Who cares?
Support for carers of people approaching the end of life

A discussion based on a conference held on 6th November 2012
“I have been campaigning for 14 years for better support of family and friends who have cared for someone at the end of life like I did. I’m so glad this conference has finally happened, and the issue is starting to receive the recognition it deserves”

- Roberta Lovick, who cared for her daughter Louise at the end of her life

Dedicated to the memory of Marco Harwood
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About us

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. NCPC work with government, health and social care staff and people with personal experience to improve end of life care for all. Visit www.ncpc.org.uk for more information.

NCPC leads the Dying Matters coalition which aims to support changing knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make ‘living and dying well’ the norm. Visit www.dyingmatters.org for more information.

This report was produced in partnership with

Age UK - www.ageuk.org.uk
Carers Trust - www.carers.org
Carers UK - www.carersuk.org
Help the Hospices - www.helpthehospices.org.uk
Macmillan Cancer Support - www.macmillan.org.uk
Marie Curie Cancer Care - www.mariecurie.org.uk
Sue Ryder – www.sueryder.org
Executive Summary

• Carers – by whom we mean people who provide unpaid support to a family member or friend – are a crucial, but too often overlooked, part of end of life care.

• There are unique issues facing carers of those approaching the end of life, including: difficulties coping as the person’s physical, emotional, social and spiritual needs become more complex and/or demanding; having to coordinate care and professionals on a 24/7 basis; having conversations about resuscitation, artificial feeding and stopping treatment, organ donation and funeral wishes; dealing with feelings of loss and grief; bereavement.

• The Government’s ambition for meeting more people’s preferences at the end of life can only be achieved if we give their carers the knowledge, skills and support they need to take on this demanding role. The ambition to help more people to die in the community, rather than in hospital, especially requires investment in carers.

• NCPC, Carers Trust and partners came together to hold the first ever national conference focusing on the needs of carers of those approaching the end of life on 6th November 2012. This report explores five emerging themes highlighted there -
  1. Carers have their own needs
  2. Carers are expert partners in care
  3. Carers need support in every setting
  4. Carers need to be acknowledged into bereavement
  5. Caring shouldn’t be a fight

- and aims to help each reader identify the action he or she can take in relation to each one.

• This issue is not going away: there are at least half a million people currently caring for someone at the end of life, and this number is rising in line with an increasing number of deaths each year. Together we need to support this growing army of carers to make a ‘good death’ the norm for everyone.
Introduction

Why this issue

Carers – by whom we mean people who provide unpaid support to a family member or friend – are a crucial part of end of life care. As our society ages and more people live with long-term conditions and general frailty, there will be more people supporting their partners, mothers, fathers, brothers, sisters, children and friends throughout the journey, and ultimately, at the end of life.

The national End of Life Care Strategy, published by the Department of Health in 2008, recognises carers not just as givers of care, but also as people in need of support. The six-step pathway set out in the Strategy clearly states support for carers should be provided at every step of the journey.

However, neither Strategy engaged with this issue in any detail.

Carers should be supported, not just because it is the right thing to do, but in order to enable them to care, in the way that they want to. A key part of the Government’s strategy is to meet more people’s preference to die at home, rather than in hospital. However this policy has significant, and frequently overlooked, implications for unpaid carers. A home death invariably involves providing both practical care oneself as well as coordinating a range of professionals and agencies coming in and out of the home, both on a 24/7 basis. This is during a time when the needs of the person being cared for may be greater than ever, and the carer’s emotional state is at its most fragile.

We know from our contact with carers, former carers and the people they support, and academic research, that, despite some improvements, there remains a mismatch between the Government’s vision and reality. The first national survey of bereaved carers revealed that only half of carers of dying people reported receiving the help they needed.

This issue has not yet received the attention it deserves. We came together to change that.
Why we held the conference

A range of resources has been published supporting those providing care to someone at the end of life (see ‘Useful resources’), but to our knowledge a national conference bringing people together to discuss the topic had never been held before.

