SOCIAL CARE

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**Introduction**

George Holley-Moore, Macmillan Policy Manager for Cancer Care and Support, on the vital role of social care in supporting people with cancer and their carers.

We know that cancer does not just affect a person’s physical health. It can have a far-reaching impact on their mental health, finances and employment, and relationships. Many people with cancer will also have practical support and social care needs. This could be directly because of a cancer diagnosis, or due to another long-term health condition. Many people with cancer tell us that, too often, these needs are not met.

Macmillan has a strategic ambition to improve practical support for people living with cancer. The cancer population is getting older, in line with the general population, and more people are living with cancer for longer, many with unmet social care needs.

Today, around half of people diagnosed with cancer will live for at least 10 years, and at least 625,000 people in the UK are estimated to be facing poor health or disability after treatment for cancer. That is approximately one in four (25%) of people living with cancer.

Often people do not automatically associate a cancer diagnosis with social care needs. This may include some health and social care policy makers. But for many people, cancer is now a long-term condition. These people often have specific and complex social care needs due to the length and nature of treatment, the impact of treatment on mobility, their ability to perform daily tasks or the emotional impact of a cancer diagnosis.

Then there are the people who care for someone with cancer. In the UK there an estimated 1.5 million carers for people living with cancer, and half of these carers receive no support at all. Yet 70% of carers for people with cancer have experienced some form of emotional impact including stress, anxiety and depression.

**Social care at the end of life**

Getting the right social care is particularly important for people at the end of life. With the right support, 73% of people with cancer would prefer to die at home, yet only 29% actually do. This edition of *Sharing good practice* highlights the vital role that social workers have in helping to meet the holistic needs of people with cancer at the end of their lives, including helping people to die at home and providing emotional and psychological support.

There are currently around 50 Macmillan social workers in post, working within the community and as part of multidisciplinary teams. From helping to prevent emergency hospital admissions, to providing emotional support to bereaved families, these professionals are key to providing good end of life care, and there are some fantastic examples of that in this edition.

**What is Macmillan doing?**

The Policy, Campaigns and Influencing Team at Macmillan works to influence national and local government policy to ensure that statutory services meet the social care and practical support needs of people living with cancer.

We do this through working with colleagues across the organisation, the voluntary and community sector, people living with cancer and other stakeholders.
to ensure that policy and decision makers are aware of the specific needs that people living with cancer have, and how policy, funding and services can be best used to meet these needs.

In England, the government’s long-awaited green paper on adult social care is likely to be published in the summer, and Macmillan will make a formal response to this. We will also be making the case for a sustainable funding settlement for social care in our influencing work around the government’s Comprehensive Spending Review, also due this year.

We know that the reality of local government finances means that statutory services will not meet the full range of people’s needs around social care and practical support. That is why our work with NHS, voluntary and local authority partners on innovative approaches to service delivery is so important. Some of these projects include:

• The Improving the Cancer Journey in Glasgow, which offers every person newly diagnosed with a cancer a link worker to help identify non-clinical needs and signpost to relevant support.

• The Macmillan Local Authority Partnership programme, which is mapping how people with cancer access local services, and what unmet practical support needs these services can meet.

The insights that we are gaining show that services are too often fragmented, meaning people are not aware of what support is available and how to access it. We want to show policy makers that better integration between the voluntary sector, the NHS and local government can produce services that are centred around the person with cancer and result in better outcomes. This is so important at a time when access to funding is very difficult.

For more information about Macmillan’s work on social care, visit www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/social-care.html#300456

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Many people find it difficult to talk openly about death and dying. This can make it more difficult for people at the end of life to get support, and to ensure their wishes are fulfilled. A huge part of my role as a Macmillan Social Worker is to facilitate these difficult conversations and help people to plan for the end of their lives – from where they want to die, to the type of funeral they would like to have.

Northumbria Healthcare NHS Foundation Trust delivers hospital and community services in Northumberland and North Tyneside and adult social care services in Northumberland in partnership with Northumberland County Council. Four Macmillan community-based social workers are part of a range of Macmillan support for people affected by cancer.

We specialise in supporting adults who are the end of life (approximately 12 months left to live) and their families. My starting point is to find out what matters to the people I am there to help, and what needs to happen for them to live as well as possible for the remainder of their life and have a ‘good death’.

**A range of services**
We provide a range of support to people with cancer and their families, including:

- psychosocial and emotional support
- facilitating and co-ordinating hospital discharges
- helping people access social care services, which supports people to remain at home and avoid unnecessary hospital admissions
- advice and support on a range of complex issues such as finance, housing and safeguarding.

Utilising the guidance given through ‘Deciding Right’, a North-East initiative for making care decisions in advance, we support people to use the tools and legal powers that are available to them so that their end of life wishes are respected and understood. We also help to make sure that legislation to protect the rights of people who are deemed not to have mental capacity to make decisions about their care is upheld.

