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**WE ARE
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**Improving support for older people
looking after someone with advanced cancer**

This briefing paper is about the findings and recommendations from a research project conducted at the University of Nottingham, with funding awarded by Macmillan Cancer Support. The project was set up to study the experiences and main support needs of older carers* looking after someone with advanced cancer and to facilitate the active involvement of carers in the research process

Key findings

Looking after someone with advanced cancer approaching the end of their life has a substantial and enduring impact on older carers

Various factors contribute to the diverse quality and impact of end of life care experiences for both the person with advanced cancer and their caregiver. These include:

- factors relating to the care giver and care recipient, such as the communication style and quality of relationship between them, the availability, provision and quality of informal support, and the duration of the end of life care phase
- factors external to the care giver and care recipient such as the availability, provision and quality of formal health and social care services for both the care giver and the person with advanced cancer

The quality of the professional care provided to the ‘patient’ makes a vast difference to the carer’s experience

The quality, timing and way support is provided to carers makes a vast difference to their overall end of life care experience

The support services most important to older carers include:

Regular health checks and prompt health care

Practical help and equipment

A 24hour ‘manned’ helpline

Assistance with form filling

Regular visits by a palliative care specialist

Reliable written information

* The term ‘older carer’ is used in this briefing paper as a short hand term to describe people over the age of 55 who support or look after someone they know, informally and without pay





Research Methods

Carer involvement

From its inception, this research project has been about exploring the experiences and support needs of older carers, through meaningful collaboration with older carers. Older carers have therefore been involved throughout the project.

Older carers

- contributed to the project design and reviewing draft versions of the research funding application
- assisted with the recruitment of older carers
- co-facilitated one of the workshops
- contributed to the final report by producing reflections on participating in the research
- commented on a draft version of the final report
- co-produced a briefing paper on the involvement of older carers in research

Recruitment strategy

To facilitate the recruitment of a diverse sample of older carers from contrasting locations, the lead researcher contacted pre-existing research partners, local and national community based organisations, radio and print media organisations and web-based groups. (Seymour et al, 2006) The research partners, and Macmillan Cancer Voices were particularly valuable sources of participants, together facilitating the recruitment of more than half of the total sample.

Participants

34 people took part in the study. 29 people attended workshop meetings and five people were interviewed. The sample was made up of 21 women and 13 men. 15 people had been aged between 55 and 64 when caring, 12 between 65 and 74, and 3 were aged 75 or older. 19 of the participants were or had been spousal caregivers. Five participants were current carers.

Data collection

Workshops and interviews were chosen as the method for gathering data. From early June to late July 2010, workshop meetings were conducted at the Isle of Wight, London, Nottingham, Scunthorpe and York. During the same period as the workshops, one joint interview with two older carers and three individual interviews were conducted with people from Bridport, Cheltenham, Glasgow and Sheffield.

Participants were encouraged to talk about their own experiences of caring and their experiences of and needs for support as an older carer. At the workshops they were asked to consider together "What are the priority support needs of older carers of people with advanced cancer?"

Data analysis

The interview and workshop data were analysed to identify the main topics and issues. Individual and group similarities and differences across the sample were explored.

Details about the involvement of carers in research during and since this project are presented in another briefing paper: 'Older carers and involvement in research. Why, what and when?'

Findings

The impact of looking after someone with advanced cancer

Looking after someone approaching the end of their life has a substantial and enduring impact on older carers. Some of the effects described by the older carers in this study were positive but many were problematic. Commonly, looking after someone affects older carers in relation to their...

Roles, responsibilities and relationships

Emotional, mental and physical health

It was like an emotional roller coaster

I had feelings of isolation like I was in a bubble... weird

The psychological demands and responsibilities were more challenging than the practical

My own health needs were on hold while my husband was ill

to take him out in the chair, the battery thing it was so heavy. I had a bad back as well ... about 18 months into it I was absolutely shattered... I couldn't take any more

Although It was really hard... looking after my wife was a privilege, not a burden

Looking after my Dad gave us an opportunity to get to spend time together, really get to know each other...I got to know him and appreciate him

From feeding my mother, like when she fed me as a child – we had this bond

He wouldn't talk with me or let me do anything for him ... We had arguments...

Even though they live miles away...it brought the family together... our special time

My wife didn't want me to see her undressed anymore and we'd always been so relaxed with each other before, for so many years ...

I bathed her in bed because she wasn't strong enough.