Our intention was to increase the profile of this issue and to help individuals and organisations to identify ways they could better support carers in their communities. Importantly, we wanted to give carers and former carers an opportunity to share their stories, both as an end in itself and as hearing the voice of the true ‘experts’ brings the issue alive, and mobilises professionals to act differently.

Who came to the conference?

83 people attended. Of those:

- Professionals: 13, 16%
- Carers and former carers: 70, 84%

We were keen from the outset to involve as many current and former carers as we possibly could. This was made possible by bursary places funded by the organising partners.

What was the feedback?

- 97% delegates rated the day as ‘good’ or ‘very good’
- 90% rated the variety of speakers as ‘good’ or ‘very good’
- We asked delegates what they would do differently as result of the conference. Answers included:

  - “Gave me new perspectives on innovative ways to support carers”
    - Community Clinical Nurse Specialist

  - “I feel much more aware of carer issues after the death of a loved one”
    - Carers Wellbeing Support Worker, carers centre

The purpose of this document

This report sets out initial thinking on support for carers of people approaching the end of life and the emerging themes highlighted at a national conference held on 6th November 2012. It is not intended to cover everything, nor does it seek to provide all the answers. We hope the report resonates with the experiences of carers and former carers, and provides useful food for thought for decision-makers, commissioners and service providers.
### Emerging questions and themes

#### How many carers are there?

| Half a million people die every year in the UK[^1] | If every dying person has just one member of their family or a friend caring for them, at least **half a million** people are caring for someone at the end of life in any given year. Most carers will look after that person for **several years** prior to the end of life, and there is often more than one carer involved, so in reality this number is likely to be much higher. |

Over a third of carers give **20 or more hours of care a week.** This has increased by five percentage points in the last decade[^5]

In total there are **6 million people caring in the UK** at any one time. That’s 1 in 10 people[^6]

This issue isn’t going away: the number of carers is set to **increase by 60%** (by 3.4 million) in the next 30 years[^7]

#### What do carers of people approaching the end of life do?

In one respect carers of people approaching the end of life do the same things as other carers. For example, managing practical tasks (housework, shopping and cooking), personal care (dressing, washing, toileting), providing emotional support and other day-to-day activities.

But there are also unique issues carers face as the person they support approaches the end of life. For example, the physical demands of caring may become more exhausting as the person’s condition progresses and their physical, social, emotional and spiritual needs become heightened or more complicated, making it harder to cope. As more professionals become involved in the person’s care, the carer often takes a lead role in coordinating, chasing and communicating with them. This can be time consuming and frustrating if there isn’t a single point of contact to help.

> “She does everything for me that paid professionals don’t do”
> – Jim Edwards, living with end-stage emphysema with support from his wife and carer Jo

[^5]: Data from the Care Quality Commission, 2017.
[^6]: Calculated based on a carer survey conducted in 2019.
[^7]: Predictions based on population growth and increased longevity, 2022.
There may also be specific decisions to make about end of life care. For example, professionals may need to know whether the person would want to be resuscitated, artificially fed or given antibiotics to treat recurrent infections. This can be complicated if the carer is not sure what the person being cared for wants and is unable to find out, for example if they cannot communicate their wishes or have lost the capacity to make decisions. In the absence of a Lasting Power of Attorney, it is the healthcare professional’s responsibility to make this decision on the basis of an assessment of the person’s best interests. However this is not always understood by carers, who sometimes feel as though they are being asked to make decisions on the person’s behalf. Sometimes it is not understood by professionals, who sometimes do ask, or appear to ask, carers to make these decisions.

These issues are in a context of the person trying to cope with the imminent loss of the person they are caring for, and the end of their role as a carer. This can add unnecessary pain and distress to an already difficult situation.

“Caring is incredibly exhausting, often doubly so at the end of life”
– Thea Stein, Chief Executive, Carers Trust

What do carers need?

