CANCER SURVIVORSHIP

Supporting the two million people living with or beyond cancer
Two million people in the UK are living with a diagnosis of cancer. Some will have been recently diagnosed, so will be in shock and heading for active treatment; some will be approaching the end of their life; some will have practically forgotten they have had a cancer diagnosis; and others will be living with late effects – the consequences of the disease or its treatment.

The survivorship agenda is about saying we must help people not just at the time of diagnosis, treatment and end of life but through the whole journey. This help should not be limited to medical issues; it should mean supporting people with any emotional, practical and financial issues their cancer has caused. It is about supporting the whole individual.

Nurses are particularly tuned into this area. They understand that the person is being treated, not just the tumour. When someone of working age is diagnosed with cancer, their household income typically halves. Nurses often pick up on this, but they don’t – and probably shouldn’t – have detailed knowledge of welfare benefits. However, they should be able to refer individuals for expert advice. Macmillan has been putting such advisory services in place. Forty per cent of cancer survivors say they feel abandoned when they finish active treatment. They should not feel like this. We need to find ways to support them and their families at this transition point and later on, when some of the late effects of the cancer or its treatment may rear their heads.

The National Cancer Survivorship Initiative (NCSI) in England is considering how people’s needs should be assessed at this transition. This assessment should cover medical need and consequences of cancer or its treatment that may need to be addressed in future – how they could be identified and self-managed as appropriate and how people could get back into the system quickly if necessary.

Nurses responsible for this care planning would also discuss any practical needs a person might have and the impact cancer may have had on their emotional life, finances and ability to work, and refer them to support services.

Returning to work after cancer treatment can be difficult because of fatigue and loss of self-confidence. The NCSI is working with trade unions and employers on supporting people back into work gradually. The average GP sees around eight cancer diagnoses a year, while large HR departments see many more, and have valuable experience to share. Scotland, Wales and Northern Ireland are also addressing rehabilitation and returning to work.

While we know that two million people are living with cancer, we do not know how many have which type, how many have emotional issues or late effects, or how many are well. Research is being conducted in all four UK nations to determine this and the number of people likely to experience some consequences of treatment many years on and need access to services.

For example, the GP research database shows that women treated for breast cancer are more likely to experience cardiac problems later. They need to be informed of this higher risk, so they are aware of symptoms and how to deal with them, and of lifestyle interventions to minimise their risk.

There is no point diagnosing problems if we do not develop solutions. We need to identify interventions that make the difference between people having a good quality of life and being able to self-manage or being in distress, unable to work or perhaps returning to hospital.

We must test, evaluate, prove and roll out existing models of support and care and develop and evaluate new ones to give nurses validated tools, techniques and practices. This will also help ensure uniform access to services in the UK.

We must not underestimate the learning and development that will be required for new models and services. These will create learning needs not only for cancer nurses but also the wider nursing workforce. Macmillan will increasingly be focusing on supporting nurses to develop themselves and their job skills.
People feel ‘abandoned’ after treatment, but plans in the UK nations aim to tackle this. By Ingrid Torjesen

Cancer survivors have finished primary treatment and are living with or beyond the disease. At this point, many say they feel ‘absolutely abandoned’, says Steve Hindle, cancer survivorship programme lead at Macmillan Cancer Support.

Some will be offered a place on a self-management course or directed towards or find support groups, but many will try to cope on their own with issues such as fear of cancer recurrence and worries over money and returning to work.

Macmillan wants every patient to have an assessment at the end of their initial treatment that looks at all aspects of their life, not just medical needs, and a care and support plan drawn up. ‘This will require an integrated approach to information and support, self-management and health and social care services,’ Mr Hindle says. ‘If assessment was carried out now, we would have no real confidence that all the necessary services would be there.’

Nurses know this. A survey by Nursing Times this year found that 83% believe that survivors’ needs are not met, 72% think services to help survivors adjust to practical and emotional after-effects of treatment are insufficient, and 61% do not think survivors’ needs for services are adequately assessed.

Over 900 nurses responded to the survey. Around 40% believe that health staff need training to help them support survivors and a similar number believe survivors need better tools and information to help themselves.

Just over one-third of respondents work in specialist cancer services, yet only around 40% of the sample think they had received adequate training to help them support people with cancer; 58% had received specific training but fewer than two-thirds of these considered it adequate. And nurses want information to help them support survivors and carers (see chart).

While most nurses saw carers’ needs as part of their job, fewer than two-thirds knew of services specifically designed for carers.

Two-thirds of nurses would approach a specialist nurse or local cancer services for information on care for survivors and 87% would contact Macmillan Cancer Support.

According to respondents, specialist cancer services and GPs should be primarily responsible for meeting survivors’ needs, followed by community nurses and charities such as Macmillan Cancer Support.

