Helping young adults get back on track after cancer treatment

Young adults who have undergone cancer treatment are likely to have complex and wide-ranging support needs, as they will commonly experience issues such as cancer-related fatigue (CRF), low levels of fitness, depression, loneliness and unemployment. As a Macmillan clinical nurse specialist running a survivorship service for young people with cancer in the East Midlands, I wanted to improve the support available to them. To do this, I set up a series of partnerships with public and voluntary sector organisations.

Survivorship service
In the East Midlands, young people with cancer are seen either at the main oncology centre or, if their treatment allows, locally in one of five designated hospitals. They typically present with a variety of haematological and oncological diseases but have a higher-than-average prevalence of Hodgkin’s lymphoma, germ-cell tumours, soft tissue sarcomas and bone sarcomas.

Those aged between 18 and 25 years who complete treatment are referred to the Macmillan East Midlands Teenage and Young Adult Survivorship Service, which was established in 2015 and receives on average 75 referrals a year. The service supports young people aged 18-25 at diagnosis, but support continues up to the age of 30 (or for the duration of medical follow up).

Partnerships
I designed a range of projects based on the needs expressed by young people in their holistic needs assessments (HNA), including:

- The Macmillan One2One Support Project, which helps combat loneliness and isolation;
- BOOST, which helps young people back into education or work;
- A CRF self-management clinic.
As a lone worker and in a financially stretched NHS, I faced many challenges in developing services for a growing number of young cancer survivors. Part of the solution was to work with public sector professionals, charity workers and volunteers.

**One2One Support Project**

The One2One Support Project started in October 2015. Volunteers of a similar age visit patients at home once a week to provide peer-to-peer support. Patients and volunteers are matched based on factors such as gender, background and interests.

To set up the project in Nottinghamshire, I approached the charity Self Help UK. It already had a similar initiative for adults, so the infrastructure to train and manage volunteers was in place. The next step was to launch the One2One Support Project in Leicestershire in partnership with another adult volunteer service, this time run by De Montfort University.

Outside of these two counties a ‘virtual’ version of the project offers support over the phone.

**BOOST**

BOOST fosters social re-integration through education or work. Support with vocational and educational needs is delivered by staff working as part of career teams at local education providers.

I first approached Leicester College, with whom BOOST Leicester was launched in April 2017. Its success led to the creation of BOOST in Nottingham and Derby, in partnership with Nottingham College and Derby College, respectively. Career advisers need to understand what patients may be going through and what their needs may be, so I provide generic training.

**CRF clinic**

The CRF self-management clinic was piloted from December 2017 to March 2018 in partnership with the charity MOVE, which is led by cancer rehabilitation instructor Gemma Hillier. Three patients took part in a programme delivered by Ms Hillier and myself. We met once a month to discuss factors that compound CRF – such as lack of exercise, poor nutrition and hydration, poor sleep hygiene and mental health issues – and participants set them themselves goals to work towards, with telephone support available between meetings.

The pilot was coproduced with participants, who shaped the clinic to suit their needs. For example, they asked to receive photographs of the notes made during meetings as a reminder of what had been discussed.

**Outcomes**

The survivorship service currently supports 156 patients. The frequency of follow-up appointments differs according to their needs. At every follow up, a new HNA is conducted and these repeated assessments show that the support we provide reduces the negative effects of cancer and its treatment – physically, psychologically and socially.

So far, 40 young people have benefited from the One2One Support Project, and another seven have benefitted from phone support. Valuable relationships have flourished between patients and volunteers, who provide emotional but also practical help. For example, one volunteer helps a young woman who has lost her eyesight with daily tasks. Another helps a young man who has had a bone transplant to get out of his home.

BOOST has been very popular, with 60 referrals to date. Some have enrolled on a vocational or university course; others have accessed an apprenticeship, got work experience or obtained an interview. I have been approached by professionals caring for adult cancer patients who want to use BOOST in adult services.

The CRF clinic pilot has proven beneficial to participants, who were assessed before and after. For two out of three, quality of life had significantly improved.

“**This is an outstanding example of integrated working and holistic care, harmoniously drawing together a number of partners**” (Judges’ feedback)

**Sustainability**

The One2One Support Project and BOOST have been designed to work without my intervention, as young people can be referred by any health professional caring for them. However, they do require ongoing promotion and explanation, as health professionals need to be reassured about using services run by volunteers or organisations outside of the NHS, and patients and families need to understand what they can expect.

Working within the rules of patient confidentiality sometimes creates obstacles: for their support to be effective, it is useful for BOOST career advisers to know what young people are going through, but patients have a choice as to whether or not they want information about them disclosed.

**Conclusion**

For a lone worker to meet the multitude of needs of young people living with and beyond cancer is challenging, to say the least, so forging partnerships has been hugely beneficial. I would definitely encourage collaboration with public and voluntary sector partners to improve the support offered to young cancer survivors.

Other challenges encountered are staff shortages and staff changes at the public and voluntary-sector partners.

To ensure equitable access and enable us to offer face-to-face survivorship clinics in the five designated hospitals as well as at the main treatment centre, I am working towards securing permanent funding for an additional clinical nurse specialist post. An application has been submitted to Macmillan to fund an additional post on a fixed-term basis. My hope is that this will form the basis of a robust business case to demonstrate the need for permanent funding.

Plans for the future include:

- Expanding the One2One Support Project;
- Rolling out BOOST to other parts of the East Midlands;
- Exploring ways of increasing access to self-management resources for CRF across the region with an online programme and via social media;
- Discussing with stakeholders early screening and intervention to reduce the impact and severity of CRF.

**References**


**Contact**

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