**Transferable skills**
As a former serving member of the armed forces, and as a Senior Social Worker for Royal Navy Royal Marines Welfare, I worked closely with the families of service personnel who had been killed in Afghanistan as well as those who returned with life changing injuries. Alongside practical support, a huge part of my role was providing emotional support and therapeutic intervention, which I enjoy immensely.

My current Macmillan role has allowed me to continue with this. I love the daily interaction with people and learning more about the person I am supporting and their life history. When working with the elderly it is sometimes easy to overlook the fact that they have lived very full and interesting lives and built up resources of strength and resilience that can be drawn on during difficult times.

Discussing a person’s wishes for the end of their life is not something I jump into straight away. It takes time, and the concept of relationship-based practice...
is key in developing trust and a safe space in which to have these types of conversations. It is an incredibly humbling experience to hear a person’s deepest fears and hopes for the future, and to know that I have in some way helped them to navigate this process.

**Overcoming challenges**
By its very nature, social work can be emotionally challenging. I am fortunate to have a solid team of social workers around me, along with my Macmillan colleagues, all of whom are an excellent source of professional and emotional support.

Resources are an issue across the country, particularly the strain on care agencies within our communities and a nationwide lack of funding for social care. As our population continues to live longer, people with life-limiting illness are living with more complex needs than ever before. A multi-agency approach including third sector parties is needed to take a creative approach to meet people’s needs.

If someone has a palliative diagnosis, they will certainly have social needs. A more positive outcome is likely if these needs are addressed early. Even if practical support needs do not present themselves, a referral to the Macmillan Social Work service can go some way to ‘planting the seed’ about the potential for future support, and to start developing a professional relationship early to help facilitate end of life discussions at an appropriate time.

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Helping people live life as much as they can
Macmillan Specialist Palliative Care Social Worker Heather Jinks reflects on her 13 years supporting bereaved children and families in North Lincolnshire.

My role is to provide emotional support to people at the end of their lives, and to support families and children both pre and post-bereavement. The work is very varied and no day is ever the same. I might be supporting a child to help prepare them for the death of a parent, or talking to the parent about how to support their child and helping them to create a memory box. Or I might be supporting an elderly person who lives on their own and has been told they are terminally ill, to provide them with a listening ear and a chance to offload.

As the only specialist palliative care social worker in North Lincolnshire, I often see the same people across a range of settings, such as the hospital, their local community or a hospice when they are very near the end of their life. It’s a privilege to see people throughout that journey, and it gives them a sense of consistency and a familiar face.

I also run a bereavement group for bereaved children and their remaining parent once a month. This means parents can get some bereavement support without having to find someone to look after their children. I also run a 6-week bereavement course at the hospital.

Some people are group people, and others aren’t, so I meet with them first to explain what groups are like and see if they would like that or prefer individual counselling. We’re all about working around people, and not expecting them to work around us. But for most people, groups seem to work well. And they help me to reach more people in the time that I have.

Feeling integrated
One of the big challenges of my role is being partly-funded by two different organisations. One third of my post is funded by the local council social services, and two thirds is funded by Northern Lincolnshire and Goole NHS Foundation Trust. I am based at Scunthorpe Hospital as part of the Macmillan palliative care team, but the local council holds my contract. There can be a lack of clarity around who is responsible for providing me with IT services, a phone etc, which can be very frustrating. But my supervision now comes under the trust, as my work is usually very connected to what someone is going through with their health condition.

Being integrated within the palliative care team at the hospital also works well. They can refer people to me, and I also get referrals from the hospital social work team, who deal with getting people home from hospital with the right care, as well as the Macmillan home healthcare team. I am also involved in the teaching programme for nurses and healthcare assistants at the hospital, so I tell them about my role and what constitutes an appropriate referral.

Results and rewards
Social work is emotional work, and there are times when I need to get out for a walk and have a good breathe. When you are working with a lot of young parents and little children it can be stressful. But there are lots of good things too, particularly knowing that you are supporting someone through a really difficult time in their life.
I’ve got a very good relationship with a lot of the local schools now. We set up a bereavement policy when I first came into post, and I have done a lot of training with schools on how to support bereaved children, and pre-bereaved children. When I first started, local schools were quite nervous about dealing with bereavement, but they are a lot more confident now, and proactive about getting in touch with me for advice and support.

Over 13 years, some of the first children that I supported are now young adults. It’s lovely when I see them growing up and knowing that they have got through that time with a lot of support and are now doing well. Or when someone’s been married for 50 years, they lose the love of their life and think they will never get through it. But with the right support, and having someone to listen to them, they do get through it.

Sources of support
I would love to have more hours in the day or another palliative care social worker working with me. A lot of other areas have palliative social work teams, and my job remit is huge, so another person would be really nice. We have started taking on more non-cancer referrals, so I’m hoping that may open a few doors and help make the case for funding another post. Sometimes I get support from a social work student, which is really motivating. They question things that we automatically do, which is a really positive thing.