The diverse needs of carers have been considered in a range of reports before this one (see ‘Useful resources’). The list usually includes:

There was a clear message that no two carers’ needs will be the same. The best way to find out what a carer needs is by asking. However there are some common themes that emerged during the conference which can be a useful starting point for anyone thinking about the needs of carers of those approaching the end of life:
1. Carers have their own needs

Most carers don’t recognise themselves as such. They simply consider themselves a son, daughter, partner, sibling, parent or friend. It is debatable whether carers need to formally label themselves ‘carer’ in order to get the help they need. It is certain, however, that services need to recognise and respond to the needs of carers, whether they call themselves ‘carer’ or not. In the case of Ian Leech, who spoke at our conference, he was simply ‘Dad’:

“I didn’t have a clue that I was a carer. I was just a part of this ‘system’ that was looking after our daughter, and doing the best we could. It was only afterwards that I realised I wasn’t just a parent, I was a carer”
– Ian Leech, who cared for his 20-year-old daughter Mel until the end of her life in 2008

Being a carer has a big impact on people’s lives. Taking on the role can lead people to lose touch with their sense of self. As one speaker said, “I feel like I’m losing my identity, my raison d’être.” Opportunities to reclaim this for a moment are valued by carers.

Emotional support is valued by carers, but is often lacking. There was a strong message that often simply feeling heard can be all that is needed:

“What would make life easier for me? A person on the other end of the phone, morning, noon and night, who you could just get rid of the frustration – like the Samaritans”
– Jo Edwards, carer of 68-year old husband Jim who is living with end-stage emphysema

Listen to Jo and Jim’s story at www.dyingmatters.org/page/caring-personal-perspective
2. Carers are expert partners in care

Simply asking “How can we work together to best look after [the person being cared for]?” is an excellent way to help a carer feel involved, reassured and in control. This can be asked by professionals across a range of settings, including at home, in care homes, hospices and hospital (see 4. below).

It is important to recognise that a carer’s role might change. For example, when the needs of the person they care for become complex or upon moving into residential care. In the case of the latter, the carer will have an important role introducing staff in the new setting to the person they care for, especially if the person approaching the end of life is unable to communicate or interact. Crucially, that the carer’s role has changed, doesn’t mean their role has ended. Likewise, their needs might change, but this doesn’t mean they’ve stopped having needs. On the contrary, changes in circumstance and transitions can cause the carer to develop new and sometimes profound needs. This can also be the case when the caring role comes to an end, for example, upon bereavement (see point 5).

Did you know?

The Samaritans are available to listen to people approaching the end of life, their carers and former carers. It’s not just for people feeling suicidal. Call 08457 90 90 90 or visit www.samaritans.org

Carers Trust host a discussion board and live chat room for carers. Visit www.carers.org/carers-chat

A new helpline has been launched in Wales specifically for carers of people at the end of life. Call the Dying Well Matters helpline on 0300 100 2011, from 10am to 10pm.

Top tip

Asking a carer “Are you OK?” will often return an answer of “Yes, I’m fine”

Asking this question a second time might give you quite a different – and more truthful – answer, such as “I need help”

With thanks to: Roberta Lovick, who cared for her daughter Louise at the end of her life, and offered this piece of advice at the conference. Several delegates recorded it as their ‘one thing I’ve learnt today’ on the conference evaluation form, proving that is often the small things that make a big difference.
3. Carers need support in every setting

Since the launch of the End of Life Care Strategy there has been a concerted effort to allow more people to die in the community, where this is their wish. The implications of this policy on carers are significant.

Dr Christopher Bailey from the University of Southampton highlighted at the conference clear evidence that carers are frequently overwhelmed by the number and force of the ‘psycho-social’ demands placed upon carers trying to facilitate a home death. Findings from the first ever national survey of bereaved people shows there is wide variance in the support available:

It is worth noting that this question was only asked where the person had been at home for some or all of the last three months of life. Whilst half of families said they got all the support they needed, which is positive, it is important to note that over 5,000 carers said they didn’t.

