services.

Carers Support groups in local areas.

Freephone advice line - 0800 917 68 44.

Free annual events for those registered as a carer with the Carers Support Service.

Stress-busting and relaxation activities.

Quarterly newsletter "We Care"

Information on benefits/ health/ organisations and services/ your rights.

The Carers Support Service is based at:-  
2A Railway Street  
Beverley, HU17 0DX

Opening times:  
Monday to Friday: 9.00 am - 5.00 pm  
Open door policy:  
Monday to Friday: 10.00 am - 1.00 pm

**National Support...**

**The Princess Royal Trust for Carers** - Is the largest provider of comprehensive carers support services in the UK.

The Trust currently provides quality information, advice and support services to almost 354,000 carers, including over 20,000 young carers, through its unique network of 144 independently managed Carers Centres, 85 young carers services and interactive websites, [www.carers.org](http://www.carers.org) and [www.youngcarers.net](http://www.youngcarers.net).

Northern Office:  
Suite 6, Oak House  
High Street, Chorley  
PR7 1DW  
Tel:(01257) 234070  
Fax: (01257) 234105  
Email: [infochorley@carers.org](mailto:infochorley@carers.org)

**Carers UK** - Is the voice of carers. Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. Carers give so much to society yet as a consequence of caring they may experience ill health, poverty and discrimination. Carers UK is an organisation of carers fighting to end this injustice. They will not stop until people recognise the true value of carers contributions to society and carers get the practical, financial and emotional support they need.

Carers UK  
20 Great Dover Street

London, SE1 4LX  
Tel: (020) 7378 4999  
Fax: (020) 7378 9781  
Email: [info@carersuk.org](mailto:info@carersuk.org)  
Website: [www.carersuk.org](http://www.carersuk.org)

Carers line for advice about your caring situation: Tel: 0808 808 7777 (Wednesday and Thursday 10am -12pm and 2pm - 4pm).

### For the bereaved...

GP – your GP may be able to refer you for counselling, or offer advice or reassurance on some of the difficult grief reactions you may experience, which may affect your health or daily life.

**Dove House Hospice Family Support Team** -  
Tel: (01482) 784343

British Association  
for Counselling and  
Psychotherapy - For  
information about counsellors  
in your local area Tel: 08457  
90 90 90  
Web: [www.bacp.co.uk](http://www.bacp.co.uk)

### Cruse Bereavement Care -

Tel: 0870 167 1677 or [www.cruse.org.uk](http://www.cruse.org.uk) - there is also a separate helpline and website for young people on 0808 808 1677 or [www.rd4u.org.uk](http://www.rd4u.org.uk)

Thank you for reading this. If you would like to become more involved, or have any ideas or suggestions on how we can improve this booklet, please contact Bill Chappell, Service User Involvement Co-ordinator on (01482) 784343.

If you have a complaint and feel that you are unable to complain to the Hospice you may complain direct to the Care Quality Commission at the address below:

Yorkshire and Humberside Region  
Care Quality Commission  
Citygate  
Gallowgate  
Newcastle upon Tyne  
NE1 4PA

Telephone: 03000 616161  
Email: [north@cac.org.uk](mailto:north@cac.org.uk)

For full details please see our leaflet: Comments, Compliments, Complaints



Dove House Hospice, Chamberlain Road, Hull, HU8 8DH  
Tel: 01482 784343, Email: [hospice@dovehouse.org.uk](mailto:hospice@dovehouse.org.uk)  
[www.dovehouse.org.uk](http://www.dovehouse.org.uk)



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