After intense lobbying from organisations such as Macmillan, UK governments are beginning to recognise that cancer survivors need more support and each of the four nations has begun to make progress on this. England set up its National Cancer Survivorship Initiative in 2007. Its steering group, co-chaired by Ciarán Devane, chief executive of Macmillan Cancer Support and Professor Mike Richards, the national clinical director for cancer, is looking at issues important to survivors’ and carers’ quality of life. These include information and support, post-treatment care planning and late effects of treatment.

The NCSI is working on a vision document with the ambition that by 2012 survivors will receive the care and support they need to lead as long, healthy and active a life as possible.

Workshops have been held to gather survivors’ and carers’ views, pilots on post-treatment services began in September in partnership with NHS Improvement. Integrated care and support will be required from a range of bodies, including health and social care, the voluntary sector, employers and education.

In its 2007 strategic framework Designed to Tackle Cancer in Wales 2008–2011, the Welsh Assembly Government said it was necessary to assess the needs of cancer survivors.

Macmillan surveyed and brought together survivors to determine their emotional, practical, financial and psychological needs and how they might be met. It hosted an event with representatives of the Welsh Assembly Government, the NHS, local government and the voluntary sector to agree a way forward. Wales survivorship lead and nurse Gillian Knight unveiled her recommendations in March.

Scotland acknowledged the need to support people living with or beyond cancer in its action plan Better Cancer Care published last year. As well as setting up a national steering group to look at cancer issues, including survivorship, Scotland has recognised the importance of benefits and financial advice services by giving Macmillan £500,000 to provide access to such services across Scotland.

Northern Ireland is to publish a cancer service framework in the spring, and Macmillan has been working to ensure it addresses the issues facing people living with or after cancer, including information and support, and benefits and financial advice.

### Training needs: % of nurses who want training on different issues facing survivors

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<thead>
<tr>
<th>Training Topic</th>
<th>Training Need</th>
<th>Percentage</th>
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<td>Assessment and planning care for primary cancer treatment</td>
<td>66%</td>
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<tr>
<td>Long-term effects of cancer treatment and how to manage them</td>
<td>71%</td>
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<td>Emotional problems associated with cancer survival</td>
<td>66%</td>
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<td>Effect of a cancer diagnosis on work life and finance</td>
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<tr>
<td>Needs of carers</td>
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<td>Long-term effects of childhood cancer</td>
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<td>National initiatives to address the needs of cancer survivors</td>
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<td>Services available for cancer survivors</td>
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Follow-up services for cancer survivors need a radical shake-up, according to Macmillan Cancer Support.

The charity believes that follow-up services must be more targeted at those people who are in most need, while ensuring that anybody can get back into the system when they need to. Survivors will have care plans that meet their clinical, informational and emotional needs. This will enable them to self-manage their condition as fully as they wish to.

‘Follow-up is currently seen by patients as the way that any recurrence of their cancer will be detected,’ says Stephen Hindle, cancer survivorship programme lead at Macmillan Cancer Support. ‘The reality is that the vast majority of recurrences happen between follow-up appointments, patients spot something different with their body, and they need to be able to get specialist services immediately.’

‘We would like to see a system of prioritisation, called risk stratification, where patients who are most at risk, both clinically and emotionally, are given more support but that everyone is supported to the level that they need.’

Macmillan wants all patients to receive a standard assessment at the end of treatment that looks across all the domains of a patient’s life. This would lead to a survivorship care and support plan, which would be revised on a regular basis. This would address any clinical needs, identify any emotional or practical support required and refer the survivor to a self-management programme, highlighting appropriate support groups. It would also assess the carers’ needs.

Cancer survivors say they need support dealing with practical difficulties, advice on benefits and returning to work. They want more information about the effects of cancer on their sexuality, libido and body image, and also need support on handling relationships with their partner and/or family. Macmillan wants nurses to be able to signpost survivors to such information.

A survey by Macmillan found that only a small proportion of managers realise that the Disability Discrimination Act applies to people who have had cancer. While most managers want to support people with cancer, the majority don’t know what to do for the best. Macmillan is working with vocational rehabilitation organisations to develop guidance for employers and on a possible national vocational rehabilitation scheme.

Incorporating a self-management programme into follow-up not only enables survivors to make as many of their own decisions as possible, it also acts as a support network. ‘Self-management can empower people to take more control of their lives, and to minimise the fear and anxiety that some people feel,’ explains Mr Hindle. ‘One of the real issues for people is that because they know they have had cancer, any pain or symptom makes them fear that it is metastatic disease that has spread. It is a hugely worrying time for people.’

As adverse effects of treatment may only become apparent many years later, any information patients have received at diagnosis and treatment is likely to have been forgotten. Macmillan wants to see information-sharing improved and a system developed where the treatment the patient has been through, and its potential consequences, is flagged with the GP.

Some groups, including children, adolescents and young adults, have very specific needs. These include how to maintain or get back into education and issues around self-image and confidence, as looking different and not being able to join in can be especially difficult for them. Fertility issues may also be more relevant as well as the potential long-term effects of treatment.