It is also important to pay attention to the experience of carers in hospital settings. When hospital admissions are unnecessary, they ought to be avoided. When admissions are necessary, carers should be treated with respect by hospital teams and fully involved in the person’s care, where this is the wish of the person approaching the end of life. Unfortunately this is not always the case, as delegates heard from Roberta Lovick at the conference workshop, who spoke about her daughter being “wrenched” from her in the last hours of life by the Accident & Emergency team. Support for carers at the time of death is lowest in the hospital setting:
The need to support carers ‘where they are’, rather than where services happen to be based, was identified as a key priority. Ensuring that appropriate services for carers in community settings are commissioned is part of the answer, but we also need to build compassionate communities. That is, communities in which individuals can positively care for people nearing the end of life, with compassionate support from families and friends, local services and businesses and, where applicable, their employers. Delegates heard several examples of this, for example:

- Age UK is piloting the use of trained volunteers to provide older carers of those nearing the end of life with practical and emotional support at home (see tinyurl.com/AgeEOL)

- Marie Curie Helper volunteers provide support to people at the end of life and their carers within their own homes (www.mariecurie.org.uk/en-gb/Commissioners-and-referrers/Referring-patients/Marie-Curie-Helper)

- NCPC is working with acute hospital trusts to meaningfully involve carers of people approaching the end of life during hospital stays (www.ncpc.org.uk/carers). In Birmingham, this will be part of a wider three-year compassionate communities project led by Heart of England NHS Foundation Trust, NCPC and the Dying Matters coalition (www.dyingmatters.org)

- Hospices are holding dedicated activities for carers, for example: Valentine’s Day meals for people using the hospice and their carers; discussion groups on personal topics such as intimacy; and ‘Looking after yourself’ social events
4. Carers need to be acknowledged into bereavement

Support when caring comes to an end is a neglected area. Ian Leech spoke about his experience of mental distress one year after his daughter’s death. He went to his GP who signed him off work with a sick note which cited the cause ‘a natural reaction to grief’, rather than depression, which Ian appreciated. Brian, another former carer who attended the conference, spoke of his depression after the death of his wife. As he said, “No one should have to wait for counselling for three months after bereavement when suicide is a serious option”. Both natural reactions to grief and depression should be taken seriously by all those surrounding the former carer, professionals and public alike, and followed up with the appropriate support.

Funding for bereavement support is lacking. For example, delegates heard from Carers Trust’s Thea Stein that many Local Authority contracts for carers centres stipulate that carers aren’t eligible for support after bereavement, leaving the charity to meet this cost. The recent Palliative Care Funding Review recommended that the new funding system being introduced for palliative care should not include support for families and carers, including bereavement support. That, it argued, should be met by society, not the state. This places the onus back on voluntary and community sector providers, who largely meet the need but find it difficult to get funding for their services. The National Bereavement Alliance, a group of bereavement organisations including Cruse Bereavement Care and the Bereavement Services Association, has come together to raise the profile of this issue at the national level.

At the local level, small actions can truly make a big difference. For example, some care homes hold memorial services/ events on an annual basis to remember residents who have died and to celebrate their lives. Involving family and friends, fellow residents and staff members in organising these events can be particularly therapeutic to those who had built strong relationships with the resident but were unable to attend the funeral. Another example is noting the anniversary of the death and sending a card to the person’s family. Ian Leech warned delegates that sometimes carers experience two anniversaries: the actual date of death and the day of the week the death occurred on. He also challenged the widespread assumption that ‘time heals’. Ian suggested that “time gives you the ability to manage your grief”.

It is also important to remember that sometimes loss and grief are experienced before the person has died:

“It sometimes feels as though I’m going through a period of bereavement: I’ve lost the man I fell in love with. At the same time, I can’t imagine life without him”

– Kate Harwood, who supports her husband Marco who has frontotemporal dementia.
5. Caring shouldn’t be a fight

There was a strong recurring message that caring involved a constant ‘battle’ with ‘the system’. For example, one carer at the conference described her experience of losing income from her husband’s disability living allowance upon him entering a care home. This made it difficult to find the money to visit him, or take him on trips.

