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CANCER SURVIVORSHIP

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EMPOWERING PEOPLE

GIVING SURVIVORS THE SKILLS, SUPPORT AND CONFIDENCE TO TAKE CONTROL OF THEIR LIVES

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DH Department of Health
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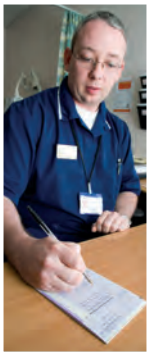

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FOREWORD

CIARÁN DEVANE AND MIKE RICHARDS

The right pathways

Some 1.8 million people in England (and 2 million across the UK) have had a cancer diagnosis at some point in their lives. This is rising by 3.2 per cent each year. While many cancer survivors will be well following successful treatment, others will be managing the effects of their cancer or its treatment, coping with other chronic conditions, or living with active or advanced disease.

We need to enable commissioners to consider how effectively and efficiently health and care services are supporting the cancer survivor population. Many cancer survivors have significant unmet care and support needs and have more contacts with the NHS than the wider population.

> Many cancer survivors have significant unmet needs

Improving outcomes: a strategy for cancer, which was published on January 12, describes the ambition to deliver outcomes for cancer patients in England which are among the best in the world. The strategy defines improving outcomes for people with cancer as not just about improving survival rates, it's also about improving the experience of cancer care as well as outcomes for those living long term with a cancer diagnosis.

The actions being taken through the National Cancer Survivorship Initiative to support the increasing numbers of cancer survivors suggest that improved care pathways and better coordination have the potential to deliver better outcomes, better experience of care, and more efficient use of resources as services are more personalised and unplanned healthcare use is reduced.

Improved care pathways will enable investment in supportive care and specialist services for those who need them, including for those with chronic late effects of cancer treatment.

Ciarán Devane (left) is chief executive of Macmillan Cancer Support. Professor Sir Mike Richards (right) is national cancer director at the Department of Health

A NEW APPROACH

A model of supported self management for the majority backed by vastly improved systems is going to revolutionise cancer care, says Adam Glaser

Having cancer can affect every aspect of life, from the physical and emotional effects of the diagnosis and the treatment through to relationships with loved ones to wider social and work life.

No two people with cancer have the same needs and priorities. However, health and care services have usually taken a one size fits all approach following cancer treatment – centred around routine outpatient appointments to check for recurrence.

The problem is that this often doesn't provide the support that people need and many feel abandoned following cancer treatment. Cancer survivors report poorer health and wellbeing and have more unplanned contact with health services than the wider population.

A health and wellbeing survey by Macmillan in 2008 found 90 per cent of cancer survivors had visited their GP in the last 12 months, compared to 68 per cent of the wider population.

The rapid expansion in the number of people living with and beyond cancer – over 3 per cent each year – means the current approach to cancer follow up care is simply unsustainable.

The Department of Health, Macmillan Cancer Support and NHS Improvement are now working in partnership with a range of organisations through the National Cancer Survivorship Initiative (NCSI) to develop and test new pathways of care that can lead to better outcomes and experience for patients alongside reductions in unnecessary and unplanned hospital appointments and admissions.

New pathways

The NCSI has developed optimal care pathways that mean survivors will have:

- personalised risk stratification supported by comprehensive holistic assessment and care planning at key points;
- support to self manage, where appropriate;
- access to case management support and/or specialist services, for example for late effects of cancer treatment, or to assist with staying in or returning to work;
- access to appropriate information including access to lifestyle advice and physical activity interventions; and
- for children and young people, planned and informed transition from paediatric to young person to adult services, where appropriate.

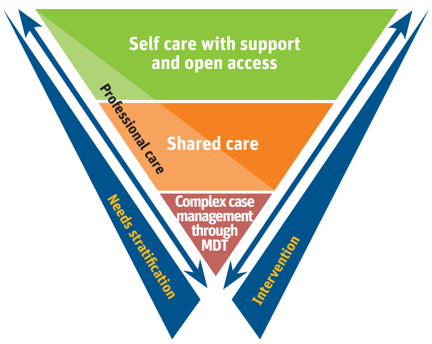
2m+
people in the UK living with a diagnosis of cancer

1.24m
cancer survivors had their diagnosis more than 5 years ago

3.2%
growth per year in the number of cancer survivors

4m
The number of cancer survivors there will be in the UK by 2030

RISK STRATIFIED MODEL OF CARE



MDT= Multidisciplinary team

Individual needs differ – that is why a personalised and holistic approach is required. Personalised care plans, developed in partnership between individuals and healthcare professionals give people a better understanding of their condition, its treatment and possible late effects. This can empower people to manage their care and ensure that the full range of their needs are understood and addressed.

In common with long term conditions management, personalised risk stratification and assessment for cancer survivors is likely to lead to:

- a small number of people with highly complex needs requiring specialist management, for example for the effects of cancer treatment;
- slightly more people needing a case management approach, with more intensive support; and
- the majority able to be supported to self manage.

Proportions will depend on individual needs, types of cancer and types of cancer treatment. Risk stratification enables better matching of services to individuals' needs and more efficient use of resources.

This new approach requires appropriate care coordination systems, the development and implementation of robust remote monitoring systems for routine tests and rapid access processes that enable access to the appropriate team if there is a suspicion of further disease or late effects of the cancer or treatment.

The NCSI has piloted models of improved care and support for adults, young adults and child survivors in test communities around the country.

During 2011, NHS Improvement's cancer improvement programme is working with 13 clinical teams at seven cancer centres within the NHS to prototype whole risk stratified pathways of care for adults living with breast, prostate, colorectal or lung cancer.

Survivors of childhood and young people's cancer present some unique challenges for health and social care services. Working closely with clinical teams, the NCSI has identified these and NHS Improvement is coordinating work across England to assess the implications of delivery of risk stratified aftercare to meet these needs in the most effective manner.

Substitution of routine outpatient based follow up with coordinated and supported self care offers the potential to both enhance the quality and productivity of care delivered to the growing number of individuals living with and beyond cancer and to ensure those with specific needs have these met. However, this will only be possible if local health economies invest in measures to enable the changes. ●

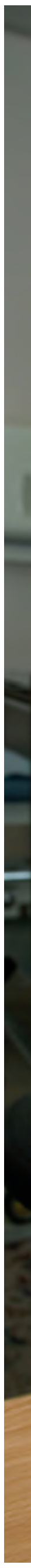
Adam Glaser is clinical director of the National Cancer Survivorship Initiative

FIND OUT MORE

→www.ncsi.org.uk
→www.improvement.nhs.uk/cancer/

The traditional patient pathway is inflexible and financially unsustainable. Ingrid Torjesen on three new tools that can tailor care and save unnecessary hospital trips

FORWARD PLANNING



There are two million people in the UK living with and beyond cancer and that number is expected to grow by more than 3 per cent per year because of the increasing incidence of cancer and better survival rates.