I also think being part of Macmillan makes a difference. Macmillan professionals don’t just think about the physical side of things, or think of the person as the condition. We look at the support someone has, their emotional wellbeing and financial situation, and I think that’s so important.

We are also very aware of people’s time. Time is limited, and someone dealing with cancer doesn’t want to be seeing lots of people at lots of appointments. They want to be living the life that they have left, especially in the palliative care sector. We are aware that people don’t want to be sitting with us sometimes – they need to be with their kids or living their life as much as they can. So that’s what we try to help them with.

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Supporting people with cancer to celebrate their legacy

Macmillan Palliative Care Social Worker Wendy Ashton on her award-winning work to support people at the end of life in Carlisle.

As a Macmillan Palliative Care Social Worker in North Cumbria, I work as part of the Family Support Team at Eden Valley Hospice. Together we try to make a difference to people’s lives by offering social, emotional, spiritual and psychological support.

In November 2018 I was presented with the ‘Making a Difference’ Social Worker of the Year Award, in recognition of my work supporting people with life-limiting illnesses and their families and carers.

I have worked at the Eden Valley Hospice for the past eight years, where my role focuses on providing emotional support to patients and families, specifically around discharge from hospital and advanced care planning.

Life can be short, but as hospice social workers we support patients and families to live life to the full. We support patients to make difficult decisions relating to end of life care, such as getting their affairs in order, making memories, achieving goals and funeral planning.

Macmillan has supported me throughout my time in post with training courses and literature as well as assisting with support grants and advice.

Legacy frame project
The legacy frame project was an idea I had in March 2017 after working with a client on their ‘bucket list’. This is usually a list of dreams and achievements that people want to fulfil before they die. But often as the illness takes over, these dreams are not achievable and this can cause upset and disappointment.

I think it is just as important to look at what you have already achieved in your life, and celebrate all those things. That’s why I came up with the idea of creating a legacy frame, where we support someone nearing the end of their life to put together a collection of small items that represent special memories, such as pictures, medals, badges or tickets. These are all held together in a wooden frame, which can be kept by the person or passed on to family, friends or loved ones as a keepsake or memory.

An example of a legacy frame.
Legacy work isn't about death and dying, it's about life and living. It's about making connections and sharing precious moments with the special people in your life. Legacy work provides a unique opportunity to reflect on your life and process through the events and people who shaped it. It can be a means of moving on, not only for you, but for the people around you.

Leaving a legacy frame gives your loved ones something to hold on to, something that can provide healing and comfort. It's a reminder of who you were, what you loved, what was important to you and what contributions you have made.

The aim of the project was to enable and support patients to participate in a creative project and offer psychological and emotional support. We began by interviewing patients and the wider multidisciplinary team about their thoughts on the creative arts project. Feedback was positive, and I completed a pilot frame. I developed a 4-session programme on a once-weekly basis, with each session lasting approximately 1.5 hours.

Session 1 was about thinking of ideas for the frame. Sessions 2 and 3 were for gathering items and building the frame. And session 4 focused on finishing touches and putting together a guide on the back of the frame, which explains what each item represents.

The sessions usually have a 1:1 ration of staff to patients, or 1:3 in a group setting. Referrals to the sessions can be made by the palliative care team, carers or family members, or the person can self-refer.
Results
Art and creative work can help promote emotional stability and help with depression6. Participants reported feeling a sense of personal fulfilment as this is a short, time-limited project that someone can manage within the timescales of their illness.

The project also allowed participants to reflected on their lives with emotional support from social workers. They completed the project with a finished frame to keep and take home, providing their loved ones with something tangible to hold on to, that can provide healing and comfort in the future.

The project is ongoing, and so far 11 people have taken part. One person who created a frame said, ‘Legacy seemed a scary word but I really enjoyed the project. It’s a snapshot of my life and I’m so glad I did it.’ Another person who displayed the frame at her father’s funeral said, ‘The frame is a memory of my dad I will treasure for ever. It portrays who he was and his life in a snapshot.’

Further information
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Resources

Macmillan Cancer Support (2012). *Hidden at home: the social care needs of people with cancer.* Support is often needed when people no longer require acute care and return home. This report provides further evidence of unmet needs of people affected by cancer.

Macmillan Cancer Support (2011). *More than a million: Understanding the UK’s carers of people with cancer* A report by Ipsos Mori for Macmillan to determine the number and profile of people caring for someone with cancer in the UK, and the impact of caring on their lives, including the need for support.

Dying Matters: Raising awareness of dying, death and bereavement Provides a range of resources to help people start conversations about dying, death and bereavement. Available at [www.dyingmatters.org](http://www.dyingmatters.org) (Accessed April 2011).

References

2. Figures quoted from expert consensus collated as part of Macmillan Cancer Support’s 2013 report *Throwing light on the consequences of cancer and its treatment.*
4. Ibid
Have you got an idea for a future issue of Sharing good practice? Get in touch at macvoice@macmillan.org.uk