

Caring Conversations

Cancer carers – working together, making a difference

Caring Conversations is a new series of resource papers by the Association of Directors of Adult Social Services (ADASS) in support of implementation of the refreshed national strategy for carers published by the Coalition Government in November 2010. This is also the first time Macmillan Cancer Support and the Association of Directors of Social Services have come together to say something about supporting cancer carers in line with the Macmillan vision for cancer survivorship, which is:

“People living with or beyond cancer, and their carers, should have easy access to high quality care, treatment and support to meet their medical, practical, emotional and financial needs for years after treatment. They should be respected and included as equal members of society and be able to take as active a role as they wish in their care and treatment”.

Few cancer patients travel their care and treatment pathway alone. Families, friends and carers share that journey but their visibility as equal partners in cancer care varies. There is a need to improve our understanding of what it is like for carers and how we can work in partnership with them during all stages of their journey. Carers provide emotional support, practical help and physical care. Older cancer carers are a significant sub-group. Some may also become patients, or the cancer patient themselves may assume a substantial caring role.

So, in this **Caring Conversations** paper we are inviting local statutory agencies, patient and carer organisations to grow local conversations about the experience of cancer patients and their carers and what would improve it. Whilst suggesting some conversation points, the most valuable resource for local discussion will be local experience and feedback from patients, carers, health and social care professionals, providers and third sector partners such as Macmillan Cancer Support. Do celebrate what works well, talk about what matters and try to agree on what would make a real difference to caring outcomes locally.

Cancer carers – some facts

The patient and carer experience of cancer and social care services is set to become an increasingly important outcome measure in the assessment of the quality of services. In the UK, it is estimated there are some 2 million people living with and beyond cancer, 1.6 million of whom are living in England. The number of cancer survivors is estimated to double by 2030. **There are an estimated 1.1 million people caring for someone with cancer in the UK, of whom 905,000 are in England.**¹

¹ “More than a million”, Macmillan Cancer Support, November, 2011

Cancer is no longer a death sentence. It is increasingly clear cancer survivorship needs to move up the agenda of adult social care. It needs to be as much a social care concern as it is a health care priority. This is because^{2 3}:

- 25% of cancer carers spend more than 20 hours caring each week
- nearly 1 in 4 cancer carers have been a carer for more than a year
- a quarter of cancer carers feel abandoned
- two thirds experience anxiety
- only one in five people with cancer felt their carers' needs were met by health and social care.
- 48% of cancer carers are in employment, and 79% of cancer carers live separately from the person they care for.

Levels of public awareness of the role and needs of carers are generally low. Approximately half of cancer carers don't see themselves as a "carer". Half of cancer carers (49%) get no support, and 70% have not had a local authority carer's assessment. Having accessible and timely information is a critical component of carer support. Information can do a lot to help carers anticipate some of the things they and the person they support may face. Timely information can relieve worry and stress and help to prepare for the "ups and downs. Information is also a critical component of meaningful partnership, choice and control.

Knowing who to go to is vital. People often ask people they know. Improved public awareness around cancer survivorship is needed. The voluntary sector has a key role here as people often look to this sector for independent advice and support.

Cancer carers speaking

"Hello, and how are you?" Macmillan Cancer Support, 2009

Carers feel forgotten, alone, even invisible

Any number of times people asked me "How's your wife" or "How's Margaret?" but very rarely did they say "How are you?"

Working with professionals is about sharing the care. We both have a role to play.

You may feel overwhelmed by the circumstances and inadequate for the task but you will gain knowledge and skills with the passing of time and amaze yourself.

Social Care for Cancer, Macmillan Cancer Support, 2008

No one gave us anything. Unless I searched for the information... I wasn't given a thing.

They give you loads of leaflets, its leaflet overload really... if you could just sit for 15 minutes and talk to someone.

When I got back from the hospital I just wanted to sit on the sofa but I had to come in and start all over again...the waiting list is so long... I applied for a rail... it took them five months [patient].

Improving Support for older people looking after someone with advanced cancer, University of Nottingham, 2011

My district nurse was very good... [she] put me in touch with the carers group

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

He didn't want the hospital... he wanted to be at home... he got that wish and I got my wish.

More than a million, a report by Ipsos Mori for Macmillan Cancer Support, 2011

I worry more and I'm not sleeping well. It just affects everything really. I can't go out much because I worry about leaving him.

I think that my mum, potentially, is missing out on lots of stuff because she has no money... Mum could be getting the Carer's Allowance. There's [other] stuff my mum could get but I don't really know what's available.

