

In this article...

- Needs of people living with cancer along different disease trajectories
- Role of allied health professionals in cancer care
- Importance of volunteers and support workers in cancer care

Living with and beyond cancer 2: the role of allied health professionals, support workers and volunteers

Key points

1 People living with cancer experience different problems and have specific needs according to prognosis and cancer type

2 Lengthy cancer treatments and long-term side-effects can negatively affect a person's physical and mental health

3 Allied health professionals have relevant expertise for helping people recover from and adapt to life after cancer treatment

4 Support workers and volunteers have a role in delivering holistic needs assessments and health and wellbeing education events

5 Cancer care teams in hospitals and the community need the right mix of skills and roles

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Abstract People living with cancer are far from a homogenous population. Their disease trajectory and support needs vary widely according to the cancer group they belong to. To respond to those needs, cancer care teams need the input of allied health professionals, support workers and volunteers. Allied health professionals in particular have a role to play in helping patients recover from and adapt to life after cancer and cancer treatment. This article – the second of a two-part series on living with cancer – highlights the different needs of people living with cancer and the roles and skill mix needed to deliver recovery package interventions.

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People living with cancer have specific support needs, whether it is to help them recover from treatment, avoid or manage adverse side-effects, maintain or regain function, or maximise quality of life. Allied health professionals (AHPs) play a significant role in providing services that meet these needs, while support workers and volunteers also play an essential part – complementing the work of AHPs and clinical nurse specialists (CNSs).

This article explores the needs of people living with cancer and draws on a case study to demonstrate how AHPs and other health professionals can help deliver the recovery package interventions recommended by the National Cancer Survivorship Initiative between 2008 and 2013 (Bell, 2017; Macmillan Cancer Support, 2014a).

Different needs by cancer group

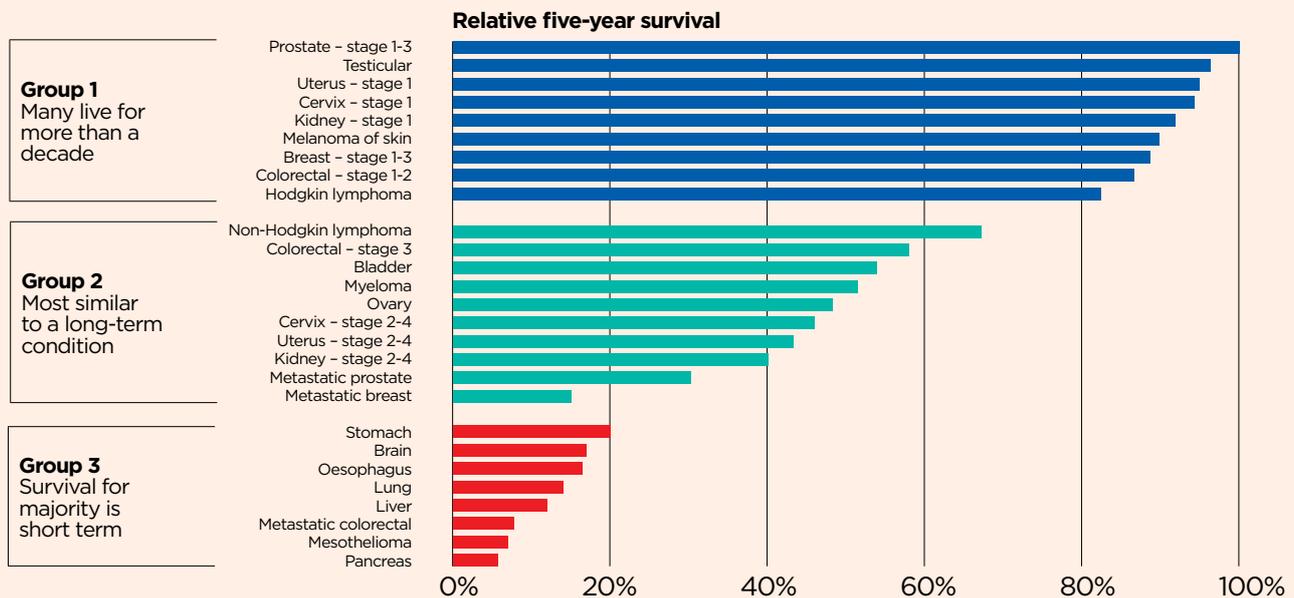
People living with cancer are not a homogenous group and their needs vary widely.