Part of the solution lies at the national level, with policy being divised in such a way that doesn’t inadvertently make the system harder for carers to navigate and access what they need. NCPC, Carers Trust and our partners will continue to lobby policy-makers with this message.

But changes can be made at the local level too. Professionals and volunteers working across settings at the local level (for example, GP practices, hospitals, care homes, carers centres, hospices, helplines) have a vital role in equipping carers with the right information at the right time. Crucially, everyone involved in the person’s care must clearly communicate with carers:

“We don’t know what we don’t know. Check and double check our understanding of any directive or communication:
1. Tell us what you’re going to tell us
2. Tell us
3. Tell us what you’ve told us and why”
– Brian, former carer

Local commissioners also have a vital role:

“If you were to tell commissioners that there is a resource available, around the clock and every day of the year, that can help people to be cared for and die in the place that they want to be, which helps keep dying people out of hospital, that is low-cost or free to the NHS, they would want to know more. Well, that resource is people. We call them carers. We need to invest in supporting carers, because without them the system will collapse.”
– Simon Chapman, Director of Policy & Parliamentary Affairs, NCPC

As the Secretary of State’s Mandate to the NHS Commissioning Board says, “For all the hours that most people spend with a doctor or nurse, they spend thousands more looking after themselves or a loved one”.

Actions

The action required to improve the experience of carers will be different for each reader. We hope that this report helps you to identify the action points most relevant to you. There are three clear messages from the conference:

1. First, that it is the responsibility of everyone who comes into contact with carers to do what they can to make sure the carer has the skills, resources and strength to care. Professionals should also establish how much a carer wants to take on, and what they don’t want to do, and build that into support plans.

2. Secondly, that this is an issue which affects not only health and care, but also our relationships, employment, welfare system and society as a whole.

3. Thirdly, that it is often the simple things that make the big difference to carers of people approaching the end of life. For example, giving carers the right information at the right time:

“I feel there is a large divide between the ideal according to policy makers and what a carer actually needs and gets. For me, I desperately needed practical advice on what was available to help me care at home, and consistency of information. I found that the eligibility criteria differed between health and social care services, with much uncertainty and confusion about who was paying for what. I still feel the onus is on carers to find all this out for themselves - which is hard when in the thick of a caring role.”

– Kate Richmond, who cared for her aunt Enid who had terminal cancer

As organisations NCPC, Carers Trust and our partners remain committed to highlighting and supporting the needs of carers, and will continue to involve carers and former carers in everything that we do. NCPC’s next steps include:

• Discussing how we can take this agenda forward with our partners
• Establishing a Carers and Bereavement working group in 2013, strengthening the link between the way in which people die and carers’ experiences of bereavement
• Continuing to campaign with Help the Hospices, Macmillan Cancer Support, Marie Curie Cancer Care, Motor Neurone Disease Association and Sue Ryder for free social care at the end of life (www.ncpc.org.uk/social-care). This would make a considerable difference to both people approaching the end of life and their carers if implemented by the Government.
Useful resources

A range of discussion documents and resources have been produced on this issue. They have been brought together into one place at:

www.dyingmatters.org/page/carers-looking-after-someone-approaching-end-life

Presentations from the conference can be found at www.ncpc.org.uk/carers, as can *Caring until the very end*, a 19-page special feature published as part of this project in *Inside Palliative Care*, Volume 20, June 2012 NCPC, London.

Feedback

We would be very grateful to hear your comments and suggestions. Please call us on 020 7697 1520, email policy@ncpc.org.uk or write to us at NCPC, The Fitzpatrick Building, 188-194 York Way, London, N7 9AS.
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This report was written by Alice Fuller, Policy & Parliamentary Affairs Lead, NCPC.
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