Under the current system of hospital follow up, cancer patients are called back at set intervals to check for signs of recurrence, even though most recurrences are spotted by patients themselves. Patients are different and this "one size fits all" system does not take account of the wider support needed by some and forces others to attend unnecessary, time consuming appointments.

With an increasing number of cancer survivors, this approach will become unsustainable so the National Cancer Survivorship Initiative has been looking for a better way of doing things.

NCSI project manager Noeline Young, says: "It is about being able to offer individualised care, rather than routine care, and about tailoring that care to that patient's needs. With that comes a better quality of care and some potential cost savings."

The NCSI has tested an assessment and care planning process at 11 hospital sites, where a clinical nurse specialist offers a checklist (self assessment tool) to enable patients to talk about concerns. Ms Young says people often don't feel comfortable bringing up some problems – such as sexual issues – but will indicate them on the self assessment tool, which gives the opportunity to open up discussion.

A care plan is drawn up, summarising the issues the patient has raised and outlining how these will be resolved by the patient, healthcare professionals or other services. The plan also sets out goals agreed with the patient, which may be lifestyle related such as stopping smoking or starting an exercise programme, or something to look forward to, such as a holiday at the end of treatment.

A copy of the plan is given to the patient so they can refer to it and show it to other health professionals, official organisations and share it with carers or family.

> **'For the swine flu jab did we know which patients were on chemotherapy? No, because we don't code chemotherapy'**

In testing, this assessment was done at the end of treatment but it is now recommended that it be performed nearer to diagnosis to identify concerns earlier. Assessment and care planning should not be a one-off but be revisited and built on at key stages in the patient journey. The process was tested face-to-face and over the phone and face-to-face was preferred for the first assessment. A paper assessment and care plan was produced, but the next step to be tested is a computerised system that can be incorporated into electronic records.

Assessment and care planning for all cancer patients will have workforce implications for cancer nurse specialists, Ms Young admits, but this could be addressed by moving some workload to junior staff or a care coordinator. "In some cases... [specialist nurses] are doing up to two days worth of non specialist work per week."

Only a minority of patients currently receive a formal care plan but in the test sites more than half said having one made them more confident to plan for the future.

Useful summaries

Once a patient has completed active treatment, the oncologist will send the GP a letter outlining what has happened to them and their long term prognosis. However, this rarely provides full details of the treatment given or specifies their holistic needs, potential side effects or consequences of treatment that the GP should look out for.

The NCSI has been trialling a more detailed treatment summary. This document specifies the type of tumour, details of any chemotherapy, medication, radiotherapy or surgical treatment, and the risk of any potential long term treatment effects and their likely symptoms.

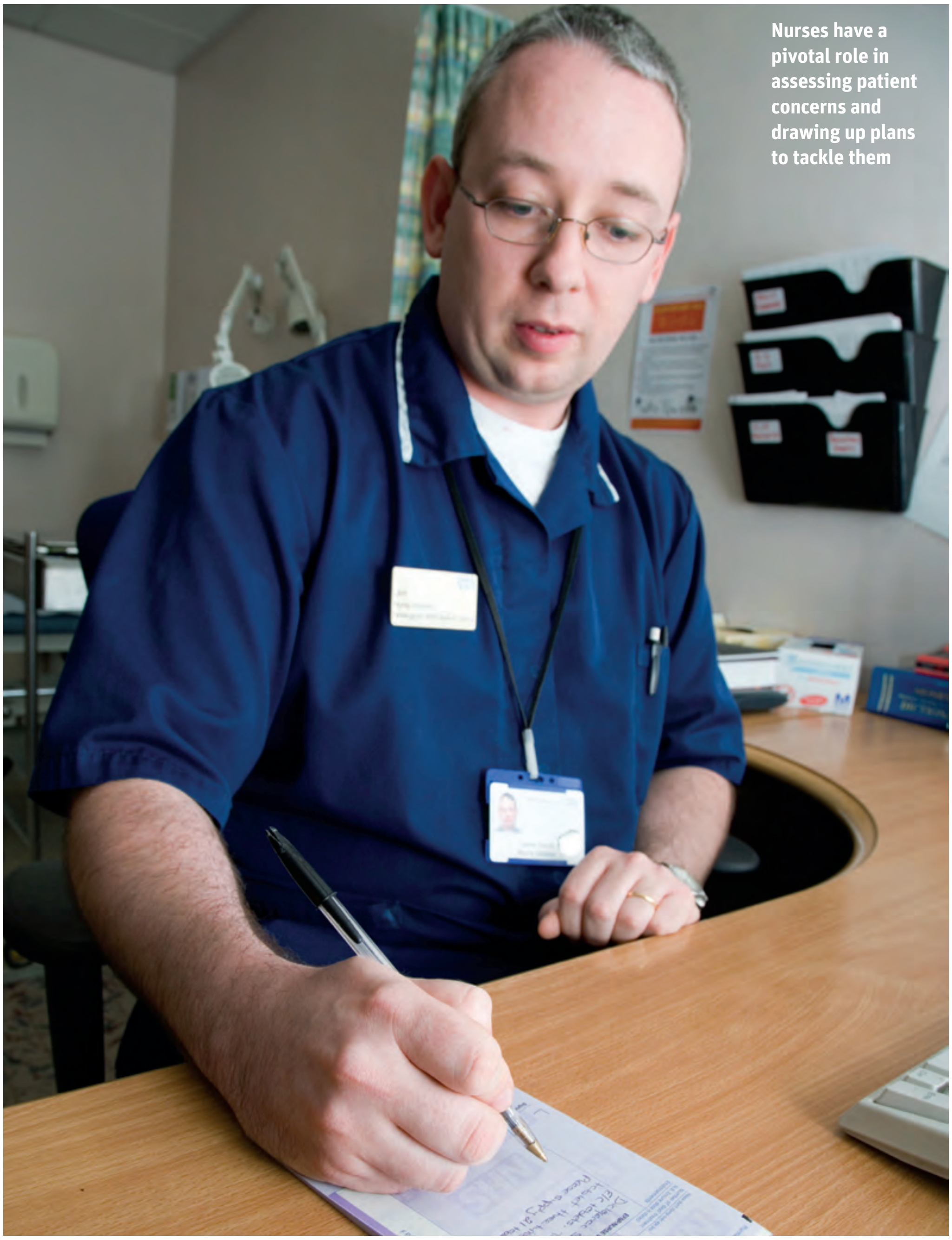
In particular, it flags actions GPs need to take, such as adding patients to an osteoporosis or coronary heart disease register and gives information about the patient's social support network, how they have coped emotionally and any financial or employment difficulties.

