A Glasgow based project has significantly improved the support available for people affected by cancer who are experiencing cancer-related cognitive changes. Being treated for cancer can have lasting physical, psychosocial and economic consequences, and one of the key concerns can be coping with the emotional effects of a cancer diagnosis and adjusting post treatment.

The Cognitive Rehabilitation and Support Project was set up to raise awareness, knowledge and skills/confidence in health and social care staff, third sector colleagues and employers in the identification and support of patients who are experiencing cancer-related cognitive changes by providing training and relevant self-help materials. For people who were experiencing significant degrees of impairment, a cognitive rehabilitation group intervention was offered which was designed to address difficulties related to cognitive dysfunction following cancer treatment.

The project is part of the Transforming Care After Treatment (TCAT) programme, which is testing and spreading new ways of supporting people with cancer.

**How the Project Worked:**

The project aimed to provide additional specialist, tailored psychosocial interventions to support patients and their carers who are experiencing cognitive impairment secondary to their cancer or its treatment. There were three methods used to achieve this vision:

- **Training** was provided to health, social care, 3rd sector colleagues and employers/Occupational Health departments to raise awareness and give guidance on how to support people affected by cognitive impairment.

- Information booklets/resources were compiled for use in community, acute and primary care settings, outlining specific self-help and management strategies relevant to cancer-related cognitive changes.

- A cognitive rehabilitation group intervention was offered, designed to address difficulties related to cognitive dysfunction following cancer treatment.
Cognitive Rehabilitation Intervention

A triaging process was developed, whereby those patients who had been identified/assessed as having mild cognitive deficits post-treatment were directed to lower intensity support via self-help information and guidance. This was achieved through the use of existing supports and structures such as the holistic needs assessments performed by the Improving Cancer Journey team, Occupational Health assessments, Welfare Rights Officers, and follow-up appointments with medical/nursing staff. Patients assessed as having more complex problems were directed to the cognitive rehabilitation group.

183 referrals were received in total, of which 66% (n = 121) accepted a cognitive rehabilitation intervention, either in a group or individual format.

The majority of individuals taking up the intervention were women (68.85%)

68% of participants were of working age and 53% of individuals reside in areas of greater poverty (SIMD 1 and 2).

Individuals with breast (40%) and haematological (20%) cancers were most commonly referred to the project.

94 completed quality of life and psychological functioning outcome measures were collected from individuals who completed the programme, either for individual or group sessions. Outcome data indicates that group participants’ distress reduced significantly post intervention.

Development of the CRCC self help materials

Three short educational videos on CRCC aimed at patients and their families were produced by NHS Greater Glasgow and Clyde Medical Illustration department which featured two service users speaking about their experiences of living with and adapting to cognitive changes secondary to their cancer treatment.

Results

Group participants described benefitting from the intervention in helping them understand and better manage cognitive changes post treatment. The group format appeared to provide not only an opportunity to create a shared understanding of cognitive challenges but a sense of camaraderie amongst peers.

What next?

One of the themes that emerged from the project was a call for greater awareness of cancer related cognitive changes, especially within employment settings. Given that just under 70% of participants were of working age, this is an important area of unmet need in cancer survivors.

The Project recommends for the following actions to be implemented:

• Liaise with the regional cancer networks to raise awareness of the potential impact of CRCC on patients’ quality of life in the survivorship phase;
• Raise awareness of the availability of the CRCC information resources across the regional cancer networks;
• Support NHS Psychologists and Specialist OT’s working within oncology services to deliver the CRCC intervention on an ongoing basis, in partnership with third sector colleagues.
• Support the ongoing provision and revisions of CRCC patient information.

Staff Training and Awareness Raising

Staff training was delivered by means of the project conference entitled: “Memory and concentration changes after cancer treatment. What do we know? What can help?” A patient booklet on cancer related cognitive changes was produced and circulated to clinical teams; Third Sector; Local Authority; and Primary Care for use in their roles in supporting individuals.

“We bonded whilst sharing tips for getting round problems, laugh at the things we’ve done. We felt less isolated”

“We were able to talk about our experiences and all the stupid, silly things we’ve done. I think every one of us came away with new coping strategies.”

October 2018