In 2015, Macmillan Cancer Support published exploratory work proposing that there are three main groups of cancers (McConnell et al, 2015). The aim was to classify the 200 or so different types of cancer into three broad categories to aid service design. This work was included in the recommendations laid out in the Cancer Strategy for England (Independent Cancer Taskforce, 2015).

The three cancer groups are organised according to the survival rates for different cancers at different stages (Fig 1), and can be roughly described as follows:

- Group 1 (the 'longer-term survival' group) encompasses cancers where 90% or more people live at least one year after having been diagnosed, more than 80% live five years or more after diagnosis, and many go on to live for at least 10 years;
- In Group 2 (the 'intermediate' group), patients have a moderate survival – the chance of one-year survival is more

Fig 1. Three broad cancer groups



Source: McConnell et al (2015)

than 50% but under 90% – and their experience is the closest to that of people with long-term conditions;

- Group 3 (the ‘shorter-term survival’ group) features cancers where fewer than 50% of patients survive for one year.

According to the group they belong to, patients experience different problems from cancer and/or its treatment. They will, therefore, have specific and differing needs at different points along their disease trajectory.

People in the ‘longer-term survival’ group may have fewer hospital admissions directly related to their cancer, but many still live with the consequences of cancer and its treatment. Some face recurrence or second primary cancer years after primary treatment. This means self-management

with appropriate support is key, alongside a focus on recovery and the management of long-term side-effects. AHPs have a key role in helping patients recover, sustain recovery and improve quality of life.

People in the ‘intermediate’ group often experience relapse or recurrence. This means that they face an uncertain future, with what appears to be ongoing, complex care needs. Overall, they probably need, on the whole, a balanced mix of acute intervention, self-care and chronic illness management, which AHPs can help deliver alongside CNSs.

People in the shorter term survival group will have symptoms such as pain that may impair their ability to function – or they may be receiving palliative treatments and require supportive rehabilitation. Having input from the AHP to maximise quality of life can help this group live life to its optimum and remain out of hospital. AHPs can help the patient to maintain function for as long as possible and help with symptom management – particularly physiotherapy and relaxation techniques in pain management.

Role of allied health professionals

Considering the predicted rise in the number of people living with cancer (Bell, 2017), it is all the more important to understand the breadth of support they require to adapt to life after treatment. Patients recovering from cancer and its treatment often experience long-term side-effects

such as fatigue, swallowing difficulties, continence problems, breathlessness or lymphoedema.

Additionally, cancer treatment is often much more complicated than a single operation or one course of chemo- or radiotherapy. Many patients undergo a combination of the above, with treatment plans spanning 12-18 months. Reconstructive surgery, if needed, extends the duration of treatment – especially if several operations are required.

“Allied health professionals can empower people living with cancer to take control of their health”

These ongoing interventions and long-term side-effects often have a negative impact on physical and mental wellbeing, so people find it difficult to return to a normal level of activity, or to return to work if they are still of working age.

AHPs work in a number of professions (Box 1) and many have expertise that is particularly relevant for helping people to recover from, and adapt to life after, cancer treatment. In *Allied Health Professions into Action*, NHS England recently highlighted how the skills of AHPs can be used to transform health, care and wellbeing service delivery (NHS England, 2017).

Working in the acute, community, primary care and home care settings, AHPs

Box 1. Allied health professions

Allied health professionals include:

- Physiotherapists
- Occupational therapists
- Dietitians
- Arts therapists
- Orthoptists
- Paramedics
- Chiropodists and podiatrists,
- Prosthetists and orthotists
- Radiographers (diagnostic and therapeutic)
- Practitioner psychologists
- Speech and language therapists.

offer effective prevention strategies that support self-care and self-management. They can empower people living with cancer to take control of their health, by helping them with their diet, exercise and mental wellbeing,

AHPs are also among the principal groups of professionals who are qualified to deliver rehabilitation interventions – they can assess functional capacity; advise on pain management; support patients with cognition problems; intervene through vocational rehabilitation activities; and give advice and support to nursing and medical colleagues, patients and employers on reasonable adjustments for a successful return to work.

