

## SUPPORTING THE TWO MILLION PEOPLE LIVING WITH OR BEYOND CANCER



IN ASSOCIATION WITH



NHS Improvement

# CONTENTS



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## AFTERCARE



Increased survival means that for many patients cancer is now a long term condition and follow-up services need to change to reflect this.  
**Page 2**

## PERSONALISED ASSESSMENT



Taking a holistic approach to each patient's needs and creating a personalised care plan would benefit both patients and the NHS.  
**Page 4**

## SELF MANAGEMENT



Quality of care for cancer survivors can be improved by giving relevant information and support to patients to promote self management.  
**Page 6**

## TAILORED LONG TERM SUPPORT



Support for cancer survivors has to be a lifelong process which recognises that patients' needs can change.  
**Page 8**

## FOREWORD

CIARÁN DEVANE AND SIR MIKE RICHARDS

# We could deliver better support for less money

Whether at the point of diagnosis, receiving treatment, trying to get on with their life after treatment or reaching the end of it, many cancer patients have unmet physical and psychological needs.

We need to better support them to live as well as they can with and beyond their cancer.

There are two million people living with cancer in the UK, and the number is increasing by 3 per cent a year. This increasing demand for services and high level of unmet need mean that we need a fundamental shift in the way that we support cancer survivors.

Given the current financial pressures, it is good news that we believe we can improve the quality and quantity of survivorship services in a very cost-efficient way. That is what the National Cancer Survivorship Initiative is setting out to achieve.

Instead of the rather formulaic approach to follow-up that exists at

**'We are investigating new models, where the patient's care plan outlines to them when to seek help and from whom'**

present, all patients should receive an assessment of their needs, resulting in a care plan, with the resources identified to deliver it, and information and support on what to expect in the future.

Instead of routine, regular hospital follow-up appointments, which consume a lot of NHS resources and are sometimes of doubtful value, the National Cancer Survivorship Initiative is investigating new models, including telephone and self-triggered follow-up, where the patient's care plan outlines when to seek help and from whom.

Early results suggest that if we increase coordination of care, quality of communication and quality of information provided to patients to better support them in the community, their demand for acute sector resources is reduced. This is good for patients and good for the NHS. ●

*Ciarán Devane is chief executive of Macmillan Cancer Support, and Professor Sir Mike Richards is national cancer director.*

*For more information see [www.ncsi.org.uk](http://www.ncsi.org.uk)*



# LIFE AFTER TREATMENT

The National Cancer Survivorship Initiative believes a total approach must address the cancer survivor's personal, physical and practical needs, writes Ingrid Torjesen

There is no getting away from the fact that a diagnosis of cancer is a scary, possibly life threatening experience. The shock of the news and the stress of the treatment on the patient are profound. They will affect a person physically and impact on their family, social and work life. Luckily, for an increasing number of people the diagnosis is no longer a death sentence. But, even for those, life may never be quite the same again.

Two million people in the UK are living with cancer and this number is increasing by 3 per cent each year because improved diagnosis and treatment is lengthening survival, and the population is ageing. By 2030, four million people are expected to be living with or beyond cancer.

While treatment is improving all the time, many survivors do not get the longer term support they need.

Macmillan Cancer Support survivorship programme lead Stephen Hindle says: "Macmillan's 2006 *Worried Sick* report tells us that 26 per cent of people feel abandoned at the end of their treatment – this is a driver to change the system."

Most follow-up care takes place in hospitals, is clinically led and focuses on picking up recurrences and late effects. But this does not meet patients' wider needs and is unlikely to be sustainable as patient numbers increase in the future.

A Picker survey in 2009 found that 43 per cent of survivors wanted more information and advice and a study of patients at 66 UK cancer centres, published in the *Journal of Clinical Oncology*, revealed that one in four had at least five unmet

physical and psychological needs in the first year after treatment.

A Macmillan survey found that cancer survivors have a health and wellbeing profile similar to someone with a chronic condition such as diabetes or heart disease. They are more likely to visit their GP, attend accident and emergency and use other NHS services than the wider population. They are also more likely to have difficulty with daily life, social activities and relationships with their partner, and be prevented from working in the career of their choice.

Nine in 10 survivors have been financially disadvantaged by their diagnosis of cancer and on average the under 55s see their income halved. Not surprisingly, 40 per cent of cancer survivors say that the financial impact of cancer has had a negative impact on their quality of life. However, three-quarters of survivors say they have been offered no information on welfare benefits.