Mr Hindle says young people need support in getting their first job. ‘It’s hard to find work when you have had cancer, even harder when you’re looking for your first job.’

Cancer survivors have highly specific needs, and follow-up services must address these, says Ingrid Torjesen

‘One of the real issues for people is that because they know they have had cancer, any pain or symptom makes them fear that it is metastatic disease. It is a hugely worrying time’
Hilary runs an IT department and was diagnosed with breast cancer in 2006. She had a breast mastectomy, reconstructive surgery and radiotherapy.

As a civil servant her employer had set policies on how she should be treated at work.

‘Interestingly, I wasn’t treated as well as some would have been because my boss had her breast cancer before me,’ Hilary explains.

‘You might expect that might mean she would actually be better with me, but she had gone into secondaries at the time I was going through primary. Either she didn’t want me too close to her experience or my experience was too close to hers – or possibly both.

‘I think it was a difficulty for her line manager to realise whether she was actually capable of dealing with the situation – probably they should have separated us because it must have been very hard for her.’

As a single mother of two sons aged 17 and 19, she found it difficult to cope.

Even though breast is a common form of cancer, Hilary found it very hard to access local support services. The nearest had closed down, the next nearest closed while she was ill and all the others seemed to take place during the day when she was at work.

One did telephone was focused on the emotional side of things rather than the practical side that she actually needed.

‘I tried to contact the PALS people to get some help and it was a couple of weeks before they got back to me, by which time I was pretty much on the mend and really didn’t need it,’ she recalls.

During radiotherapy Hilary got very bad chest pains and does not know whether this was owing to the implant or because she was doing too much.

‘If you are tempted to do something when you don’t have support, you don’t know what damage you are possibly doing yourself in the longer term,’ she warns.

Melanie was just 20 when diagnosed with mouth cancer in December 2005. She had an operation to remove the tumour and a bone graft was taken from her hip to replace some of the tissue removed.

As a single mother of a 15-month-old daughter she insisted on leaving hospital just 10 days after surgery due to childcare issues. ‘I just wanted to go home for her but in all honesty I knew I wasn’t well enough. I couldn’t speak and I couldn’t walk properly. That first night I was on my own literally with my baby and it was very difficult,’ she says.

Her daughter had a place at a nursery, open 8am to 6pm, which was invaluable when Melanie began a six-week course of radiotherapy. She drove every day from her home in Croydon to Guy’s and St Thomas’ in central London.

‘If it was rush hour and I got on the train I was conscious of not being able to get a seat. I still wasn’t good on my feet and my hip would play up,’ she explains. ‘I was also conscious of what I looked like. I had had major surgery to my face, it wasn’t as though I could hide it and people stared.’

Every time the radiotherapy nurses asked how she was feeling, Melanie said everything was fine – but it wasn’t.

‘During the last few days of radiotherapy I got really ill,’ she recalls. ‘I couldn’t get myself to the hospital because I was in so much pain. I had severe ear ache and you are not supposed to drive with an ear ache – I had to ask for help.’

The hospital contacted adult social services but the help given was limited. ‘Social services would only help me, they wouldn’t help my daughter,’ Melanie says.

‘A carer was organised and she would come round and do my ironing and cleaning. Really what I needed was someone to bear the burden of picking up my daughter so I didn’t need to worry about it.’

Melanie had reconstructive surgery to her face in June 2006 and started university that September, but is worried about finding a job when she graduates this summer.

‘My confidence has gone now. It is on my mind and I don’t think it should be as you need to be quite positive. I have survived and I am not completely un-understandable,’ she says. ‘Everyone likes to think everything is politically correct but there is prejudice.’

Melanie does not think she has recovered emotionally from the changes to her looks and voice. ‘I think I suffer with relationships and building friendships,’ she says, adding that relationships suffer because she is afraid to have any more children.
HOW CAN NURSES SUPPORT SURVIVORS?

As survivor numbers grow, specialist services will need support in meeting their needs, says Ann Shuttleworth

People with little personal or professional experience of cancer services might assume that moving on from active treatment and into life as a cancer survivor is a cause for celebration. However, cancer specialist professionals, patients and their families know that the situation is not so clear-cut.

‘Sometimes it’s easy for professionals and carers to think: “But you’ve been lucky, you’ve survived and there are people much worse off than you”,’ says Jacqui Graves, Macmillan development manager for Thames Valley and Northamptonshire. ‘But patients aren’t comparing themselves with other people – they are comparing themselves now with themselves before cancer.’

Having previously worked in head and neck cancer, she cites this group as an example.

‘Around half of people with head and neck cancer survive but these tumours can leave patients with huge issues,’ she explains. ‘Many have their tongue removed or end up with disfigured faces, which are extremely difficult to come to terms with. They may be unable to kiss or eat, they may never regain intelligible speech. They go through a bereavement process like people with severe burns do, and some just can’t get over their experience.’