I was doing all I could...the tasks didn't bother me

Material circumstances

I had to take them to the hospital which was a 50 mile round trip, and no matter how much money you've got it's draining. Sometimes I was doing it three times a week and you just can't afford it. So after a while we filled in a claim form

I needed information. They said my father can't go home, he'll have to go into a nursing home. And I said but who pays for it, "Oh you do, and he'll be assessed"... I couldn't afford to pay... I'm an only child and I've got no partner, brothers or sisters, there's nobody but me

Bereavement experiences

I was constantly ill after he died...

I still remember with great distress how bad it was for him gasping for breath... that was very distressing to watch

Looking back on it now I should have pushed it a bit further... I feel guilty about that

Friends disappeared ... and haven't come back...

Providers and types of carer support

The older carers identified many individuals, groups and organisations as providers of support for them

The carers described various experiences of informal support from friends, relatives and neighbours, with some also mentioning support received from local voluntary people and or community based groups and organisations such as churches and other religious institutions and pensioners action groups

The carers received a range of formal support services from health and social care staff from charitable and statutory organisations such as from hospices, Age UK, Carers UK, Macmillan Cancer Support, Marie Curie Cancer Care, the NHS and Social Services

Collectively, the carers referred to experiences of a range of practical, medical, nursing, financial and or technical help, information and or advice; emotional and or spiritual support; equipment and or adaptations, and opportunities for a break

Examples of what the carers had to say about their experiences and views of support are presented in their own words on this and the next three pages

Spiritual support

I saw this lovely lovely chaplain.

We got support from the community and the local church ... Everyone got involved.

Medical-nursing help, advice and information

My district nurse put me in touch with the carers group.

The GP was so good. I said to him that she wanted to die here and he said that's okay, I'll tell you what to do.

The specialist nurse was brilliant when I finally found her.

The appointment with the doctor was very useful because he actually told me, instead of these second hand garbled messages that I didn't know what to make of, he made time to tell me the facts himself.

Emotional support

... I went to the carer support group at the hospice...

The children are always phoning us up ...

My GP always asked me how I was coping ...

We've formed a group and we go out once every six weeks which is nice.

Provision of technical equipment and adaptations

I said to the district nurse about getting some kind of aids, like a commode or toilet seat, something to go across the bath.

Practical help

My neighbour cooked something for me for when I got back from the hospital.

I found them very helpful at the tax office.

People outside the family, a couple, a neighbour and a sister-in-law, proved to be the lifesavers for me.

Written information and Helplines

I phoned the Carers Centre and they sent me lots of leaflets.

The people at the benefits office were really helpful.

We had this thing called Pal Call so you can actually ring the hospice... we were given advice... a real life line.

Breaks and respite care

Friends used to visit and sat with my husband so I could have a break.

At first I would leave him with his friend which was good but when he got really poorly I didn't like to leave him at all.

The nurses came during the night, which was a great help because that allowed me a few hours sleep.

Many people and organisations are often involved in end of life care, some exclusively in relation to the person who is dying and others who may help both the dying person and the person looking after them at home

Carers may receive practical, nursing, financial and or technical help; emotional and or spiritual support; information; advice; equipment and or opportunities for a break

The quality and amount of informal and formal support experienced by older carers varies substantially

Common concerns and problems with support services for carers

Inadequate support and information

I said to the district nurse about getting some kind of aids, like a commode or toilet seat, something to go across the bath. And she phoned up and got an appointment for a month's time... so I had to fit a board across the bath with a plastic bag on it so she could have a shower, and she was all bruises from lifting her off the toilet.

I needed to be told more about all the medication they gave him, and what it was for. When he came out of hospital he was given this big bag of medication, and even though you've a vague idea what it's for, you want to really know.

Apart from the last two days I didn't get any support from any organisation or anything... It was nothing for me and I just felt as if oh well I'll just carry on regardless, and you do don't you?

My GP only came once the whole time after my wife came out of the hospital... never said anything to me about how I was or help I could get...

Whenever I've spoken to the Benefits Helpline they've been as confused as I am ... there's a gap of good, reliable advice or consistent advice, that kind of thing.

We got really bad advice from an ex-specialist nurse who was covering the usual person. She said "You've got to wait three months before you can apply" so we never did anything about it. The district nurse was very upset later and said if she'd known she would have got it for us. We didn't get any disability living allowance until the end of September, and he died in November.