A personalised and holistic approach is needed to address the range of survivors' physical, psychological, social, spiritual, financial and information needs.

Adam Glaser, Department of Health clinical director for the National Cancer Survivorship Initiative, says: "The care needs of one patient may be very different from the needs of another, even if they had identical diseases and treatments. This is because social and psychological factors may come into play. We must have some way of personalising and risk stratifying support for this increasing number of long term survivors."

This strategy will ensure that



**'The care needs of one patient may be very different from the needs of another, even if they had identical diseases and treatments'**  
**Dr Adam Glaser**

people with the greatest needs get the greatest support and those who have fewer needs have access to care if they require it. To achieve this, patients need personalised assessment and care planning to understand their needs. They will then be given tailored information, which includes consequences of treatments they should be on the alert for, to help them self manage as much as possible; and also be referred to services as required.

The National Cancer Survivorship Initiative is developing a structure for services through better models of care. To facilitate implementation of these, it is likely there will need to be a greater emphasis on paying for packages of care rather than individual episodes of care.

For this approach to succeed, there must be a shift in attitudes to cancer and its treatment, starting from diagnosis. This means greater emphasis on personalisation, wellbeing and self management, and a move away from a single clinical follow-up model to tailored approaches, including patient reported outcome measures.

PROMs on patient satisfaction and quality of survival will give a "true handle on what it is like to live beyond cancer", so we can refine the individual package of care and the whole service, explains Dr Glaser.

"The overwhelming message for patients and their families is that cancer does not necessarily equate to a death sentence. We aim for life after treatment. Our vision is to support people to concentrate on recovery, and health and wellbeing after their cancer treatment." ●

# A NEW APPROACH TO AFTERCARE

The cancer story is changing and follow-up support needs to reflect the fact that for some patients cancer is now a long term condition, says Ingrid Torjesen

Twenty years ago, cancer was considered to be an acute condition that either killed or could be cured. It was a death sentence for many patients and the aim of treatment was often to extend life for a few months.

Improvements in diagnosis and treatment now mean that 50 per cent of patients will live five or more years and, for some cancers, such as breast, five-year survival rates are as high as 80 per cent.

As a result, rather than an acute condition from which they either recover or die, for an increasing number of patients cancer is a



## FIVE KEY SHIFTS

In order to achieve its vision for improved care and support of cancer survivors, the National Cancer Survivorship Initiative believes five key shifts are required

**1** A cultural shift in the approach to care and support for people affected by cancer, so there is a greater focus on recovery, health and wellbeing after cancer treatment, and an understanding that incurable cancers have different illness patterns, which for some patients mean they have several years of good quality life

**2** A shift away from the one size fits all follow-up regime towards assessment and personalised care planning based on individual risks, needs and preferences

**3** A shift away from a clinically led approach to follow up care to supported self-management, based on individual needs and preferences and with the appropriate clinical assessment, support and treatment

**4** A shift from surveillance based clinical follow-up to a personalised information prescription and specialist support that enables early recognition of and preparation for the consequences of treatment as well as signs and symptoms of secondary, recurrent or advanced disease

**5** A shift from an emphasis on measuring clinical activity to measuring patient reported outcome measures in aftercare services

chronic illness that may follow a relapse and remitting pattern over several years.

However, our perceptions of cancer and the way we provide care to survivors have not kept pace. The National Cancer Survivorship Initiative believes five fundamental shifts in our approach to care of cancer survivors are needed (see box, below left).

Follow-up for survivors is still modelled on that for an acute medical problem whereas what is increasingly needed is follow-up support for a long term condition.

A survey by NHS Improvement in 2007 revealed that both health professionals and patients believe the main purpose of follow-up is to pick up recurrence early (see box, right). In reality, three-quarters of recurrences for common cancers, such as breast, are picked up between appointments by patients themselves.

Meanwhile, patients are missing out on the support, information and rehabilitation they need to get on with their lives and get back to work. A recent study published in the *Journal of Clinical Oncology* found that around one in four patients have unmet

physical and psychological needs in the first year after treatment. And a Macmillan survey in 2008 found that people living with a cancer diagnosis have a health and wellbeing profile similar to somebody with a chronic illness, such as diabetes or heart disease, and are more likely to develop illnesses, such as heart failure, osteoporosis and diabetes, which would respond to lifestyle interventions.

