Supporting people living with and beyond cancer

In this article...

- A description of four new nursing roles
- The importance of one-to-one care for people with cancer
- The nine Macmillan patient outcomes

Macmillan Cancer Support has developed four new nursing roles designed to cope with the increasing number of people who are living with and recovering from cancer.

Clinical nurse specialists (CNSs) could be filled by a level 4 post (nhscareers.nhs.uk). However, the study looked at only six tumour types in England, so Macmillan extended the Frontier model to estimate the gap in supply for all tumour types across the UK. Macmillan's theoretical model (currently unpublished) estimated the number of nurses that may be required to meet current needs in a perfect system. It took into account demand across the care pathway, including acute care, survivorship, metastatic cancers, proactive aftercare and palliative and end-of-life care.

Additional evidence from the National Audit Office (2005) and Picker Institute (Sheldon and Sizmur, 2009) suggested that in some cancers only half of patients benefit from the current follow-up system. While support is generally good during diagnosis and treatment, there appear to be gaps during the aftercare stage and on diagnosis of metastatic disease.

FIG 1. THE MACMILLAN OUTCOMES

<table>
<thead>
<tr>
<th>I was diagnosed early</th>
<th>I understand, so I make good decisions</th>
<th>I get the treatment and care that are best for my cancer, and my life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Those around me are well supported</td>
<td>I am treated with dignity and respect</td>
<td>I know what I can do to help myself and who else can help me</td>
</tr>
<tr>
<td>I can enjoy life</td>
<td>I feel part of a community and I’m inspired to give something back</td>
<td>I want to die well</td>
</tr>
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5 key points

1. By 2030, four million people are expected to be living with and after cancer in the UK
2. Many people with incurable cancer can live for years with a generally good quality of life, with the right support
3. Many people cured of cancer have unmet health needs and are at risk from the effects of cancer and its treatment
4. Over a quarter of patients feel abandoned after treatment
5. The UK needs a workforce to meet the needs of the changing story of cancer

In 2010, the Labour government announced a five-year commitment to delivering dedicated nursing for all cancer patients, “offering truly first class care, in their own homes”, which has been continued by the coalition government. This encouraged Macmillan Cancer Support to complete the task it began in 1975 to give every patient the opportunity to receive effective one-to-one support along the whole cancer care pathway.

The Department of Health commissioned Frontier Economics (2010) to undertake modelling to quantify the benefits and costs associated with one-to-one support for cancer patients. Macmillan contributed to the analysis of the study findings, which estimated that up to 33% of the work currently carried out by
Possible solutions
Support for patients involves finding the right person with the right skills and knowledge to meet individual needs. Though a specialist nurse might best do this, it may equally be done by a district nurse. One-to-one support might best be understood as a service delivered by an integrated team of specialists (CNSs and allied health professionals – levels 6 and 7) and generalists (support workers – level 4, district and practice nurses – levels 6 and 7) who support patients along the whole pathway, according to intensity and individual needs.

It is unlikely we will end up with such a simple solution as investing in a specific number or type of posts. The priority must therefore be that the workforce achieves the nine outcomes Macmillan developed with cancer patients (Fig 1). While these outcomes were developed for and by cancer patients, they will resonate with all patients with long-term conditions (LTCs). We are developing a variety of ways in which Macmillan can provide all people affected by cancer with one-to-one support. It will include some direct funding for extra professionals, some investment in whole care pathway redesign and piloting new roles.

Not all people affected by cancer are allocated a CNS or a key worker, which makes a difference to patient reported outcomes and experience (DH, 2010). We also know that existing models of follow-up are unsustainable if the number of people affected by cancer continue to increase at current rates. Solutions include redesigning the cancer care pathway, reprofiling and integrating the workforce and how it supports the pathway, and developing new models of aftercare.

Levels of care
Emerging models for aftercare (National Cancer Survivorship Initiative – www.ncsi.org.uk) demonstrate that care needs should be assessed at key transition points along the care pathway and a plan of care developed to reflect risk stratification into one of three levels of care:

- **Supported self-management:** patients are given information about self-management support programmes or other types of support, signs and symptoms to look out for and who to contact if they notice any, scheduled tests such as annual mammograms, and how they get in touch with professionals if they have any concerns;

- **Shared care:** patients continue to have face-to-face, phone or email contact with professionals as part of follow-up.

- **Complex case management:** patients are given intensive support to manage their cancer and/or other conditions. Cancer survivors may move between the three levels according to how their cancer and its treatment progress. The proportion in each level will depend on tumour type. Risk stratification means that the clinical team and the person living with cancer decide about the best form of aftercare based on their knowledge of the disease (type of cancer and what is likely to happen next), treatment (possible short-term and long-term effects or consequences) and the individual (other illnesses or conditions, and amount of support needed).

New healthcare roles
Macmillan has developed four new roles that are being piloted as part of the one-to-one support implementation project. They are: Macmillan support worker; Macmillan nurse primary care; Macmillan nurse community care; and Macmillan complex case manager. We see these new roles supporting the three levels of aftercare.

**Macmillan support worker:**
- Supervised by a registered practitioner in an existing health or social care team;
- Coordinate care by providing a single point of access into the service, helping people to navigate the system;
- Coordinate care for people with non-complex care needs;
- Coordinate education and support for people with non-complex care needs.

**Macmillan nurse primary care or community care:**
- Existing practice nurse or district nurse;
- Released sessionally (for up to six sessions a week) to provide care and support for people at risk stratified into level 2 – shared care;
- Share care – between acute and primary/community care and between the professional and patient;
- Use existing skills with LTCs and enhance for cancer;
- Actively manage the treatment summary and cancer care review and support the transition to living beyond cancer;
- Facilitate education and support of patients/carers and primary or community healthcare teams;
- Support local cancer service redesign.

**Macmillan complex case manager:**
- Existing case manager/modern matron in LTC;
- Released sessionally to manage a complex caseload;
- Proactive case management of people in the community with cancer and multiple comorbidities, using LTC skills and liaising with the cancer multidisciplinary team;
- Arrange education and support of patients/carers and community healthcare teams;
- Support and influence local cancer service redesign;
- Support and influence commissioning of local cancer services.

Conclusion
Cancer is becoming – for many – an LCT that requires support and care from the community workforce, rather than a continued reliance on specialists who are predominantly based in acute care. Macmillan will be piloting the new roles through the one-to-one support implementation project to see if they are fit for purpose and can demonstrate improved patient outcomes and experience, as well as being cost-effective.

We envisage that evidence from the pilots will provide us with compelling arguments to influence decision makers and support the case for redesigning the cancer care pathway and the integrated workforce that is required to implement it. The new model of aftercare and the roles should enable nurses to do their job better, improve patient experience and be transferable to other LTCs.

The pilot began on 1 August in 16 sites in all four UK countries, piloting 62 posts. Each site is testing a combination of at least two types of role. Initial progress reporting has been established and formal evaluation has commenced, starting with baseline data collection.

We will keep Nursing Times readers informed of the project’s developments and its findings next year. To find out more about Macmillan and how it supports nursing roles go to tinyurl.com/Macmillan-HCP, NT.

References

For a Nursing Times Learning unit on fatigue in cancer patients, go to nursingtimes.net/fatigue

www.nursingtimes.net / Vol 108 No 38 / Nursing Times 18.09.12 13