Support workers and volunteers

In areas of the UK where the recovery package has been implemented, care pathways have been redesigned and different roles are being used to deliver the interventions. These include holistic needs assessments (HNAs) and health and wellbeing education events (HWBEs), which are both delivered with the help of support workers.

HWBEs are also delivered by volunteers trained as lay tutors, who are often themselves living with cancer. Some teams also use volunteers to help deliver HNAs, both in cancer clinics and in information and support centres.

Volunteers help patients log into the HNA electronic tool and complete the assessment. Having listened to patients' concerns, they can signpost them to written information and online resources, leaving CNSs to focus on more complex needs and support.

Ensuring the right skill mix

All people living with cancer should have access to the interventions of the recovery package. To ensure patients receive timely information and support tailored to their needs, cancer care teams and community settings must ensure they have the right mix of key skills. Reviewing the workforce is, therefore, a crucial part of the re-designing of cancer care services.

CNSs are experts in their field, but it can be challenging to employ enough to ensure equity of support for people living with cancer (Macmillan Cancer Support, 2014b). Equally, there are large gaps in the support available in the community to help people self-manage once the acute treatment phase is over.

Using AHPs, support workers and volunteers working closely with core cancer teams, both in acute hospital and

Box 2. A patient's recovery from treatment for mouth cancer

After being diagnosed with mouth cancer, John Parker*, a 63-year-old accountant who has taken early retirement to spend time with his wife, received surgery to remove the tumour and nodes on the left-hand side of his neck. The operation involved taking a skin graft from his left wrist and using it to replace the tissue taken from his mouth.

Mr Parker falls into group 2 (intermediate survival) as he was diagnosed with stage 3 cancer that had spread to his lymph nodes. He has been affected by treatment so may experience ongoing problems. If the cancer returns, he may move into group 3.

After surgery, Mr Parker received the following support:

- Immediately after the operation, a physiotherapist taught him exercises to improve movement in his neck and wrist;
- Throughout radiotherapy, he had weekly appointments with a physiotherapist for a range of movement exercises to maintain function;
- After surgery and throughout radiotherapy, a dietitian helped him monitor his diet and optimise his food intake;
- A speech and language therapist assessed and helped him manage his swallowing difficulties.

As a result of treatment, Mr Parker experienced extreme fatigue, which initially limited the amount of physical activity he was able to do. After the end of treatment, he saw a support and rehabilitation worker who conducted a holistic needs assessment. This confirmed that Mr Parker had high levels of fatigue but also showed that he was experiencing anxiety. The support worker referred him to the local Macmillan Cancer Support centre for:

- Massage and relaxation therapy, which helped him deal with his anxiety and relax;
- Participation in a fatigue support group, through which he received information and advice to help him increase his activity levels and move forward.

A clinical nurse specialist compiled a treatment summary documenting the treatment Mr Parker had received, potential side-effects; and signs and symptoms of recurrence to look out for – this was shared with Mr Parker and his GP. He also attended a health and wellbeing education event, which boosted his confidence in taking control of his health. Six months after diagnosis, Mr Parker had a cancer care review with his GP, which helped him to understand his symptoms and reinforced wellbeing advice.

It is now 18 months since completing treatment and Mr Parker has put on some weight and is planning a holiday with his wife. He does still experience fatigue but knows how to pace himself and access support when he needs to. The biggest adjustment for Mr Parker has been managing his diet better and taking more physical activity, which he has done by taking up golf.

* The patient's name has been changed to protect his identity

community settings, ensures patients have access to the right support at the right time with the right skills. Box 2 presents a patient case study showing how crucial that support can be. **NT**

- For more on the recovery package and the role of specialist nurses in cancer care, read the first article of this two-part series – ('Living with and beyond cancer 1: how well are we helping patients?') at: nursingtimes.net/7019374.article

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