People receiving active treatment for cancer have a clear focus – they want to successfully complete their treatment. They are receiving regular and intensive professional support, and most will also have the support of family and friends.

As treatment ends, survivors can experience a range of negative emotions and practical challenges, yet their first follow-up appointment may be months away. There is increasing acknowledgement that patients, cancer is becoming a long-term condition rather than a death sentence.

‘Patients don’t compare themselves with other people – they compare themselves now with before the cancer’

‘To date there have been clear treatment care pathways and a clear end-of-life care pathway is emerging, but now we are identifying what a survivorship care pathway looks like,’ says Ms Graves.

As with many long-term conditions, nurses will have the opportunity to play significant roles in this pathway.

‘To date there have been clear treatment care pathways and a clear end-of-life care pathway is emerging, but now we are identifying what a survivorship care pathway looks like,’ says Ms Graves.

Survivors can have a range of needs, depending on individual circumstances, but they can include needs for support in:

- Coming to terms with what has happened to them and how their lives have changed;
- Coping with changes in relationships;
- Dealing with employers and returning to work;
- Accessing benefits or sources of financial advice.

While they can address these support needs, short programmes provided by some cancer services are offered at a specific time and delivered over a short period. However, when cancer is a long-term condition, patients’ needs will change over time. With an established care and support pathway, services could be provided in settings such as primary care, enabling patients to access them as needs arise.

Ms Graves believes primary care teams will increasingly take responsibility for the long-term management of people living with and beyond cancer. ‘They will increasingly receive yearly follow-up from primary care teams in much the same way as people with diabetes, asthma and other long-term conditions,’ she says. ‘Primary care needs to start taking responsibility for this group of patients rather than deferring to the specialists.’

And with clear care pathways and referral criteria to ensure patients return to specialist services where necessary, nurses are well able to take on this work. They are accustomed to providing monitoring and
follow-up, and using protocols that enable them to refer patients for medical assessment or back to specialist services.

As a high-quality survivorship pathway is developed, assessment and care planning will be as important at the end of treatment as it is at the beginning.

‘At the end of active treatment there needs to be an end-of-treatment assessment to identify patients’ ongoing needs, problems and issues and to implement a survivorship care plan,’ says Ms Graves.

And care plans that involve non-specialist services mean clear channels of communication between cancer services and other settings will also be vital to ensure patients have access to the support they need as they move out of active treatment – and that they receive prompt referral back into specialist services if necessary.

Once a survivorship pathway is established, primary care nurses may well run group programmes similar to those currently run by specialist services. If so, they may benefit from involving other professionals in developing and/or delivering the content. Penny Boon (pictured below), who helps to run the Moving On With Confidence programme at Buckinghamshire Hospitals NHS Trust, believes interprofessional working is worthwhile.

‘We were very fortunate to work with the Macmillan clinical psychologists in developing our course,’ she says. ‘They helped to ensure it really addresses the emotional issues patients face.’

But patients may experience a wide range of needs, and nurses may not be the most appropriate people to address them. Instead, their role may involve identifying needs – or helping patients to acknowledge them, and to refer them to other services.

‘Nurses can’t be expected to know everything about these areas so they need places to refer patients to,’ says Ms Graves. ‘For example, we need vocational rehabilitation advisers. They will know employment law and be able to have a conversation with employers.

‘We know cancer survivors’ energy and concentration span reduce while they are receiving treatment, and they don’t always come back. Patients often tire easily and it difficult to retain information, so they may need to go back to work part-time or even into another role within the organisation. It’s not just about getting them a pay-off – we want them back in work.’

In some cases patients may need help to move into a new career. In such cases vocational support may be an obvious need, but they may also need emotional or psychological support – particularly if they are unable to return to a career they loved.

Where patients experience emotional problems related to any repercussions of their illness, they may need referral for counselling or other psychological therapies. They can also be advised to seek support from services such as Relate if they have relationship difficulties.

However, Ms Graves points out that this will be a very new way of working for most nurses, and they will need training to deliver a survivorship care pathway. This training will enable nurses to develop the skills to raise difficult issues such as psychosexual or relationship problems sensitively so that patients feel able to discuss them. It must also enable nurses to know when they can support patients themselves and when to refer them elsewhere for more specialist input.

But one of the key changes required in nurses and other healthcare professionals – in both acute and primary care settings – is a shift in attitude. They need to learn to see that cancer can be a long-term condition, and that cancer survivors have needs that go beyond simply monitoring them for a recurrence of their disease.

Moving On With Confidence is a six-week course run at Buckinghamshire Hospitals NHS Trust for people who have finished active cancer treatment. It was developed by Macmillan clinical psychologists Denise Cottrell and James Parker and Macmillan cancer education and information facilitators Penny Boon (pictured p7) and Liz Turnbull (pictured p6).