Any issues the patient raised in their assessment are also given in case it is useful for future management. As with the care plan, a copy of the treatment summary is given to patients to refer to, show to other professionals and organisations and share with carers and families.

This summary has proved popular with GPs; in testing, 80 per cent said they found it very useful, 90 per cent wanted it to continue and half said that it had changed their management of cancer patients.

That change would include some GPs deciding not to admit patients as an emergency, explains Macmillan Cancer Support GP adviser Rosie Loftus. "If you know that they are palliative you might deal with that at home, whereas if you think there is still an intent to cure you might admit, so the treatment summary has got huge potential to contribute to the planning in primary care, but also the ongoing care in practical terms."

Macmillan chief medical officer Jane Maher points out: "One of the problems at the moment is that GPs code that a patient has had cancer but they don't code on their electronic record what treatment they've had, which makes it very difficult for them to pull out people who've had particular sorts of treatment." She adds: "Further down the line we will identify more risks for these people who are presently having treatment that we don't presently know. We had an example of that last year with swine flu. Did we all know who our patients on chemotherapy were for the vaccination? No,



Nurses have a pivotal role in assessing patient concerns and drawing up plans to tackle them

Patient data can be lost as child patients such as this boy in Exeter grow up

THE RIGHT START FOR CHILDREN

It is particularly important for there to be a succinct summary of the treatment and care that a child or adolescent has received because they will hopefully live for decades and go through many life phases, such as school, university, first job, marriage and children. At any time late effects of treatment or the disease itself may become an issue.

Patricia Morris, director for children and young people at NHS Improvement, says: "If the initial treatments and what happens to them as a young person is not summarised, with the best will in the world sometimes that information might be lost as individuals move on and live their lives."

The transition from children to adult services is a key time because important information can be lost at this handover. The level and consistency of support will become much less than the patient has been used to and the patient will need to start to take more responsibility for their own health as the role of their parents diminishes.

It is at this time that a cancer nurse specialist, with whom the patient is familiar, needs to undertake a comprehensive assessment and draw up a care plan with the patient, which can be revisited at appropriate intervals in the future by adult services. In particular, the importance of wellbeing and healthy lifestyle in the future needs to be emphasised.

because we don't code chemotherapy."

Ms Young admits there had been "some reluctance" among oncologists as the summary changed the way they worked. Specialists normally dictate GP letters once the patient has left the consulting room. In testing they either type into a template or dictate the information into a template.

She adds: "Healthcare professionals in the hospitals commented about primary care being more engaged in the care when they had better information."

Other professionals found that the summary helped to improve teamwork and holistic care by identifying gaps in care. "It's put the patient in the centre of care," Ms Young says.

Templates for the future

Since 2002, a cancer care review worth six points has been included in the GP quality and outcomes framework but an NCSI audit revealed these reviews are of variable quality because guidelines for them are imprecise.

Macmillan has piloted a template for the review that runs on GP computer systems EMIS and In Practice. It is an aide memoire similar to templates for chronic disease and enables GPs to direct people to appropriate support such as benefits advice – 88 per cent of GPs found it useful for identifying resources the patient may need, for example to enable them to return to work.

"At the moment the cancer care review happens six to 18 months after diagnosis," Ms Young says. "People are going back to their consultant regularly for five to seven years. That may in the future change and it may become more important that the GP sees more of the patients that are able to self care and do not need regular appointments at the hospital.

"It's about putting the bricks in place for that change. We're going to need to go back to NICE and say we've looked at this. We think use of the template should be a requirement for these QOF points."

NHS Improvement director Gilmour Frew says that, in order to get the greatest gains from assessment and care planning, the treatment summary and the cancer care review, there needs to be a complete system overhaul. Rather than one pathway, management needs to be more individualised, he explains.

"One of the traps that you can fall into here is that you can compartmentalise the different bits of the pathway, when actually for patient it's along a continuum. It should be seamless.

"We are putting those elements together into a new model of care which is risk stratifying patients based on the disease they've got, the treatment they've had and the individual themselves – a sort of personalised risk stratification." ●

PA, REPORT DIGITAL

A WAY OUT OF LIMBO

When a patient's treatment ends, they can feel abandoned. Macmillan is piloting events to help them get key services and benefits, stay well and resume normal life. By Alison Moore

Having cancer is a life-changing event. While initial concerns may be about treatment and prognosis, there are thousands of people each year who complete treatment and need to resume something approaching a normal life.

But many find it difficult. They may be fearful their cancer will recur, concerned about how it impacts on their relationships and everyday life, and lack information about options available to them such as returning to work.

And, after months when they are likely to have had close contact with the NHS, they can suddenly feel "on their own".

"They have had very intense interactions with professionals – and suddenly they feel abandoned," says Fay Scullion, senior development manager with Macmillan Cancer Support. "Patients said they would like something at the finish of their treatment where they could come together, they could discuss things with professionals and find out more about self management. So we came up with the concept of health and wellbeing clinics."

The clinics, which Macmillan has been piloting in 15 areas across the UK, are aimed at patients who are past their immediate treatment or are undergoing it. The aim is to ease the transition into survivorship – recognising that many will have to live the rest of their life with the knowledge that they have had cancer and dealing with the practical effects it has had on them and those around them.

'In a few sites, the clinics have become part of the patient pathway with patients automatically referred to them'

At these one-off events patients can learn about healthy living including the benefits of exercise and a healthy diet, welfare and employment, return to work and other services they can access. Many emphasise self management – what to be concerned about and how to access help, if needed.

Some clinics have been tumour-specific while others have been for all cancers. Various locations have been tried – including an event at a football club for male cancer patients (see box, below). Some are called events or sessions to distance them from clinical care. Some are drop in sessions and at others patients are invited to attend at a set time. Presentations look at common problems –such as fatigue – while cancer related services give out information at "market stalls" and patients can also have one-to-one sessions with staff or complementary therapists.