Jane Maher, Macmillan Cancer Support chief medical officer and national clinical lead for NHS Improvement, says a health promotion opportunity is being missed.

"We know that cancer patients are more receptive to lifestyle advice and they are more likely to take things up, because it is a teachable moment at the end of treatment," she explains.

For example, the Macmillan survey showed a third of cancer survivors do not realise exercising is particularly important for them. Few GPs are aware that most cancer survivors are eligible for exercise on prescription, says Professor Maher.

A different approach to follow-up, where patients receive a personalised assessment and care plan with tailored information and support to help them self manage but also access to the services they need when required, could avoid many unnecessary face to face hospital appointments. Pivotal to this approach is a clear understanding of the risks of future recurrence or consequences of treatment that individuals may face, based on evidence of what has happened to previous cohorts of patients.

Alastair Smith, consultant haematologist at Southampton University Hospitals Trust and national clinical lead at NHS Improvement, asks: "Do we really need to see a lot of patients who are well who could be managing themselves and be sent to have a test according to a protocol or who could be given appropriate information and their follow-up managed in primary care?"

Professor Maher implemented a self management follow up regime for breast cancer patients 10 years ago. Patients get an exit interview, information about what to look for, scheduled mammography appointments and can ring the breast care nurse at any point. The satisfaction rate is very high and the model suits around 70 per cent of patients.

She emphasises that it is vital that primary and secondary care have a shared understanding of the illness and that there are agreed cut off points for blood tests and other investigations, specialist assessment of images, and flexible access for patients back into the system via a trusted person, such as a specialist cancer nurse.

The approach is not suitable for everyone, she adds: "An anxious person overwhelmed by fears of recurrence or someone who has particular psychosocial problems or cognitive difficulties is not going to be able to cope with a supported self management programme. They will need a regular face to face appointment."

NHS Improvement is undertaking work to compare alternative regimes with the traditional approach in terms of patient experience, outcomes and costs and hopes

## WORK BY NHS IMPROVEMENT

**A 2007 survey of 3,000 cancer patients and primary and secondary care healthcare professionals found most patients preferred hospital based follow up and had not experienced any other type. But those that had experienced another type, such as nurse led, group, telephone or postal, were positive about the experience. The majority of respondents believed that the purpose of follow-up was to identify recurrences and late effects of treatment, rather than to provide psychological and other support.**

**In 2009, NHS Improvement surveyed the 28 cancer networks and found little had changed since 2007. Most patients were still receiving five years of clinically orientated hospital based follow-up rather than telephone or triggered follow-up. Whichever system they had been through was the one they preferred, indicating that a new system would be accepted once they had experienced it.**

**NHS Improvement has 38 test sites looking at new models of follow-up: 28 are piloting approaches to care and support for adults and 10 for children and young people. The models aim to improve patients' experience of care by providing a different type of follow-up more tailored to their needs that involves fewer hospital appointments but which is as safe as the traditional regime. Results on the impact of these models are expected in 2010.**

to have results by October, in time for the next three-year commissioning round (see box above).

NHS Improvement director Gilmour Frew says: "We need more evidence about what works best in terms of survivorship care. But we know that we need to make changes because the status quo is not meeting the needs of patients."

Although there are figures already to show that most patients pick up recurrences themselves, Mr Frew warns managers shouldn't "knee jerk" in the tough financial climate to cut some follow-up appointments.

"Productivity isn't the key aim for this, it is about improving the quality of the services delivered," he says. "The wrong thing to do would be to prescribe that they are only going to be paid for x number of follow-up visits."

He anticipates that alternative models will be cheaper over time, but says they will require reconfiguration of services, incorporating existing expertise and bundles of care around cancer nurse specialists.

"The difference will mainly be in experience of care for patients, but if you get the quality right and people are better supported and have better information that may have a knock-on effect on the patient's contacts with professionals and also with hospital services," he says.

However, to support this shift there will need to be a change in the way follow-up services are paid for.

Mr Frew says: "It should not be based on the more times you see the patient the more money you get, but on the outcomes of that package of care." ●

**'Do we really need patients who are well and managing themselves to be sent to have a test according to a protocol when they could be given appropriate information and their follow-up managed in primary care?'**

# THE PERSONAL APPROACH

Taking a holistic approach to each patient's needs and creating a personalised care plan to reflect these would benefit both patients and the NHS, Alison Moore reports

## SHEFFIELD'S CANCER TOOL

An assessment tool has been piloted among cancer patients in Sheffield – and has won acceptance from patients and clinicians alike.