The Macmillan-sponsored course aims to enhance coping skills and well-being, and is open to survivors of any form of cancer. The first was run in late 2007.

‘We decided it should run as a course rather than sessions that people could pick and choose from as we felt this would help give people the confidence to open up,’ says Ms Boon.

‘People need to develop trusting relationships if they are to discuss difficult issues, and this may not happen if they see different people in each session.’

The two-hour sessions begin with lunch, and cover a range of subjects to help group members identify their responses to stress and give them practical and emotional coping strategies. If necessary they are referred on to other services such as counselling or psychology, or signposted to relevant support groups at the end of the course.

Evaluations of the first two courses were extremely positive, with members commenting that they were both enjoyable and helpful, and that they had appreciated the opportunity to meet others in similar situations to themselves.
Give a man a fish and you feed him for a day. Teach him how to fish and you feed him for a lifetime.

It’s an oft-cited quote but, when it comes to self-management in health, it could not be more apt. Self-management was developed around 20 years ago by Professor Kate Lorig, of the Patient Education Research Centre at Stanford University in California, to help patients manage long-term conditions such as diabetes.

Increasingly, health professionals and patients are realising its potential for other illnesses, not least cancer.

In 2003 Macmillan launched Living with Cancer. This course teaches people to manage their conditions using five core skills: problem-solving; decision-making; making the best use of resources; developing effective partnerships with healthcare providers; and taking appropriate action (Lorig, 2007). Macmillan is to launch a new version of the course called New Perspectives. It will still be based on the Stanford course, but will include cancer-specific issues raised by past participants.

Courses usually comprise six weekly sessions, run by volunteer tutors with personal experience of cancer. They help participants discuss topics such as relaxation, diet, exercise, fatigue, managing pain and medication, and communicating with health professionals. Numbers are kept to around 12 and the meetings are highly interactive, focusing on building skills, sharing experiences and support.

The Lorig model is also used by the highly successful Expert Patient Programme (EPP), which is run in the UK for people living with long-term conditions.

A randomised trial carried out by the National Primary Care Research and Development Centre found that EPP course participants had improved partnerships with doctors, increased confidence in managing their condition and reported improved well-being and increased energy. Four to six months after the course, GP consultations had decreased by 7%, outpatient visits by 10% and A&E attendances by 16%.

The fact that self-management for long-term conditions has proved to be successful may well have helped put the conditions into the spotlight, with health minister Ann Keen recently announcing there will be personalised care plans for all such patients by 2010.

The same focus has yet to be applied to self-management for cancer survivors and few studies have tested its efficacy.

‘There have been so few behavioural interventions for people with cancer that we really

Self-management for survivors

After treatment finishes, cancer survivors need empowerment to ensure they remain healthy, reports Jo Carlowe.
do not know,’ says Professor Lorig. She intends to begin studying this within a few months. Courses like Living with Cancer remain few and far between. ‘After treatment, a lot of people are simply given the name of a specialist and fall out of the system,’ says Lynn Batehup, project manager of the National Cancer Survivorship Initiative’s self-management workstream. She believes that cancer survivors should have the same access to self-management courses as people with long-term conditions. When asked whether self-management is relevant to cancer survivors, Professor Lorig is unequivocal. ‘Absolutely. The diagnosis puts a whole new light on the future,’ she says. ‘People can live in a grey area after an acute illness as they don’t have a chronic illness but may have long-term side-effects of the cancer and its treatment. In addition, there are years – if not a lifetime – of follow-up, which brings its own fears and anxieties. How well someone gets on with life after cancer treatment depends to a great extent on how they self-manage all these life changes.’

‘Cancer can be both an acute condition and a long-term condition’

Yet many health professionals remain unclear about the meaning of self-management, and while we have focused very much here on self-management education, we need to be clear that self-management support is much more than that. Often it is confused with patient education, which is more paternalistic. ‘Patient education usually means information transfer given in a didactic approach, run by a trust or hospice and, of course, it has its place,’ says Batehup. ‘However, self-management involves no transfer of content as participants are the ones who raise the issues and share their problems and goals.’

So, for example, instead of giving out handouts, the course facilitators may say where people can access the information themselves. The aim is to ‘empower patients’. Ms Batehup says this includes teaching people to take a more active role in discussing and monitoring medication, monitoring side-effects and knowing when to report them, understanding when things are getting worse and learning to cope psychologically.

‘It’s also about role-modelling. These courses are not run by professionals – the facilitators are people with the condition themselves. It is also about peer support. Around 70–80% of people who attend the courses stay in touch, meeting regularly for coffee to discuss how they are getting on.’

The empowerment of patients throughout their cancer journey is part of the government’s Cancer Reform Strategy. As part of this, last year the National Cancer Survivorship Initiative was launched, informed by a ‘think tank’ event organised by Macmillan Cancer Support. NCSI aims to enable people with a cancer diagnosis to lead as healthy and active a life as possible. This will include pushing for survivors to have the same access to self-management courses as people with long-term conditions, with self-management integral to service provision and underpinned by commissioning.