Clinical staff, such as cancer nurse specialists and oncologists, are involved but Macmillan branded volunteers have played a key role. They have often had a cancer diagnosis themselves, or been affected by someone who has, and can offer support and insight to those still undergoing treatment or just completing primary treatment. They meet and greet, help with refreshments and guide patients to stalls. Some of the services have extended their role to incorporate an ongoing peer support service.

Early evaluation results are encouraging. Jane Rudge, senior development manager at Macmillan, says: "The model that seems to be coming out the best is a mix of practitioners and volunteers who are doing more than just meeting and greeting, and market stalls where people can get information and one-to-one advice."

Ms Scullion says: "The majority of people liked short presentations of five to 10 minutes. They like the fact they can browse."

Volunteer led self management clinics seems to contribute towards a positive outcome. Although volunteers are not free – they may need training, for example – they can keep costs down.

The key to a successful clinic is the involvement from the multidisciplinary team combined with volunteer support and dedicated administrative support to set up the event. Referral through the normal care pathway may help attendance, and patients may benefit both from written information and aural presentations.

Potential problems include lack of capacity to deal with one-to-one sessions; insufficient awareness and buy-in from staff and patients; and accessibility problems, such as events taking place at the wrong time or too far away from patients.

In a few pilot sites, the clinics have

'I HAD FELT I WAS THE ONLY PERSON WHO HAD THIS'

Dean Burnett was diagnosed with testicular cancer in his mid-40s. He has undergone surgery, will have chemotherapy at some stage and is not working due to his condition.

Mr Burnett, 46, went to one of the health and wellbeing sessions for men with cancer run by Macmillan at Lincoln Football Club.

"The event has people there to discuss things about your cancer – there was someone there to discuss how it was affecting your mind and psychology. We all sat round the table and introduced ourselves to one another. I went there feeling sorry for myself and came out feeling there were others worse off than myself."

He was able to discuss his feelings over his cancer – he feels in limbo as clinicians are still to decide when to give him chemotherapy.

"The event was really good – it was interesting to see how other people deal with it. I had felt I was the only person who had this wrong with me and going there made me realise I was not. Macmillan has been really good to me. They helped me out and got me benefits which I did not... think I was entitled to."

The Lincolnshire events are held every six weeks on a drop in basis and rotate between Lincoln and Boston. They are called events rather than clinics and held outside hospital to make them less clinical. Visitors are greeted by clinicians and volunteers who explain what is available and guide them to "market stalls" offering everything from psychology services to welfare and benefits advice. Volunteers are all male with experience of cancer and have had training.

Macmillan volunteers at health and wellbeing events. All the volunteers have had a diagnosis of cancer or been affected by someone with cancer

'Market stalls' at events help patients with issues such as healthy living and returning to work

become part of the patient pathway with patients automatically referred to them at points in their treatment. In others, the clinics are starting to affect care pathways – for example, improved access to psychology services and dietitians. One site wants to replace traditional follow up clinics for some patients with the events and others want to continue in some form.

Ms Scullion suggests the way forward is to write involvement in the clinics into the professionals' work plan, which could make them cost neutral if they replace other work.

She points out that routine follow up appointments rarely pick up cancer recurrences. Self management – in particular knowing the signs of recurrence and how and when to seek help – could to some extent replace follow up appointments for some patients. "It is about educating people on what to look for and then allowing them easy access back into the system," she says.

Some form of group education could be an efficient use of clinicians' time allowing them to concentrate on patients who really want or need to be seen regularly. Ideally, these clinics would be on offer across the UK. The evaluation is already showing positive outcomes and Ms Scullion is hopeful that they will be mentioned in future commissioning guidance. Macmillan would then want to offer support to areas who want to take up the idea. ●

'THEIR FIRST CHANCE TO TALK'

Sue Youngman, 59, is one of Macmillan's volunteers running health and wellbeing sessions in South Wales.

She works in a team of two or three volunteers, talking to a small group of patients who have mainly received treatment at Velindre hospital in Cardiff. The volunteers, who have all had a day's training, talk patients through a workbook covering eight domains of healthcare – from psychological wellbeing to nutrition – and answer questions. The volunteers are aware of their own limitations and advise patients to contact NHS staff if they have clinical queries or concerns.

Patients leave with their own copy of the workbook, a directory listing useful phone numbers and local organisations which can help them, and some tips for relaxation exercises.

"For many people it's the first opportunity to talk about how they feel away from friends and family," she says. "We are telling people that it's normal to feel like this."

Ms Youngman was diagnosed with breast cancer nearly eight years ago and says she can recognise the feeling of being abandoned as the intensive stage of treatment comes to an end and patients try to return to normal life. "It's really important that volunteers have personal experience of cancer," she says. All have either had cancer themselves or have looked after someone who has, and can empathise with the patient.

'PATIENTS HAVE FOUND IT INCREDIBLY USEFUL'

Physiotherapist Joanne Bayly helps to run a pilot scheme for lung cancer patients from the Aintree University Hospitals Foundation Trust. Unusually, many of its patients will be in the palliative stage and they will be referred to the clinic soon after diagnosis.

Patients are given an appointment and are greeted by volunteers from Liverpool's Woodlands Hospice. They get a chance to browse literature and find out about support available to them, including help from Sefton Citizens Advice, before a one-to-one assessment with either a lung cancer specialist nurse or an occupational therapist or physiotherapist. This helps to identify any health needs and give the patient information about available services and self management or whom to contact if they deteriorate.

"The patients have found it incredibly useful," says Ms Bayly. "We can talk through their fears and concerns and give them advice." Around half the patients who have attended have gone on to use specialist palliative care services.

All partners in the scheme would like it to continue. Ms Bayly says a key point will be whether giving patients this intensive input then helps them to manage their condition better and use other services appropriately.

ALAMY, FOTOLIA

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 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

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

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

ALAMY

'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." ●

LONG TERM CONSEQUENCES OF TREATMENT

ILLNESSES THAT ARE

Adverse effects of treatment are seen as ‘the price you pay for cure’ and ignored but tackling t

Most cancer treatments are associated with some adverse effects. A quarter of survivors can expect ongoing physical problems related to their treatment that will impact on their quality of life. Some problems will appear immediately but others will not emerge until much later.