The Sheffield Profile for Assessment and Referral for Care tool gathers information about what patients perceive as their problems or areas of concern, generally in advance of a consultation. Some consultants send it with outpatient letters, while others ask patients to fill it in while in their waiting rooms. Nurses also use them in consultations with patients.

Professor of palliative medicine at the University of Sheffield Sam Ahmedzai says clinicians can then use the responses to hone in on what patients are most concerned about. The form will take seconds for a doctor or nurse to read through, whereas previously even a doctor with good communication skills might take 10 to 15 minutes to find out a patient's real concerns.

"It is a starting point for a full assessment that should end up with an action plan," he says. "It asks patients questions that many clinicians would not get round to asking. For example, there's a simple little question about sexual problems and it makes it a lot easier for the patient to open that conversation."

Using the form has increased the number of patients referred to other services, such as social work, physiotherapy and palliative care. But patients are generally very discerning about what they view as a problem.

The form is already being used by other cancer services and can be used for other conditions as well. It was developed in Sheffield under the NHS Cancer Improvement Programme and can be used, free of charge, by other sites.

"Everyone by the end of next year has to be using some form of holistic assessment tool. People are looking at this and saying, this is it, why reinvent the wheel?" says Professor Ahmedzai. "Our dream is that SPARC gets built into the standard NHS IT system and can be passed on to whoever next cares for the patient."

With more cancer patients being treated successfully and living for many years, there is increasing pressure for services to think beyond the initial period of treatment.

Cancer survivors need help to come to terms with their new status and to address any problems or concerns they may have.

The National Cancer Survivorship Initiative envisages all cancer patients being given a personalised assessment and care plan that covers the period after they leave treatment and is revised as their circumstances or prognosis changes.

Macmillan Cancer Support chief executive Ciarán Devane says this assessment needs to be holistic.

"It's not just the medical bit, the emotional bit, the financial bit... it's looking after the person and the impact that it is having on the whole person," he explains.

This would mark a shift in thinking towards cancer not being an episode but often a long term condition that continues to affect people's lives for many years.

The Department of Health has recognised the role of personalised care planning on improving care. It has committed to offering a care plan to all 15 million people with long term conditions by the end of 2010.

Personalised planning is likely to involve a regular meeting between the patient and a health or social care professional, perhaps annually. The plan would reflect patients' individual needs and concerns. It is important to include carers in the planning and provision of the patient's care, but also to remember that carers may have their own needs, different from the patient's.

The National Institute for Health and Clinical Excellence's guideline on supportive and palliative care says that patients with cancer should be assessed from diagnosis onwards and offered a range of physical, emotional, spiritual and social support.

But Mr Devane says support for patients is patchy: "All the evidence is that it is done well in some places, not so well in others, not at all in some places. We need to get to a position where everyone does get an assessment."

He wants to see formal personalised care plans extended to all cancer patients.

One of the challenges is how to devise an assessment that genuinely identifies patients' needs without straining the limited time and resources of the NHS.

"Imagine you are going in to meet the doctor and you have a touch-screen PC in the waiting room that asks you a series of questions," he says.

This would allow cancer survivors to pinpoint any areas of worry. They would then go in to see the doctor, who would have the information available about their areas of concern.

"You can go into depth on the bits that you want to go into depth on. That's as

**'It is about taking some of the good practice that exists in the cancer community and some of the good practice that exists on long term conditions and putting it together'**

much about asking questions relevant to the patient as making efficient use of the clinician's time," he adds.

It would be important that the assessment was not a one-off event, but something undertaken at diagnosis and then repeated at the end of active treatment and again at regular points.

In particular, leaving treatment can be a very difficult time for patients. Research shows that 26 per cent of patients feel abandoned after finishing treatment and a Picker Institute survey in 2009 found 75 per cent of cancer survivors did not have – or did not know they had – a care plan. A similar proportion did not know who to contact out of hours about their condition.



One way this could be addressed is being tested: a “health and wellbeing clinic”, where patients at the end of their primary treatment would go to hear about signs and symptoms to look out for, what services and self management options were available, in the company of other patients also finishing treatment.