A possible short cut to this could be for cancer itself to be dubbed a long-term condition. Professor Lorig explains: ‘Cancer can be both an acute and a long-term condition. There are forms of cancer where people are in a watch-and-wait state for years and years without treatment and then there are treatments that go on for years and years. For everyone who has ever had cancer, there are years of follow-up.’

Ms Batehup says: ‘We are grappling with the issues about the benefit of cancer being called a long-term condition. We need to encourage commissioners to think about self-management for cancer.’

If classifying cancer as a long-term condition means that more cancer survivors learn to self-manage, it seems that few people will argue over semantics. ‘It has taught me to find out what the problem is and to think “what can I do?”. I was poorly and it has helped me to get back on track.’

Christine McGowan (left and above, with husband Stewart), aged 60 from West Yorkshire, attended a Living with Cancer course following treatment for non-Hodgkin lymphoma. ‘It was very good – we covered things like dealing with stress and how to deal with not being as active as before. It was run by two ladies who were brilliant. ‘We had a laugh, although some of it was serious. In one session, the women asked if we had made a will. Out of 12 people only one of us had. That was quite upsetting. One young girl got up and walked out but she came back. ‘We still meet up ourselves every couple of weeks. ‘The course taught me to tackle the way I talk to health staff. In the past, if they said: “Are you alright?” I would say “yes” even if I wasn’t. ‘It has also taught me to play a more active and equal role in managing my health. So, if given a prescription, I will ask the person to talk through it and I will check if everything is necessary or whether I can cut down on some of the medication. ‘It has taught me to find out what the problem is and to think “what can I do?”. I was poorly and it has helped me to get back on track.’

Reference
LONG-TERM EFFECTS OF

The end of treatment can sometimes herald the onset of other problems requiring support, says Emma Baines

The number of people in the UK who have had a diagnosis of cancer at some point in their life has reached two million and increases by 3% each year, according to figures collected by Macmillan Cancer Support.

One reason this figure is rising is that many more people with cancer are surviving, thanks to screening, earlier diagnosis and new treatments.

Jessica Corner, chief clinician at Macmillan Cancer Support and head of the School of Health Sciences at University of Southampton, says that although it is undoubtedly good news that more cancer patients are surviving, for many the end of treatment marks the beginning of a period of poor physical or emotional health that can continue for years.

She adds that the impact of cancer treatment on patients’ lives could be compared with having a long-term condition.

‘We think probably 20–30% of people treated for cancer have quite serious long-term effects, amounting to a disability,’ she says. ‘And one in six people are unable to work.’

Although long-term physical and emotional effects from cancer treatment are known to be common, Professor Corner says very little research has been done on this area so the exact figures are not known. ‘The focus has been on treating the cancer and, until now, not enough attention has been paid to the long-term consequences of having cancer,’ she says.

The National Cancer Survivorship Initiative being developed by Macmillan in partnership with the Department of Health in England will, hopefully, lead to a better understanding of the long-term problems survivors can experience, and will test systems of care and support to identify how these should be provided.

The physical problems patients develop as a consequence of cancer treatment vary according to whether they have received radiotherapy, chemotherapy or have undergone surgery.

Some are worst in the first few months or years after treatment and may improve over time. However, other problems will not appear for years. In addition to these physical problems, emotional problems such as depression are common.

Patients who have undergone chemotherapy suffer systemic effects. In the period immediately after treatment, fatigue is common, as well as an inability to concentrate for extended periods – an effect commonly known as ‘chemo-brain’.

‘It can take months for that to get better, and people are often not warned about it,’ Professor Corner says. These symptoms may be eased through specially designed exercise programmes, but these are not widely available.

In the longer term, patients who have had chemotherapy may develop serious conditions including osteoporosis, heart disease and even second malignancies, such as myelodysplasia and leukaemia.

Radiotherapy can cause a number of problems, depending on which part of the body was treated. In the short term, fatigue and skin sensitivity often occur.

In the longer term, patients who have had pelvic radiotherapy can develop problems affecting the bladder and bowel, fertility and sexual function, while those given radiotherapy for breast cancer are more likely to develop frozen shoulder, as well as chest and lung problems.

Another common consequence of radiotherapy is lymphoedema. This tends not to develop immediately, but can appear years after treatment. Although it cannot be completely cured once it is established, the swelling can be treated with massage techniques, exercises, bandaging and compression garments. The earlier treatment is started, the more likely it is to be successful, so it is important that patients who have been treated with radiotherapy know who to contact if they notice even mild swelling.

‘Patients should be warned that it can happen,’ Professor Corner says. ‘It’s something that primary care should keep an eye out for in patients who they know have had radiotherapy.’