Unfortunately, even for the more troublesome consequences, the link to cancer treatment is not always made immediately. Patients may be forced to go from clinic to clinic looking for a solution, money is wasted on unnecessary investigations and patients are not diagnosed and treated promptly. Even when the link is recognised clinicians often tell patients: “It’s the price you pay for cure.”

The detection and management of treatment related consequences of cancer needs to be improved and the National Cancer Survivorship Initiative has developed a framework for doing this (see box). Key to the approach is providing information for patients about possible treatment effects and educating them on how to identify them, self manage, use self assessment tools and know when and how to seek help from health professionals.

Whole new pathway

Macmillan Cancer Support chief medical officer Jane Maher explains: “The real problem with consequences of treatment is that they are invisible, so you are not just developing a pathway for something that people recognise as an illness but... for something that people don’t recognise as an illness at all.

“What we are doing is creating a pathway of care that will fit the recommendations that there should be a tariff for the consequences of cancer treatment and by this we mean a bundle of care.”

Enhancing the skills of cancer clinicians, so they are comfortable talking about the consequences with patients at the right time, rather than regarding them as mistakes or errors, is vital. This should start at the beginning of treatment but, as this is when patients are thinking about life and death, it needs to be reinforced at the end of treatment when they are looking to the rest of their lives, Dr Maher says.

For the approach to succeed, patients need to be empowered and their relationship with health professionals needs to change from a paternalistic one to more of a partnership.

One patient resource being tested is an American web based tool called Oncolink that provides patients with up to date and validated information about possible treatment consequences based on their type of cancer and treatment.

Better conversations

Macmillan project manager Chris Steele says that, while Oncolink needs adjustment for routine use by UK patients, it appears to help patients have better conversations with their GPs. They can also go back to it as they go through their cancer journey. “Something that they didn’t think relevant to them three years ago will actually be relevant now.”

The next step is for clinicians to develop a UK friendly version of Oncolink to signpost patients to useful services.

The NCSI framework has been tested in two groups of patients. The first was women belonging to a national support group RAGE (Radiotherapy Action Group Exposure), who have complicated problems resulting from radiotherapy techniques for breast cancer that are no longer in use.

The approach of structured self assessment and telephone triage followed by targeted specialist assessment and care planning at a limited number of centres with one specialist “hub” was successful and the model is being considered for specialist commissioning.

The second group was patients treated for pelvic cancers. New service models have been explored, initially at the Royal Marsden Foundation Trust, Addenbroke’s in Cambridge and Christie Hospital in Manchester, with further centres coming on board later in 2011.

Early results suggest that, after initial assessment based on a structured interview and algorithm based diagnostic pathways, a trained nurse can successfully manage most of these patients, with only the most difficult cases needing ongoing specialist services.

These patients can have complex problems because pelvic radiotherapy for prostate, cervical, endometrial, bladder or rectal cancer can lead to severe bowel problems, with some patients having to open their bowels 10 or more times a day with just seconds warning.

Dr Maher says: “There are around 8,000 new cases of inflammatory bowel disease per year and there are around 8,000 new cases of pelvic radiation related illness every year with a very similar symptom profile. But while there is a service in every single district hospital for inflammatory bowel disease, there is only a handful of services to diagnose and manage radiation related pelvic consequences of cancer.

FRAMEWORK TO IMPROVE DETECTION &

1	Information, education and awareness	Enhancing skills of clinicians to elicit problems
2		Good quality, timely information for patients
3		Education events for patients to include late consequences
4		Engagement of GPs and primary care teams
5		Routine use of self assessment tools
6	Case management	Care monitoring without hospital visits
7		Triage tools to pick up problems, and enable re-entry pathways
8	Service development	Structured diagnostic pathways
9		Access to specialist multidisciplinary assessment and care planning
10		Structured management pathways

One of these services is run by Jervoise Andreyev, consultant gastroenterologist in pelvic radiation disease at the Royal Marsden. He has developed an algorithm for the management of diarrhoea after pelvic radiotherapy, which will be incorporated in the forthcoming British Society of Gastroenterologists guidance on the late effects of cancer treatment.

He sees patients who have not responded to their GP’s or oncologist’s usual treatment for diarrhoea and been told: “There is nothing more I can do.” However, he emphasises that there are 14 different causes of diarrhoea and each cause will have a different symptom profile (bloating, leakage, abdominal pain, excess wind, diarrhoea, noisy tummy and/or vomiting).

Using his algorithm he will identify all the causes and prescribe tailored treatment, which could involve avoiding certain foods, drugs or alcohol or the prescription of another drug. The algorithm is being assessed in a trial where patients receive

OVERLOOKED

g them can transform lives and save costs. By Ingrid Torjesen

& MANAGEMENT OF TREATMENT RELATED CONSEQUENCES OF CANCER

Diagnosis and treatment	Rehabilitation	Monitoring	Chronic and progressive care: cancer and/or consequences	End of life
Joining up, managing transitions				
	Staff confident to elicit problems			
Information including late effects	Consequences of treatment information			
	Education event – Oncolink			
Treatment summary including READ codes	Treatment summary – patient information			
	Introduce self assessment tools	Information through self assessment tools		
	Telephone monitoring for acute effects	At a distance monitoring		
			Triage triggered by self assessed scores	
			Diagnostic algorithm	
			Multidisciplinary team assessment	
			Care management algorithm	
Workforce change				

One of the most unattractive consequences that it is possible to imagine is that you suffer from bowel incontinence

either an information booklet or care using the algorithm delivered by a nurse or gastroenterologist.

Dr Andreyev says: “What we hope is that it will show that doing something is much better than giving people a booklet. My feeling is that we have an impact in 70 to 90 per cent of patients.”

The case for change

Richard Surman, chairman of the Pelvic Radiation Disease Association, was diagnosed with anal cancer three and a half years ago and treated with radical combined chemotherapy and radiotherapy.

“One of the consequences, and the most unattractive consequence that it is possible to imagine with any form of cancer, is that you can suffer from bowel incontinence, which I did on a tube train,” he says. “I walked five miles through side streets to get home, so that I would avoid contact with anybody.”

The experience made him feel like “a leper”. “I was disgusted, horrified, ashamed, embarrassed. I then spent the next three months shut up not daring to be more than a few paces away from the loo and imagining that I was the only person in the world who had this condition.”

He says the attitude of his oncologists was “We seem to have got rid of your cancer, so what are you complaining about?”