Mr Devane says it is important for support to continue as people return to a more normal life, for example, through a key worker with good connections to primary care. As a result, it is important that GPs are aware of their patients’ needs. A treatment summary record, to be completed by secondary care and sent to the patient’s GP, is being trialled, as well as a template that will allow GPs to make the best use of the six-month post diagnosis review (and thereby

get quality and outcome framework points).

But what will make this happen? Many people are not getting the support they need. Faced with the increasing demand for support and care, NHS commissioners need to use resources effectively, which means considering how services can be delivered in a different way.

There is emerging evidence that the lack of knowledge and coordination on cancer can lead to extra costs, for example, when a patient ends up as an emergency admission or has higher levels of unplanned events. Good co ordination, information, knowing where to turn for help, and recognising which symptoms are important and which are not can mitigate this.

The provision of standard of written information is very variable. The vision is

that high quality information will be available electronically so that after their care planning assessment patients can be given a personalised information prescription, which helps them self manage and signposts appropriate support.

“We do have to help people stay well and stay at home and to know when they have to hit the hospital. It’s getting that into the system,” says Mr Devane.

That is likely to involve realigning services to meet patients’ needs. Some cancer nurse specialists, for example, could find themselves working in the community rather than the acute sector and will be concentrating on keeping patients at home.

“It is identifying the service changes, which don’t have to be expensive, but will generate better quality and productivity. Our priority is to ensure that, by this autumn, we can create guidance for commissioners that they can use for commissioning services in 2011-12, and this guidance can be built on in subsequent years,” he adds.

“It is about taking some of the good practice that exists in the cancer community and some of the good practice that exists on long term conditions and putting it together. When we have the evidence that there is a way to improve quality that delivers on productivity and efficiency, then what’s not to like?” ●

## THE SURVIVOR’S STORY

**Leukaemia patient Jackie Milic is one of the lucky ones – she has been receiving holistic support in Sheffield since her treatment was recently completed. She says she understands the feeling of abandonment patients can feel after their lives have seemed to revolve around hospital visits and treatment for so long.**

**“It is a difficult time,” she says. “But there’s been a lot of support. They have offered**

**counselling at a support centre – they don’t make you feel like you are unwell. You are not just a person with cancer, you are a person.”**

**As well as providing support, her nurse has helped with her family and is always ready to listen to concerns. And because she has been given more information, she does not automatically assume that every time she is unwell it is linked to her cancer.**

# A LITTLE HELP FROM YOURSELF

Clinicians can improve quality of care for cancer survivors by ensuring they have the knowledge and confidence to self manage as much as possible, explains Jo Carlowe

Over the past 10 years, mortality from cancer has fallen and around two million people across the UK are now living having been diagnosed with the disease. Yet, despite the improved survival rate, the National Cancer Survivorship Initiative has found that survivors often experience physical, psychological and social problems from the cancer and/or its treatment, including fatigue, anxiety, depression, insomnia and a fear of recurrence.

These are difficulties that cannot be solved by routine visits to the consultant, leaving survivors feeling unsupported and unsure of where to turn. Aware of this dearth, the NCSI has identified self management as a key component of its vision for the future. This is where patients take an active and responsible role in their care in the same way as they do in long term conditions such as asthma and diabetes.

Macmillan Cancer Support chief clinician Jessica Corner explains: "The amount of

time we spend in hospitals undergoing cancer treatment is overall a matter of days or weeks, even though cancer treatment may last over many months. Most of this time is spent at home in our usual lives with our families and friends.

"Once treatment is finished this is virtually 100 per cent of our time, except for very occasional monitoring visits every few months, then perhaps once a year. Looked at this way, self management is probably more than 95 per cent, or perhaps even 99 per cent, of the cancer patient's journey."

However, Professor Corner says clinicians have failed to grasp the importance of self management for cancer survivors.

"The relationship between most health professionals and individuals with cancer tends to be the health professional knowing what's best and telling patients how treatment will be and what will happen. Very little goes on to prepare people for what they are going through or to put the

## THE TEST COMMUNITY

NHS Birmingham East and North has redesigned the care and support pathway for breast cancer patients who have completed treatment for primary breast cancer.

This test community is providing a telephone based support service run by trained cancer nurses, a home based case management service for complex needs and a tailored self-management programme for patients.

The programme is modelled on work that the primary care trust has carried out on self management of other long term conditions in which patients receive pro-active telephone based coaching with bespoke software adapted to incorporate local guidelines and pathways (part of the Birmingham OwnHealth programme, a collaboration between the PCT, NHS Direct and Pfizer Health Solutions).