Patients who have had surgery for cancer often continue to suffer from pain for a long period afterwards. They can also develop lymphoedema. Many have a functional disability after having a limb amputated or an organ removed, such as a permanent colostomy after undergoing bowel resection for colorectal cancer.

One of the keys to reducing the impact of long-term effects of cancer treatment on patients’ lives is to make sure that they are fully informed of the possible treatments available and that their physical and emotional needs can be met.
consequences of treatment from the outset. They need to be given more information not only about what effects to expect but also on self-management strategies. Professor Corner believes nurses are in an ideal position to do this.

‘Nurse specialists in particular have a very important role to play,’ she says. ‘They should be making this part of their routine care for people with cancer. Right from diagnosis through to the end of treatment, they need to be preparing the patient for what’s ahead.’

Macmillan is advocating an end-of-treatment assessment to be given to all cancer patients to determine what physical effects they might develop and to put in place a care plan for them. Professor Corner adds that nurses carrying out this assessment would be well placed to prepare the patient for the emotional, physical and social adjustments that they will have to make.

‘There are always going to be adjustments,’ she explains. ‘Families may have expectations of patients getting back to normal much more quickly than they probably will.’

Nurses carrying out this assessment should look out for signs and symptoms of depression, and ensure that patients have access to any appropriate mental health care.

‘When the support that they were receiving from specialists and others who they were seeing regularly within the healthcare system is taken away, many patients can feel quite abandoned and at a loss to know what to do. The assessment at the end of treatment needs to look out for that,’ says Professor Corner.

‘Sometimes just telling patients about the risk can make them feel better’

‘Patients need to recognise that they could possibly suffer from a low mood or other emotional dysfunction, and if they do they should seek help. Something like a short course of cognitive behavioural therapy can make a huge difference to people and prevent them developing long-term serious problems.

‘Sometimes just telling patients about the risk can be enough to make them feel better,’ she says. Also at the end-of-treatment assessment, patients should be put in touch with support groups and centres and given information about where they can access further help and advice on what they might be experiencing.

In addition, they should be encouraged to further develop their relationship with their GP and to get in contact with their primary care services if they are suffering any symptoms that could be effects of treatment.

One of the problems that many cancer survivors face in dealing with the long-term effects of cancer treatment is the fragmentary nature of the care they are given. This can be addressed by improving communication between secondary and primary care to ensure the patients’ GP and the wider primary care team are fully informed of the specific treatment the patient has received, as well as the possible late effects that may be associated with it.

Professor Corner says: ‘The GP is very important because, by the time patients are developing some of these late effects of cancer treatment, they may not be connected strongly back into the specialist team. So it’s essential that GPs bear in mind that patients who have had cancer treatment even many years earlier might present with problems that are related to their treatment.

‘Nurses are very well placed for preparing patients for their future, and in providing support in the months or year immediately after treatment as a contact point to come back to, but in the longer term, then really it’s the primary care team who need to be aware of this and know what to do and where to refer people.’

LONG-TERM EFFECTS OF TREATMENT FOR COLORECTAL CANCER

Ian Rigby, aged 57, was formerly a head teacher in Surrey. He was diagnosed with colorectal cancer in 2003 and treated with a combination of chemotherapy, radiation therapy and surgery to remove tumours from his rectum and liver. By the end of 2004, his treatment was finished and he returned home with a good prognosis. He is monitored every three months with colonoscopies and scans. Although Mr Rigby went back to work in January 2005, over the following six months he started to experience fatigue. This made going about his normal life hard and working became too difficult. In January 2006, he took early retirement. Since much of his colon was removed, Mr Rigby has a permanent colostomy. He received support and training in its management from colorectal nurses before he was discharged from hospital, and was visited twice at home to ensure he was coping. However, he has concerns about the management of his colostomy and worries about developing an infection.

In addition, a few months after treatment, Mr Rigby developed a peristomal herna, possibly because his abdominal muscles were weakened by multiple surgeries. This is being managed conservatively with support garments and he sees the colorectal nurses for regular check-ups. Although he is accustomed to managing it and has adapted to the adjustments to clothing and lifestyle required, he describes the herna as an ongoing problem. Peristomal herna is a common complication of colostomy in colorectal cancer patients, occurring in up to 30% of cases. It occurs because the stoma creates a weakness in the abdominal wall that allows the intestine to protrude through.

Nurses caring for patients with colostomy should advise them on steps for preventing hernaition, including avoiding heavy lifting for at least three months, wearing a support belt during exercise and doing exercises to improve abdominal muscle strength three months to a year after treatment.

‘When the support that they were receiving from specialists and others who they were seeing regularly within the healthcare system is taken away, many patients can feel quite abandoned and at a loss to know what to do. The assessment at the end of treatment needs to look out for that,’ says Professor Corner.
Carers can often feel like forgotten figures who do not receive the support they need. ‘There is a lack of recognition of carers. Health professionals tend to focus more on the patient, so sometimes carers don’t feel recognised,’ says Ms Argyle.