Eventually he was referred to consultant gastroenterologist Dr Andreyev at the Royal Marsden, who tried various drug regimes until one worked.

“So many people who have had cancer become permanent cancer patients because of the way that they are not helped after they have had cancer. The truth is there is a normal life to get on with after cancer, but you have to be fit to take part in it,” he says. “To really survive cancer you have got to forget about it and just get on with your life.”

Alastair Munro, professor of surgery and molecular oncology at Ninewells Hospital in Dundee and the clinical lead for consequences of treatment at Macmillan/NCSI, agreed, saying: “The argument is that it’s a bit of a luxury really to be able to discuss the problems that people cured of their cancer have, because 20 years ago they weren’t cured and they weren’t around to develop the problem.

“That’s not an argument for doing nothing – it is an argument for saying things need to change.” ●

CHILDREN

People who have cancer as a child are at a higher risk of developing late consequences of treatment because they are still developing.

There is a lot of evidence to suggest that people diagnosed as children should be “transitioned” twice, says Dr Gill Levitt, a consultant oncologist at Great Ormond Street Hospital in London. When they finish school at 16-18 they should understand what disease they have had, how it was treated, the possible late effects and how to access adult services.

However, Dr Levitt says many teenagers still rely on their parents to take responsibility for their care and don’t take the information in, so they need to be “transitioned” again. “In your mid to late twenties you’re much more interested in the future and whether you can have children, and become more proactive about taking on your own care,” Dr Levitt says. “It’s an important time when you can give the information and it sticks. You can then safely move more patients out to self management.”

To support self management she would also like to see young patients at risk of developing second tumours because of treatment involving chest or pelvic radiotherapy join NHS breast and colorectal cancer screening programmes. “These patients would be fed in at an earlier stage because their risk is occurring earlier than the general population.”

Find out more

Pelvic Radiation Disease Association
➔www.prda.info

FOTOLIA

A JOB THAT IS WORTH DOING WELL

The return to work can be a low priority for clinical staff. Daloni Carlisle on the projects aiming to change all that

One of the hidden costs of cancer is unemployment: cancer survivors are 1.4 times more likely to be unemployed than people who have not had cancer. And, as is now well known, working is good for health.

That is why, in 2010-11, the National Cancer Survivorship Initiative funded seven pilot sites across England to test whether cancer patients benefit from vocational rehabilitation (VR). In short, this simply means helping people with a health condition to return to or remain in work.

“There is quite a body of evidence that vocational rehabilitation does work for people with long term conditions such as musculoskeletal disorders or cardio respiratory illnesses,” says NCSI project sponsor Maureen Dowling. “But there is less evidence around its effectiveness in cancer patients and very few services to meet their needs.”

SURPRISING NEED FOR SUPPORT

NHS Blackburn with Darwen Teaching Care Trust Plus hosted one of the pilot projects, basing it in its existing condition management programme which already had links with job centres, the NHS and employers.

The PCT’s pilot had a dedicated, staffed phone line to triage calls from people referred to the service by health professionals or employers. As well as supporting individuals, the two VR specialists (one a nurse, the other a physiotherapist) made extensive contacts with employers – including Lancashire Constabulary and BAE Systems, which together employ more than 25,000 people.

Programme director Marie Gibbons was surprised by the high number of people needing intensive support. “The work with cancer patients had a lot in common with other long term conditions and we predicted that most people would need signposting or information but that was not the case. We found that people diagnosed with cancer needed more psychological support and more work was needed with employers.”

Her experience is of a valuable service that makes a real difference to people’s lives and wellbeing.

Cancer is, she says, different. For a start many more people are surviving diagnosis and treatment – a fact not widely recognised among the general public or employers.

“Employers do not understand or like to talk about cancer,” says Ms Dowling. “People can talk about stroke or heart attacks, but with cancer there is a fear and lack of knowledge, especially in smaller companies.”

The effects of the disease and the treatments combined with the stigma and lack of knowledge combine to make it very hard for those with a cancer diagnosis to return to work or remain in a job.

NCSI and Macmillan developed a service that would operate within the NHS and use existing VR expertise; each of the seven sites was chosen as they already provided elements of VR. As Ms Dowling says: “In pilot projects that are just a year long, we did not have time to start from scratch.”

While the pilots differed – some had existing condition management programmes, some were in partnership with the voluntary sector, some hospital based and some community – they all used a four stage model developed in consultation with cancer patients, clinicians and employers.

This starts with offering early information to survivors, their employers and healthcare professionals; moving on to provide face-to-face or helpline support; then self management programmes; and finally full case management that might include specialist rehabilitation services such as physiotherapy or counselling.

The pilots ran for a year from April 2010, although each hopes to find a way to sustain services beyond the end of this period.

In September 2010, NCSI published a qualitative early findings report, which highlighted the essential role that health professionals play in recognising and responding to the employment issues that arise as a result of cancer.

It found, for example, that patients want to think about work issues early in their illness – and follow them up during the course of treatment. But health staff do not routinely ask about work worries and as a result patients do not raise them.

“It is a major concern that people are supported early on,” says Ms Dowling. “By the time treatment is finished there will be major issues of work and finance.” And as the evaluation showed, access to quality VR early on can predict and pre-empt problems that get in the way of returning to or staying at work.

Marie Gibbons, who manages a pilot in Lancashire (see box, left) says: “We need to be pushing for a pathway into VR services from primary care.”

Health professionals, meanwhile, are very focused on treatment and symptom management. While they tell patients that returning to normal is a good thing, they counsel patients against overdoing things, which may include returning to work.

“Patients are getting mixed messages,” says Macmillan VR project manager Lyn Bruce. “It’s absolutely right that health professionals are concerned about patients, but work is a major issue for patients. We are planning to do some work about the need for health professionals to talk about work earlier.” She sees clinical champions as the key to engaging clinicians early.

Ready to work: but are health workers too inclined to tell patients not to overdo things?

ALAMY

‘Patients want to think about work issues early in their illness – but health staff do not routinely ask about them’

“Consultants are critical to this,” she says. “If they put VR on their agenda, it makes a big difference to how teams view VR.”

Pilots in NHS settings located near to the clinicians referring patients to them had the most success, she says, as they could engage with consultants directly. “Consultants are not against this and are positive when they know about it,” says Ms Bruce. “Without this leadership, other health professionals may be reticent in discussing work.”

With the pilots nearing their end, Macmillan and NCSI are considering how to take the learning forward.