Andrew Donald, lead commissioner for the PCT, believes it is appropriate to include cancer under the same kind of programme as other long term conditions.

"Once you have survived [cancer], apart from the odd visit to a consultant you are virtually left on your own, but the long term effects of cancer can be profound," he says.

The scheme, which will work in conjunction with Macmillan and the National Cancer Survivorship Initiative, will be tested over the next 18 months, with results expected from November 2010.

The evaluation is looking at patient reported quality of life, changes in lifestyle factors, confidence and motivation to self manage, patterns of healthcare use, and feelings of hope and gratitude.





**'Are we only doing things that improve quality if they save costs? Maybe we should improve quality because it is the right thing to do'**



decision-making into the hands of individuals."

Typical omissions included a failure to warn people about how their treatment might affect them, how to look for signs of recurrence, how to return to the lives they led before having cancer and about lifestyle changes that help prevent second cancers occurring. There is emerging evidence to show that lifestyle factors, including physical activity and diet, can influence the rate of cancer progression, improve quality of life, reduce side effects during treatment, reduce the incidence of relapse, and improve overall survival.

Professor Corner says there needs to be a shift in culture that would see health professionals in the role of "expert facilitators" – a task for which they have yet to be trained.

Moreover, she says the system itself needs to change: "Payment processes for acute trusts, commissioning and so on, does not put a monetary value on working to help people self manage. In fact, there is an incentive to have people visit outpatient clinics and have investigations or admissions to hospital. We need to develop financial incentives to prevent this."

Commissioner Andrew Donald, executive director of NHS Birmingham East and North, agrees that commissioners have not yet been incentivised to promote self management.

"For commissioners the part that they think about is 'what does it cost and what does it save?'. You can work out the business case, but a good preventative model can't be tested unless you set up the service. There is a philosophical debate: are we saying we will only do things that improve quality if they save costs?"

"Maybe we should improve quality because it is the right thing to do."

He notes that commissioners act under the quality and productivity drive with an obligation to deliver quality and efficiency. However, he believes the innovation component is sometimes lost.

"The way you educate commissioners is to show and tell. We are on the far edge of innovation and are willing to test out ideas."

His trust is testing a cancer self management programme (see box, left) and he believes the shift of focus from treatment to prevention will improve quality and save costs in the long run.

"By focusing on prevention, you are trying to prevent other things happening such as psychological problems. If people don't get the support they need they end up accessing other parts of the healthcare system, such as mental health services, and risk becoming a burden on the NHS," he says.

Nonetheless he says commissioners have to be prepared to absorb the initial outlay required for setting up and training people in self management.

The shift in emphasis starts at the point of diagnosis, when a new relationship between healthcare professionals and patients and

## A SCATTERGUN APPROACH



**Chris Lewis, 52, was diagnosed with stage 4 mantle cell lymphoma in July 2007. He successfully received a bone marrow transplant but continues to experience health problems due to his weakened**

**immune system.**

"The cancer changed my life. I worked for over 30 years as a self employed sales consultant in fashion but I couldn't go back to this after the cancer because I was still under treatment and kept getting infection after infection. My wife is retired and I was only entitled to incapacity benefit. I went from earning a fair bit to getting just a few bob. It was a blow psychologically and financially. I'm still not sure I've got over the fact that I've not been able to return to my career.

"The staff at St George's Hospital, Tooting are brilliant but when it came to looking for things in the community I'm not sure whose responsibility that is.

"I went to Macmillan and became a volunteer for them. Because of my volunteering I have done lots of training courses and have learnt a lot about the disease but this has really been on my own behest. I am very self motivated and sought out advice but it certainly wasn't under my nose. When you sit in waiting rooms there are lots of scruffy notices pinned up that give information about support groups but it is very much a scattergun approach.

"To know about self management it has to start from somewhere and I think that needs to come from the health service itself."

can be facilitated through the use of telephone and technology. This can include the provision of tailored self management education and training programmes via groups, one to one provision or peer support networks.

Crucially, the NCSI notes that in order for self management to work, staff and the system need to change.

It advocates the provision of skills development programmes that support professionals and reflect on their consulting styles, and calls for service development and redesign.

It is different approach, but primary care trusts will have a head start, since there are already many well designed courses for health professionals in relation to other long term conditions, such as heart disease.