Inaccessible support and information

I would say very definitely, unless people go to find support they don't get it.

I said I couldn't cope on my own with my husband any more – and I desperately needed a break ... they said I would have wait until the following week by which time he had died.

His pain relief wasn't working and I used to get really frustrated trying to get someone to come and sort it out for him.

There wasn't enough available straightaway, financially or help. I found it all the hard way, every time she went into hospital it was there on the notice board, but why is it up in hospital? You'd see various leaflets there, but there's nothing on TV, no general awareness.

The specialist nurses only work Monday to Friday and lots of them are part time. C is only a couple of days a week there, and you couldn't always get hold of them - that was the other thing. I think stopping over the weekend is a bad thing, that's when some things go wrong.

I really needed to speak with someone, with someone who knows, understands ... there was no-one – I didn't know what to do or where to go. I needed a manned 24 hour helpline.

It was difficult to find out anything on how to provide care .. to preserve her dignity.

There was nobody, the Cancer BACUP thing in the hospital was closed. Nobody in the hospital gave me any information so I was permanently on the net. I didn't know what to do if he had another fit.

Uncoordinated and inefficient services

The doctors at the two hospitals never knew what the other was doing – it felt like I had to keep an eye on what was going on, telling them what had been happening – they didn't seem to keep each other informed – it was a huge worry for me.

They never had her drugs ready on the ward when my wife was ready to come home so I ended up having to drive back to the hospital again later.

... this lack of home attention, none of this was being teased out. I asked for dietary help...but they decided because things were accelerating so fast it just wasn't worth it. So everything was packing up, and she was wetting the bed... and all that. But all this time there was no help.

Uncaring, insensitive approaches

Some of them don't seem to care – it's just a job and as long as they've done her drugs they don't bother about asking how we are coping.

The day after my wife had died this driver came to collect her chair... he just came in and he never even said a word – I was so upset.

It would have been just so beneficial if somebody had come in and said do you want to talk about anything, hold my hand would have been nice.

It was almost as if we'd got the plague, and I was thinking what have I done, have I done something wrong? Like I say I sat in the chair for seven days, a week, for seven weeks, and I could have been on the moon, totally isolated.

Characteristics of good support services for carers

Under-resourced and inequitable services

I think they're very over-stretched... I know somebody whose husband died recently and he was quite ill for about two months and during that time... she never did get round to visiting...

What I could do with is someone to help me with all the jobs around the house... and the garden. I cant manage to keep it as clean and tidy as my wife. She doesn't complain but I worry as I can see it's all getting in a mess. But they just don't have that sort of help available

A good night's sleep would have helped hugely. The service is on the island... but it didn't happen... it's limited, again it's limited, there's only a set number of specialist nurses

Even though I'm the only one who does anything for him, because I'm not his family...I'm not given, not allowed to be given information by the nurses, the doctor. They won't tell me anything

I know somebody who's had the same thing only last year, and they got a wad of paperwork all about it. We got nothing at all, not even one sheet of paper....

Comprehensive

As far as looking after my mother and father the nurses we had were excellent, an excellent care package, absolutely beautiful. They came three times a day. They came during the night, which was a great help because that allowed me a few hours sleep ... And that was from the beginning ... we had excellent care all the way through...

They decided he could go to a specialist day unit and once a week he went there. They had a big bus there and then they gave him massage and therapies and all the patients talked together. It was a relief for him and I could clean the bedroom. As soon as the ambulance picked him up I'd go into the bedroom and I'd spring clean it. And then I'd have a long bath because it's something you can't have when you don't know what's going to happen next.

Organised, co-ordinated

I said to the hospital doctor I'd like to keep him at home as long as possible, but I think he'd like to be in the hospice at the end. And he said "Right, well you keep him at home and when he can't walk ring me up and we'll see he gets into the hospice". And that is actually exactly what happened, he was at home for just over seven weeks and then he was in the hospice for 10 days before he died.

They organised it so that the Hospice at Home was there before I got to my friend's. So that when I got there they went, and then I took over until someone else came in, or until it was close to someone else coming in, and that was quite useful.

I got really good support.... my husband wanted to come home and the hospital they arranged everything, and everything arrived the next day, everything he needed.

Continues overleaf...



Characteristics of good support services for carers

Emotionally supportive

My daughter and I went to the GP ... to talk about what was going on, what we were facing, and he said "This is all new to you but it's not new to us. Remember that. Anything you need you just come to the surgery, leave a message and I will come round". And then after my wife had died he even came to see me after the funeral.