A full evaluation will be published in autumn 2011, highlighting the numbers helped back to work and the economic benefits to patients, employers and the NHS. Meanwhile, Macmillan is looking again at its extensive information and online resources for employers, employees and health workers. ●

CANCER AND WORK IN NUMBERS

726,000

the number of people of working age who have a diagnosis of cancer in the UK

109,000

the number of people of working age newly diagnosed with cancer each year

90%

of cancer patients’ households suffer a loss of income or increased costs as a direct result of cancer

<40%

of people are receiving advice from health professionals about the impact cancer treatment may have on their ability to work

33%

reduction in cost to the NHS, including reduced GP consultation rates, as people move from unemployment to employment

‘THIS SERVICE SHOULD BE AVAILABLE TO EVERYONE’

Andy Holmes was helped back to work in 2010 by the pilot project in Blackburn with NHS Blackburn with Darwen Teaching Care Trust Plus after his diagnosis and treatment for prostate cancer. He describes his experience.

“I am a qualified professional working full time in a field where the work is very demanding and can be quite stressful. After nearly a year off, I felt it was time to return. As a family, we needed the money and I needed to regain a normal life.

“I knew it would not be easy. My employer’s sickness and return to work policy is driven by procedure with little room for sentiment or the best interests and the welfare of staff. My wife and family were worried about my health, especially if I did not have the right level of support.

“I decided to formulate a phased return to work plan and I discussed this with the Macmillan vocational rehabilitation specialist. She provided a non-judgmental and constructive role, giving my wife and I valuable information about my rights.

She also provided guidance and information for managers and occupational health professionals about the difficulties people with cancer face and specifically how it had been affecting me.

“One of my rights was to have the Macmillan vocational rehabilitation specialist as a representative during the “return to work” meeting with my manager. This gave me a sense of confidence at an important time. With her alongside, I felt that the plan would be accepted and I would gain the support to meet my needs while still being an effective member of staff. She also gave practical support, successfully challenging a decision by my employer not to provide a parking space near my work area during the phased return.

“Months on, I am delighted to report I am still back at work and the agreed return to work plan is effective. I still have a long way to go but so far, so good and I still have the... support when I need it. I think this is a service that should be available to everyone when they need it.”

GOOD MOVES

Doctors once told cancer survivors to put their feet up – but we now know being active is a key part of staying well. Ingrid Torjesen on efforts to get patients exercising

FOTOLIA

In the past clinicians have often told cancer patients to take it easy and rest during and after cancer treatment. But clear evidence now shows being physically active during and after treatment can assist with the prevention and management of some of the consequences of cancer treatment and other long term conditions. And there is also emerging new evidence about how it may be able to assist with reducing recurrence and death from certain cancers (breast, colorectal and prostate).

Physical activity is clinically proven to reduce cancer related fatigue; help manage depression, stress and anxiety; improve bone density, reducing osteoporosis and fractures; build muscle strength, mitigating muscle wasting side effects; improve heart health, reducing the chance of cardiotoxicity; and support weight management. It has great potential to improve quality of life and reduce follow up care costs to the NHS.

Physical activity also reduces the risk of developing other chronic conditions, such as cardiovascular disease, and type 2 diabetes. This is important as according to Macmillan research, 49 per cent of people living with a diagnosis of cancer have at least one other chronic conditions, 15 per cent have two, and 6 per cent have three.

Macmillan physical activity manager Jo Foster says: “If physical activity was a pill that could achieve the same health benefits everyone would be clamouring for the NHS to provide it.”

The Department of Health recommends at least half an hour of moderate activity on five or more days of the week, for adults. “Here at Macmillan we recommend that cancer survivors gradually build up the amount that they do, in line with recommendations,” says Ms Foster.

‘If physical activity was a pill that could achieve the same benefits everyone would be clamouring for the NHS to provide it’

But this behaviour change must also come from health professionals. Ms Foster points to the standard care pathway for physical activity (Let’s Get Moving) based on NICE guidelines, which can be integrated into cancer care.

She said: “It’s about getting a clinical nurse specialist to raise the importance of being active, highlighting the benefits... discussing options and motivating patients to make the changes needed. This includes signposting on to local opportunities, which could be anything from a walking group to exercise on referral.”

In 2009, Macmillan part funded an innovative scheme called Bournemouth After Cancer Survivorship Programme. Nurse specialists at Christchurch and Bournemouth hospital referred 200 breast, colorectal and melanoma cancer patients to BH Live, a local leisure centre where exercise professionals, trained in motivational interviewing (a behaviour change technique) support the cancer survivors to become more active. BACSUP is more of a “community hub” than a traditional leisure centre. After an initial consultation with an adviser to determine personal goals, health and fitness levels, and support behaviour change. Cancer survivors are given 12 weeks’ use of the centre, with access to everything from Nordic walking to swimming lessons to Tai Chi. Family members are encouraged to participate and there is regular support from the exercise professional.

A key aim of the project is to boost patients’ confidence. BH Live partnership lead Layne Hamerston says: “A lot of the survivors participating in the scheme are achieving activity levels and trying new things that they have never done before.”

More than 90 per cent of people who have so far been through the scheme have increased their cardiovascular fitness, reported lower levels of fatigue and improved overall wellbeing. Weight and blood pressure have been reduced in six out of ten cases. The scheme is now being extended to patients with haematological cancers.