² "More than a million", Macmillan Cancer Support, November, 2011

³ "Worried Sick: The emotional impact of cancer", Macmillan Cancer Support, 2006"

Carer experience – what hinders

Improving the support for people living with and beyond cancer requires improved support for carers⁴. People with cancer and their carers have a range of needs which include access to personalised social care and universal services. A lot of positive practice occurs now. We need to build on this. The feedback from carers also tells us that sometimes they don't get the support they need. This includes things such as **lack of**:

- awareness of their own status as a carer
- recognition of “seldom-heard from” carers e.g. with learning disabilities or mental health problems.
- recognition of carers from BME communities
- information/signposting to help
- awareness of available local services or what social care is
- take up of carer’s assessments
- understanding of entitlements to financial and other support
- someone to talk to about the challenges of cancer caring
- willingness, for various reasons, to ask for help
- confidence in services or fear of losing control
- flexibility in provision of personalised service and support arrangements
- integration across health and social care
- evidence base to drive care commissioning and deliver change
- carer involvement in service design and planning
- awareness and support on employment rights: staying in and returning to work.
- access to services for those with “low” or “moderate” needs – that bit of help that may reduce or delay the need for more intensive support
- emotional support and respite.

We need to be aware of the risk of assumptions by professionals about people’s willingness to commence, continue with and sustain caring roles. Becoming a carer and continuing with the responsibilities involved needs to be an informed choice.

Carer experience – what helps

A whole range of factors can affect the ability of people to have a positive experience of care and support. Needs are likely to vary during the cancer journey and from person to person, both in intensity and in what is needed. Points for care professionals to consider include working holistically with cancer carers within an organisational culture that is responsive to a carers’ need to:

- be treated as an individual – every situation is different
- be helped to identify themselves as a carer, particularly “seldom heard from” carers
- have their culture, lifestyle and beliefs respected
- be valued for their knowledge and skills
- be treated as equal partners in providing care
- be signposted to local and national sources of support for carers
- access high quality information
- know what the options are - have a sense of choice/control
- give feedback and know it will be used – having their voice heard
- be involved in care pathway planning and development
- have a written copy of the care plan - be offered advice on practical aspects of cancer care
- be clear it’s always OK to ask questions and share worries
- have contact numbers – including out of hours support
- be helped to plan for problems and possible emergencies
- meet people going through the same thing and access peer support
- access advocacy and independent advice services as needed
- access information on navigating the benefits system
- have support and advice on remaining in or returning to work
- get emotional support to help deal with uncertainty, stress, anxiety etc.
- be offered advice on how to stay well - be able to keep active and fit
- have a life outside of caring - take a break from caring when needed.

⁴ Improving outcomes: a strategy for cancer [DH-2010]

Some conversation points

We all have the potential to be affected by cancer at some point in our lives. It may be helpful, in terms of improved recognition and support for cancer carers, to explore some or all of the following conversation points that have most relevance to local circumstances:

- How do we identify cancer carers and help them to self-identify?
- How do we reach “seldom heard from” carers who tend to miss out on support?
- How many cancer carers are there locally?
- How are carers involved in decisions about the patient’s care and the care journey?
- What information and advice do carers have to guide them along the survivorship pathway and to sustain a sense of choice and control that is meaningful to them?
- Do we regard and treat carers as equal partners in cancer care?
- Do we ensure carers can prepare for problems and get help when they occur?
- How well are we recognising carers’ needs as well as those of the patient?
- What is the local take up of Council carers’ assessments?
- What are the outcomes of these carers’ assessments?
- How are carers signposted to local and national sources of support?
- Are there local services to meet carers practical and emotional support needs?
- How well is personalisation working for carers of people with cancer in the area?
- Have we effective local arrangements for GPs to be aware of carers’ health needs?
- Do local professionals have an understanding of the specific needs of different groups of carers and sources of support available to them?
- Do we offer/take up carers’ awareness training for those who work with carers of people with cancer?
- Do we offer older carers [those over 65 or 70] routine health checks?
- Are there effective local arrangements for signposting carers to benefits?
- What are we doing to raise awareness around carers’ employment rights?
- What carer’s skills development programmes are available locally to support self management?
- What services and supports are available for life after caring?
- How well are we communicating with communities about cancer risks and recognition?
- Does what we do promote co-production of personalised care and support outcomes that sustain choice, control, dignity and respect?
- Are there realistic opportunities for a break/ respite from caring?
- What are the big issues for local cancer carers and how do we know?
- What are cancer carers telling us about the local cancer survivorship care pathway?

Further information about carers and cancer

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Note: This paper considers the position of adult carers of adults with cancer. It does not try to cover the position of children in caring roles or adults caring for children with cancer. Macmillan has a helpful guide for young people caring for someone with cancer: **Let’s talk about you:** www.macmillan.org.uk/documents/cancerinfo/youngcarersbooklet_2010.pdf