Professor Corner says that these can be readily translated into the cancer context and says that commissioners already recognise the importance of self management, it is just that they need to increase their vision to include cancer.

"We need to sell the concept – and provide the evidence – which as yet is not available," she says.

The aim will eventually be to ensure that self management is integral to all survivors' ongoing care plans – a goal that, Professor Corner says, will require "a major attitudinal change". ●

# THE NEXT STEP OF THE JOURNEY

New illnesses can emerge years later – avoidable consequences should be avoided, and unavoidable consequences should be recognised and managed. Ingrid Torjesen reports

Improvements in the diagnosis and treatment of cancer mean that more and more patients are being treated successfully and going into remission. But this is far from the end of their cancer journey.

All treatments are associated with some side effects and these may develop years or even decades after the treatment was given. As survivors live longer, it is becoming more important to be aware of the likelihood of these potential consequences, and to have mechanisms in place to identify and track them, as well as appropriate services to deal with them.

For many patients the changes they will notice will be slight, such as a small difference in bowel habit or sex life. With the right information and support, most patients should be able to self manage these changes themselves.

However, a quarter of cancer survivors will experience more significant problems sufficient to have an impact on their quality of life, which need assessment and monitoring. And 20 years after cancer treatment, 5-10 per cent will have complicated problems that significantly affect quality of life and need multidisciplinary assessment and case management. For example, people who have been treated for breast cancer are more

likely to develop heart problems, and men treated for prostate cancer are more at risk of osteoporosis, bone fractures and chronic illnesses. Survivors of pelvic cancers, including colorectal, bladder and gynaecological, have an elevated risk of sexual, urinary and bowel symptoms.

Jane Maher, Macmillan Cancer Support's chief medical officer and national clinical lead for NHS Improvement, says: "Bowel symptoms are a particular problem. You have probably got the same number of people with problems as you have got with inflammatory bowel disease, but you have no services or infrastructure or guidelines to support them," says Professor Maher.

Problems may emerge months or years after treatment so neither the patient nor their doctors associate them with previous cancer treatment. As GPs rarely code cancer treatment in electronic patient records, the potential association is not flagged up and records cannot be used to estimate the incidence of the problems.

Even when the link to cancer treatment is made, there is no guidance for GPs on managing these patients and no specialist care planning for people with complex problems.

The Royal College of Radiologists has undertaken an audit of patients who



received pelvic radiotherapy for cancer of the cervix, which shows that five years after treatment 5-10 per cent experience severe complex problems. And the Department of Health has commissioned the British Society of Gastroenterologists to produce guidelines, due to be published in April, on how pelvic cancer survivors with bowel symptoms should be managed.

In addition, Macmillan is linking with the US initiative Livestrong OncoLink, which enables patients to access information on potential consequences of treatment they should look out for by designing their own treatment summary and care plan online.

Professor Maher says: "Preventable consequences need to be avoided by access to the safest and most effective treatments, but where they can't be prevented they need to be acknowledged.

"The vision is that the consequences of treatment are acknowledged and therefore described, measured, coded, enumerated and routinely reported. Where adverse consequences cannot be prevented, effective and accessible services are available for all patients to reduce functional impairment and alleviate distress, and the nature and content of services provided are matched to need using stratified assessment tools."

The National Cancer Survivorship Initiative is working with the National Cancer Intelligence Network to map the survivorship journeys of cancer patients to quantify the risk of recurrence and late effects of treatment. The aim is to develop a tool or framework to aid planning of

## BIRMINGHAM CHILDREN'S HOSPITAL: NEW MODELS OF FOLLOW-UP FOR CHILD SURVIVORS

This test site is looking at three models of long term follow-up in which child cancer survivors are risk stratified for risk of recurrence and allocated to three follow-up regimens:

- A postal service in conjunction with the West Midlands Regional Children's Tumour Registry for low risk patients to assess how patients are coping
- Nurse led follow-up clinics for medium risk patients who, because of their treatment and

their conditions don't need medical follow-up

- Consultant led follow up for the patients with the greatest needs.

Analysis has revealed that around 10 per cent of child cancer survivors in the region are lost to follow-up services, which is lower than national figures. Researchers are tracking these patients to find out if there are specific reasons why they have been lost to the system, which can then be addressed.



follow-up care. The specific type of cancer and treatment received will be taken into account, along with lifestyle factors and concurrent conditions to determine the patient's predicted needs. This will enable tailored information and support to be provided to patients and better enable commissioners to gauge the likely demand for specialist services.