My GP was really good, he came every day and he'd always ask if I was OK, if there was anything he could do to help me...

I think with the community nurses it was for both of us actually, because they really sort of understood how I felt.

One evening, in one of those quiet moments, one of the nurses said "Just let me give you a hug"... she just knew that at that moment that's exactly what I needed... they were so sensitive... it's not in the nursing textbook... but that personal, emotional support for the family was very, very important..

Going to the hospice was something special. The people that we met down there... they were really caring people... They're unbelievable, special.

Practical

The GP was so good. I said to him that she wanted to die here and he said that's okay, I'll tell you what to do. So with things like the morphine, I had a syringe and a little glass so I could measure the amount. He said 5mls to start and then I topped it up to the 10 with water, and when she was rough I'd put 8mls in and top it up with 2. That was a way of helping the pain... it worked very well.

There was a nurse used to come, not a specialist nurse, just a normal nurse that came through the surgery. She was lovely - she did all sorts of things that helped me when I was wiping my wife's bum and things like that, she helped in that respect. Told me what to do and got me things that helped me, cleaning things like that, and then she arranged for some help to come to help cleaning and things like around the bedroom. And they were good so that was positive.

Support from the nurses was pretty good really. In particular towards the end, the community nurses were very good. They were there on the night she died, they were really good. They sort of took over you know, which was really nice....

Clinically effective

Depending on how much breakthrough pain he had, I had to phone the district nurses to come and give him an injection... I just had to lift the phone and they were there and that was reassuring for me... I just wanted his pain under control. I could deal with everything else, it was just the pain.

The GP was brilliant with her because she slept a lot and he'd pop upstairs to see her in bed and have a chat to her and make sure she was okay. That felt very supportive and mattered a great deal to us because we felt confident that if we rang the surgery he would come, or one of his colleagues would.

Pro-active

My district nurse was very good. She would come in and see to C and afterwards turn to me and say "How are you?" In fact it was her that put me in touch with the carers group.

I didn't have to go looking... I was offered things I'd never even heard of. And when I tried to push something away they very skilfully put it back... It was only later, weeks down the track, that I realised that they were absolutely right.

Respectful and considerate

The support I got initially was from the nurse that came through the GP, and she was excellent, she was kind and considerate and most helpful.

I said is it possible for him to go to the hospice? And they said "Well we don't think he would make it there, he's only a few hours, if that..." That's what I really appreciated; they didn't just say "No!", you know, they said "We don't think it's advisable".

I'd an appointment to go and talk to the specialist at the city hospital and ... the day before it [my father] was moved to the local hospital. So I phoned him up and he said "It's fine, come and we'll talk just as we'd arranged". So I went and I was most impressed. And he told me sensibly, not unsympathetically but practically, and that was great.

Informative

One of the most helpful things the GP told me was that a lot of families think that when a patient has to go onto morphine or drugs like that they think that they're being overdosed. He said in fact it's the cancer invading the brain that does it. And that was very useful knowledge.

Support services most important to older carers

The carers in the project identified the types of support listed below as the services most generally needed and important to older carers of people approaching the end of their life

Regular health check-ups and prompt health care

Tailored and timely practical help and equipment offered routinely

24 hour / 365 days a year telephone helpline (staffed by someone familiar and experienced)

Assistance offered with form-filling, especially in relation to applications for social services and benefits

Routine regular visits by a specialist palliative care professional to assess changing needs and provide / organise appropriate help and support

Routine provision of comprehensive and reliable (not IT-based) information



Improving support services for older carers

Conclusion

Factors influencing different experiences of caring

The findings suggest that a combination of 'intrinsic' and 'extrinsic' factors influence caring experiences (for both carers and recipients of care).

Intrinsic factors tend not to be easily malleable nor influenced by formal support measures. For example, intrinsic factors include the quality of the relationship and communication style between the carer and the person they are caring for; others include the availability, provision and quality of informal support, their previous experiences of and attitudes to health care and the duration of the end of life phase. Health and social care staff need to be aware and respond to these factors but they are unlikely to be able to change or resolve them.

In contrast, extrinsic factors are those aspects of the caring experience that are not predetermined; rather they are external to the caring dyad, subject to influence and can be altered to facilitate a more positive caring experience. For example one key extrinsic factor is the provision of appropriate, relevant and timely information to both the patient and their carer.