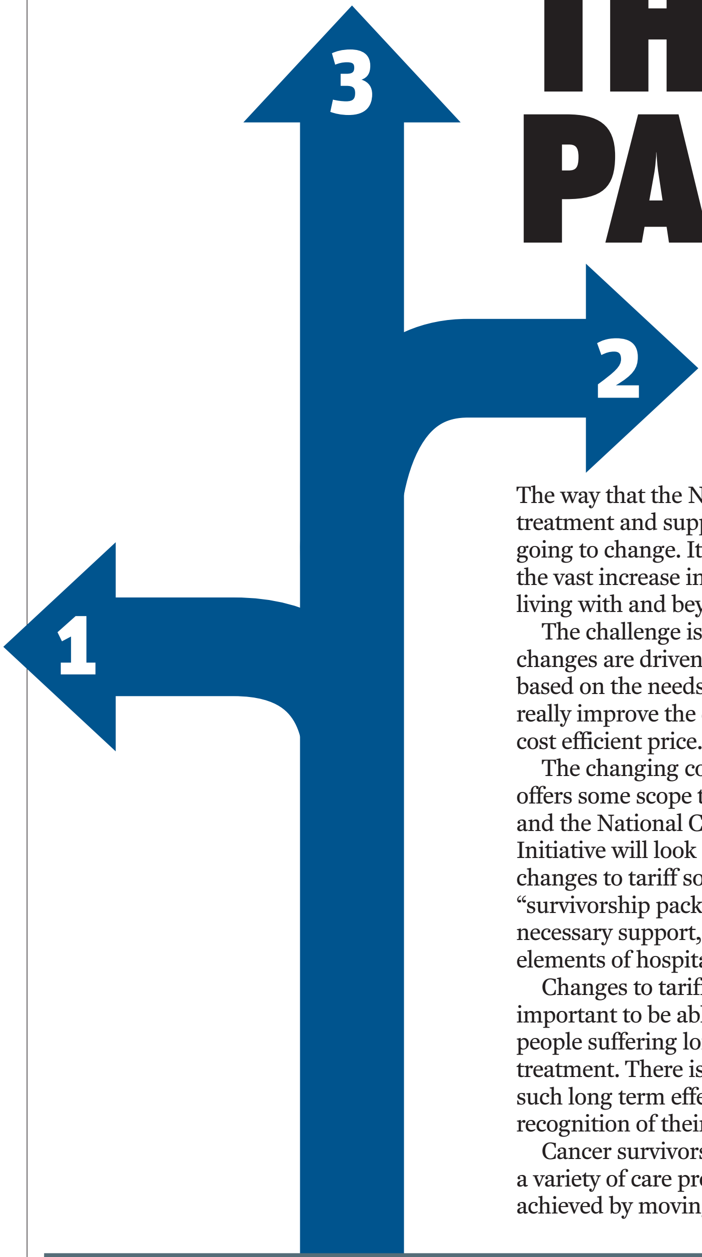
Ms Foster says the potential cost savings to the NHS of commissioning such services are huge. The Bournemouth scheme costs £190 per patient and a randomised controlled trial of a similar scheme in Glasgow (Active after Breast Cancer) found there was an average saving of £1,500 per patient over six months in terms of reduced unplanned emergency admissions and GP appointments. ●

‘I DIDN’T HAVE THE FATIGUE’

Mariette Mason was first diagnosed with breast cancer at 32. After a lumpectomy and radiotherapy she tried to get back to normal. Then 21 years later she had to have a full mastectomy followed by chemotherapy for a new primary

“Between the operation and my chemo I really did work hard on my cardiovascular fitness. I walked everywhere, I went to the gym and I got myself a personal trainer,” she says.

And it paid off. “Yes I was unwell but I didn’t have the fatigue that everyone talks about. I think because I was fit I needed lower dosage of treatment.”



THE WHOLE PACKAGE

Commissioning joined up care will be vital for future cancer patients, says Steve Hindle

The way that the NHS and social care offer treatment and support to cancer survivors is going to change. It will need to, to cope with the vast increase in the number of people living with and beyond cancer.

The challenge is to ensure that these changes are driven by the best evidence, based on the needs of cancer survivors, and really improve the quality of their lives at a cost efficient price.

The changing commissioning landscape offers some scope to introduce new ideas, and the National Cancer Survivorship Initiative will look at the potential of changes to tariff so that commissioners buy "survivorship packages" that offer the necessary support, rather than single elements of hospital based activity.

Changes to tariff are particularly important to be able to provide services for people suffering long term effects from treatment. There is currently no tariff for such long term effects – and little recognition of their devastating nature.

Cancer survivors may need support from a variety of care providers; this can be achieved by moving to an approach based on pathway commissioning across providers rather than intervention (provider-centric) based commissioning.

Ensuring survivorship issues fit in the NHS Outcomes Framework will be important, as will the inclusion of survivorship in the new NICE quality standards.

Other levers for change include the cancer patient experience survey results and a survivorship survey, being piloted, which will give us further insight from users into the long term physical and emotional impact of cancer and its treatment.

Through engaging with commissioning consortia, we will seek to ensure changes to cancer follow up are based on evidence, and to head off unhelpful changes – for example, local rulings that patients can only have two follow up appointments – until we have proper evidence.

Information will need to flow better between acute and primary care. One tool to improve this will be treatment summaries informing primary care of patients' treatment, likely next steps and possible consequences of treatment.

Improved information flow will be necessary to support "remote surveillance". This is so that clinicians and users can have faith in the effectiveness of supported self management in spotting recurrences and ensuring prompt treatment.

Pilot work to date indicates that self management can do this and the next 12 months will be about gathering evidence through the work that NHS Improvement are leading in the prototype sites (see box) and the work that Macmillan are leading across three whole system networks: University College London Hospitals and UCL Partners in north London; the Manchester health and social care economy; and Northern Ireland.

Finally we are reviewing the ways in which we can provide the developing body of survivorship evidence and engage with the large number of clinicians and managers interested in developing both their own understanding and their services to provide better care and treatment for cancer survivors. ●

Steve Hindle is survivorship programme lead at Macmillan Cancer Support

THE NEW WORLD OF RISK STRATIFIED CARE

The next step is to redesign the pathway by "risk stratifying" patients who have finished active cancer treatment into three groups according to their disease, treatment effects and individual circumstances.

NHS Improvement is leading the testing of risk stratified pathways in 13 tumour specific projects in seven NHS communities.

The majority of patients, who are at low risk in terms of disease, treatment effects and individual circumstances, do not need regular follow up and will be supported to self manage – with remote monitoring tests overseen by specialists and results relayed direct to the patient and their GP. Rapid access will be available to specialist services should they be required. A smaller group unable to self manage for whatever reason will get care in partnership with a member of the health or care team. Those with the most complex needs will receive regular face-to-face follow up with a range of health professionals and specialists.

All patients will have their needs assessed and be provided with a written plan of care, a summary of their treatment and a guide to what to look out for in the future. Information is key to personal choice and confidence in self managing, or managing in partnership with care providers. This information could be provided as a one to one session, in an information day, a health and wellbeing clinic or as a tailored course.

It is anticipated that more individualised care will enhance the patient experience and improve efficiency by reducing hospital visits that add no value and unplanned contact with the NHS.

NHS Improvement director Gilmour Frew hopes that testing will prove the potential for future models of risk stratified care based on the individual rather than tradition, and will help to form a package of care based on a pathway of care rather than individual activities.