

MEET THE ACTIVATED PATIENT

The right training can energise survivors to self manage and hopefully reduce use of services. By Ingrid Torjesen

Supported self management in cancer care is a fairly new concept, although it has become a familiar term in long term conditions such as asthma and diabetes. Currently patients who complete curative treatment enter a "routine" follow up programme of outpatient appointments at regular intervals to be checked for signs of treatable recurrence, and monitor drug therapy and side effects of treatment.

Lynn Batehup, project manager of the National Cancer Survivorship Initiative supported self management workstream, says many patients who respond to curative treatment will move on well to being cancer survivors but may experience a recurrence or late treatment effect. While they may need to make lifestyle changes to stay healthy and be vigilant for returning disease, they don't usually need to be in active contact with a specialist team unless they experience a problem. Few are taking drugs and any ongoing tests or monitoring can be done remotely.

Supported self management in long term conditions has been shown to reduce bed days, drug usage and improve clinical outcomes – and the hope is that it can do the same in cancer.

The HOPE course

Macmillan, as part of the NCSI, has been piloting in Birmingham a self management course for patients (HOPE), developed by Coventry University, and a training course for cancer clinicians in how to support patients to be more active and self manage.

Both courses are built on learning from the Health Foundation's co-creating health programme for self management for long term conditions which has three strands: activating patients and supporting them so that they can become more active about managing their own health; developing clinicians' skills so that they can support patients to do this; and then looking at how the service and the processes within the NHS need to change to underpin this.

Ms Batehup says: "An activated patient is not just a passive recipient of care but active and responsible for managing their care."

HOPE patients were recruited through NHS Birmingham East and North and Heart of England Foundation trusts. They had been treated for breast cancer and were part of a telephone follow up pilot. Potential participants were initially invited to a taster session to learn more about the course and what it would entail. Six or seven people then joined each course.

Each course consists of a two and a half hour session every week for six weeks delivered by a cancer nurse specialist alongside an expert patient. The course was based on evidence based techniques built around a theoretical framework of positive health psychology to help enhance wellbeing. The purpose was to equip patients with strategies to help them manage fatigue, emotions and stress, and to encourage them to eat healthily and participate in exercise and other activities. It tried to encourage patients to look for the positives and have hope for the future.

Weekly goal setting was an important part of the course, says Jill Kneale, a HOPE tutor and a lead cancer nurse at Heart of England Foundation Trust. "Each week patients left the group with activities to achieve. If they'd only been able to achieve them partially, that was a big step forward; but if they hadn't been able to achieve at all, the group helped an individual to look for why they hadn't."

Those attending the course said they felt more confident about resuming normal activities, such as meeting up with friends or family, less fatigued and more hopeful.

Joan Hatfield attended the HOPE course in summer 2010 after treatment for breast cancer. She was diagnosed in December 2008, had a lumpectomy, lymph nodes removed, six months of chemotherapy, a month of radiotherapy, and is in remission.

Ms Hatfield says: "No matter what we



Leaflet for Helping Overcome Problems Effectively (HOPE) supported self management for breast cancer survivors

discussed, what we talked about and what our hopes and fears were, the most helpful thing was to share those with people who knew where you are coming from."

The most useful skills she learned were deep breathing to relax and relieve stress, and how to look for the positives in life. "When I first went into the course almost everything every day was negative because it was such a horrible thing to go through and looking forward, it was the worry and fear of 'is it going to come back?'" she says. "The course taught us to look for positives on a day-to-day basis, from something as simple as seeing my grandchild smile to the sun shining or the snow falling."

Ms Kneale says the difference between



To do list: HOPE patients set goals at each weekly session

'Up to 80 per cent of breast cancer patients could go into supported self management'

HOPE and a support group is that HOPE is not ongoing, although participants can then join a support group or carry on meeting up themselves. Ms Hatfield says the people who were on her course have not met up since but are still in touch via Facebook and text message. "We do keep in contact to see how... [the others on the course] are doing."

As not all patients will need a six week course like HOPE, a new project is running at Southampton University Hospitals Trust. This short workshop for patients who have had curative treatment for bowel and testicular cancer is also being developed with Coventry University.

Ms Batehup says: "Although the change may be slow, there is going to be a shift away from routine one size fits all outpatient follow up to something like the risk stratified approach based on what patients need."

Three levels of care

The NCSI vision is for three levels of care: most patients will be supported to self manage, a small proportion will enter shared management with professionals, and the small number who need intensive specialist support will join the complex care management pathway. Ms Batehup estimates that up to 80 per cent of breast cancer patients could go into supported self management, as long as they are prepared

for this and have rapid access back to specialist advice if needed.

However, she admits that only a few would probably get access to a self management programme like HOPE. Most patients, after assessment, will be given tailored information incorporating goal setting, how to monitor their health and what to do if they have a problem.

If patients are to self manage, clinicians need the skills to support them. Clinicians are used to a "do to and for" rather than a "do with" culture and need to enter a power sharing relationship with the patient. Then, rather than having to take all the responsibility themselves, they can promote joint agenda setting, shared decision making, partnership working and choice.

A pilot course called Patient Partnership in Care, consisting of three half days over three months, has been doing just that in Birmingham and Hillingdon.

Cancer clinicians already do a mandatory advanced communications skills course called NHS Connected, delivered through the cancer networks. The PPiC course adds skills for motivational interviewing, core communication and positive psychology, which they could incorporate into everyday consultations to develop patients' self management ability.

Much of the course is spent practising particular skills in short sharp bursts with

actors who understand self management – participants find this most useful.

At the end of the course, participants make an action plan, listing skills learned and how they will put them into action. In between sessions they receive email support from the facilitator. Before and after the course, their patients are asked to fill in a questionnaire to rate their performance so it can be compared.

Macmillan is now working with the NHS Connected programme, which is being revamped, to see if a condensed one-day version of the course can be integrated more closely with the core programme. It is likely that this will require some follow up at a distance, such as teleconferencing and use of NHS Connected's online forum, to provide ongoing coaching and support.

Patients take the lead

Inigo Tolosa, a clinical psychologist at University Hospitals Birmingham, says the course taught him the importance of tailoring interventions to individuals. He learned how to find out what really mattered to patients, such as their children's health, what techniques had worked for them in the past in stressful situations, and how to use this information to encourage lifestyle changes, such as quitting smoking. He adds that the skills learned are also transferable to a wide range of long term conditions.

"It's helped me in two ways," he says. "I am obviously going more with the patient's agenda, but also it's quite fascinating that they report that they feel that I am doing a better job with them. That is pretty powerful feedback and difficult to ignore."

He emphasises that the patient is well placed, as the expert in their condition, to take a leadership role. "If you have got a really brilliant GP, that might be the closest to the best clinician you can have, but actually the best person is the patient because they know what the different clinicians say, they know themselves and they know their capabilities." ●