Key extrinsic factors which have a major impact on the carers experience and are potentially amenable to change include:

- The availability of health and social care staff
- The recognition, respect and involvement of carers in care planning and decision-making
- The provision of emotional support
- The provision of practical support and equipment
- The provision of Information
- Clinical effectiveness

Health and social care staff should be aware that many carers have difficulty in considering their own needs for support and tend to focus on the patients needs. Older people who are looking after their spouse often do not identify themselves as 'carers' so tend not to approach or request services publicised or promoted as being for carers.

I didn't think of myself as a carer - I was just looking after my husband. So I never really took any notice of the leaflets in the doctor's waiting room.

Recommendations

Support services for older carers should be targeted at the following priority needs:

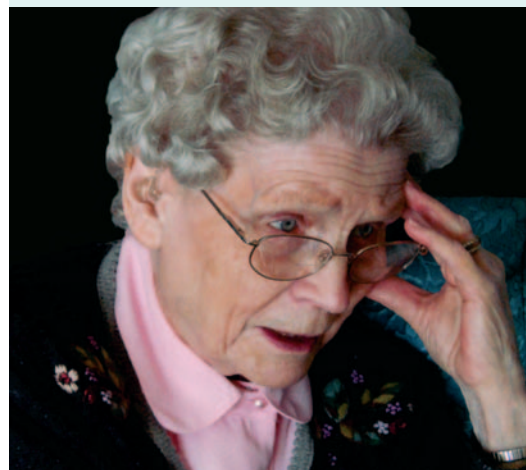
Practical help – Providing carers with assistance with general household activities such as shopping, cleaning and cooking is highly valued, most especially by older people and those who are frail

Routine health checks – carers need regular checks for the health problems associated with ageing that have the potential to be exacerbated by caring. As well as considering physical health, the areas checked on should reflect the stress and anxiety of caring

Respite care – Carers need to have regular breaks, providing them with a few hours, a day or a night when someone else is responsible for care. This time can be used for shopping, cleaning, sleeping or to do whatever is needed/ required

Emotional support – carers need people with personal experience of caring to be on hand to listen and offer advice. This could be accessed through support groups and carer organisations and needs to be available 24 hours a day

Information – written or verbal information needs to be delivered at the right time in the right way. Carers want to be given information directly not to have to ask or go looking for it. Information about practical help and also about clinical matters, including skills for care for the dying, is required



To improve end of life care planning and the provision of support for older carers, commissioners, service managers and front line staff should focus on:

- The importance of the equitable distribution and accessibility of support services for carers
- The need for staff involved in end of life care to recognise, respect and involve carers in care planning and decision-making
- The need for support services to be provided to older carers on a proactive rather than reactive basis, to pre-empt and avoid crises, and unnecessary distress and problems
- The need to avoid confusion, duplication and breaks in support that can arise from multiple care plans and service providers – a single holistic common assessment and a nominated case manager overseeing the different services involved in supporting the dying person and their carer/s is commended
- The need for staff to express genuine concern for carers' emotional needs and to have sufficient time allocated to offer support and explore solutions to problems
- The importance of support services and equipment being delivered and concluded sensitively and at an appropriate time
- The need for comprehensive, easily accessible and reliable information, practical advice and support
- The need for carers to be provided with accurate information and guidance about personal health budgets – training about financial management should be developed for staff supporting carers (and patients) who are taking on this extra responsibility

Organisations and publications providing support and information for older carers

Age UK*

0800 169 6555 / 020 8765 7200

www.ageuk.org.uk

Publications - Advice for carers. A practical guide' and 'From us to you. Top tips to you from older carers'

Benefit enquiry line

0800 882200

Carers allowance unit

0845 608 4321

Carers Direct

PO Box 4338 Manchester M61 0BY

0808 802 0202 www.nhs.uk/carersdirect

Carers UK

20 Great Dover Street, London SE1 4LX

Careline 0808 808 7777 www.carersuk.org

Crossroads Care

10 Regent Place, Rugby CV21 2PN

0845 450 0350 www.crossroads.org.uk

Cruse Bereavement Care

0844 477 9400

www.crusebereavementcare.org.uk

Macmillan Cancer Support

0808 808 0000

89 Albert Embankment, London, SE1 7UQ

www.macmillan.org.uk/HowWeCanHelp/HowWeCanHelp.aspx

Princess Royal Trust for Carers

0844 800 4361 www.carers.org





Recommended reading

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