A separate risk stratification is being undertaken for children and young people because they have additional needs. Long-term effects are particularly relevant to child survivors. Two-thirds of children treated for cancer will develop some sort of chronic illness within 10 years and, because they were treated at such a young age, they may also experience more problems than adult cancer survivors.

Hearing problems, heart problems, endocrine changes causing weight changes and fatigue, and reduced fertility are all long term physical effects affecting child cancer survivors. They may also experience psychological effects as they grow older. There may be body image issues – which will be especially pronounced during puberty and young adulthood – due to scarring, short stature or hair loss.

There is also the psychological impact of the trauma itself, and the weeks and months of treatment that took them out of school, which can affect their career and economic prosperity. Lower than anticipated academic results may affect their ability to go on to further education, and gaps in the CV may affect entry into employment.

Patricia Morris, NHS Improvement director cancer, says although these issues are well recognised by paediatric services, as they grow older some children and their families may not receive the support they require. Around 40 per cent of child survivors lose contact with cancer services because they have moved home, feel they do not need follow-up any longer, have had enough of hospitals or just want to get back to as normal a life as possible. When this happens there is a greater risk that potential late effects will not be picked up, so it is especially important that child survivors have a comprehensive care and treatment plan accessible to their GP, other health professionals and the patient themselves.

A plan developed by Great Ormond Street Hospital for Children Trust and The Christie Foundation Trust is being tested. It is a comprehensive summary of all treatment received – the type, intensity and number of sessions of radiotherapy, surgery and chemotherapy regimes – and all the potential risks. The Yorkshire Cancer Network is testing an IT version of the plan, which would ensure the most current information was included and accessible.

“There must be that continuity, something written down and comprehensive, so that it is not lost,” says Ms Morris. “Some issues will become more prominent and be of more concern as these patients get older. A 13-year-old child may not be that conscious of asking questions about their fertility, but as they reach 20 or 25 that might become a big issue.” ●

## VOCATIONAL REHABILITATION

A third of cancer survivors are unemployed and while 83 per cent return to work, more than half are off work for at least six months. Few receive any medical or rehabilitation advice. There are 774,000 working age people with cancer in the UK and less than half have been advised by their doctor about the impact of their treatment on their work. Half have not been offered flexible working arrangements and 80 per cent of employers are not aware that cancer is covered by the Disability Discrimination Act.

Fatigue, reduced cognitive functioning or reduced freedom of movement can impact on a survivors' ability to return to work. Low self esteem and anxiety about finances can change how a survivor sees themselves – this can exacerbate depression and anxiety.

Lyn Bruce, vocational rehabilitation project manager at the National Cancer Survivorship Initiative, says rehabilitation is no optional extra and vocational rehabilitation should be a key part of this for people of working age. However, it does not get a very high profile.

She says cancer survivors need information, and in some cases referral to support or specialist services, to enable them to continue at work or to return to work. It may be that the survivor will not be able to work at the same intensity, need aids or adaptations, or to work more flexibly or in a different role.

Existing generic government programmes supporting people to return to work, such as Pathways to Work, are generally for people who are either on long term incapacity or other benefits. So there is a gap in support for people who want to continue to work or are not eligible for benefits.

The NCSI has developed a four stage model for vocational rehabilitation for cancer survivors (see below) and has invited proposals for taking these forward.

## FOUR STAGE MODEL FOR VOCATIONAL REHABILITATION

**1** Information and support through electronic and printed mediums for survivors, employers and union reps

**2** One-on-one support and signposting through telephone helplines and digital mediums

**3** Self-management programmes accessed during or after treatment

**4** Specialist vocational rehabilitation services (psychological support, etc)

# GOOD DAY?

When you're living with cancer, the good days really matter. The day you got something sorted out. Finally got some answers. The day you just had a chance to talk about what was on your mind. And felt better for it. At Macmillan we have a team of cancer support specialists whose role is simply to help you have more of the good days. Answering your questions about cancer. Helping you sort out your money worries. Or just being there for a chat, when it's not such a good day. All you need to do is give them a call. Why not do it today?

For answers, help or just to chat about your day, call us free on **0808 808 00 00** (Monday to Friday, 9am - 8pm)  
Or visit us online, anytime at [macmillan.org.uk](http://macmillan.org.uk)

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