Mr Burton recalls: ‘Within an hour of diagnosis, my wife was supported throughout by the medical profession but, as carers, we don’t get support. We might be standing on the sidelines, but our journey is just as fraught.’

Lack of communication and information about the illness are among the problems carers face. There is also an assumption that they automatically know how to be carers, when often they are not equipped to deal with the clinical aspects involved.

Caring often means juggling work responsibilities. Even though carers have the right to request flexible working, many small companies are unable to grant this. Some will find a loved one’s health degenerates to the extent that they have to reduce their working hours or even give up their job. ‘Often if the carer can’t work, the household suffers, so financial worries can be a major problem,’ says Ms Argyle.

Mr Burton had to give up work to care for his wife, then spent his savings on equipping their house to meet her needs. ‘Now I’m penniless,’ he says.

The physical strain of caring can take its toll. A survey by Carers UK found that those caring for five years or more tended to have chronic conditions such as back problems. Mr Burton, who has developed chronic osteoarthritis, points out: ‘You you don’t look after your own health – it’s the price you pay for being a carer.’

Looking after someone with cancer can take a huge emotional toll, as Mr Burton explains. ‘I was an engineer, a problem-solver,’ he says. ‘But the minute your partner becomes sick, you become emotionally driven.’

Often, the effort to ‘put on a brave face’ can result in feelings of extreme isolation for the carer, he says. ‘While the patient is concentrating on getting well, as a partner, you’re asking: “What if they die? How will I cope? What do I tell my children?”’ he says. ‘I was trying to stay calm and upbeat. The strain is indescribable. It feels like you’re totally alone.’

The experience of caring often continues after treatment is finished, says Charlotte Argyle, Macmillan Cancer Support’s lifecare transition manager. ‘Some patients are considered to be cured, but might have disabilities or long-term care needs as a result of their illness.’

Alex Burton cared for his wife until her death eight years ago. She had primary breast cancer and secondary bone cancer for two years. ‘From the minute of diagnosis when I became a carer to her death, her needs and my situation as a carer evolved,’ he says.

38% of cancer carers spend more than 30 hours caring each week

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29% of cancer carers have been a carer for a person for over five years
61% have not received information, advice or support on emotional aspects of a cancer diagnosis

Nurses can help to alleviate this sense of isolation and play a vital role in supporting carers. Often patients are too ill to take in details about their condition, so, with their consent, carers ‘should be given as much information as possible’, Ms Argyle advises. She adds that those new to caring may not feel confident enough to deal with, for example, administering medication or delivering intimate care. Nurses should check this and offer information about organisations such as Macmillan Cancer Support and social services departments, which can support them. Carers often become closely involved in patient care so healthcare professionals should treat them as experts on the patient’s condition.

‘Nurses should involve carers in the planning and provision of care for the patient, and treat them as equals,’ she urges. It is also important to recognise that carers have different needs from patients, Mr Burton says. Nurses should try to establish carers’ practical and emotional needs and offer information or tell them where they can find support.

However, as Mr Burton points out, supporting carers is about more than giving out leaflets. ‘Sometimes, when you’re feeling strung out, a leaflet is the last thing you need,’ he says. ‘You want to talk to another human being about how you’re feeling.’

24% of carers feel abandoned

carer, you got through a real learning process. I was there at the end for my wife. I nursed her through to her last breath. These experiences changed my perceptions of life forever.’

Mr Burton is using his experience of caring to improve life for carers. He is setting up a support group and taking a carers support course. He would also like to see the role of ‘carer support specialist’ created to improve nurses’ understanding carers’ needs.

Nurses being aware that where there is a patient there is a carer can make a huge difference. As Mr Burton puts it: ‘The patient is always asked how they are. But it would be great if a nurse could turn around to the carer and say: “Hi, how are you today?”’

While acknowledging nurses are often pushed for time, he urges them to ‘spend some time with the carer – however little that may be’ to give them the opportunity to share their fears and talk through their concerns.

While caring can be physically and emotionally challenging, it can also be rewarding and fulfilling. For Ms Lilie, who lost her husband, work partner and best friend, ‘positive things have come out of extreme pain’.

‘I’ve become a fundraiser for Macmillan which has involved doing the Inca trail, taking a trip to Nepal and I’m running the New York marathon this year.’

Mr Burton says being a carer taught him a lot about himself. ‘You may think you know who you are but, when you become a carer, you’re feeling.’

ONE IN FIVE cancer patients felt that their carers’ needs were met by health and social care services

SOURCES OF SUPPORT

Macmillan Cancer Support
www.macmillan.org.uk
Provides practical, medical, emotional and financial support and campaigns for better cancer care

Macmillan CancerLine
Monday to Friday 9am-8pm
Freephone 0800 808 2020
Textphone 0808 808 0121
cancerline@macmillan.org.uk

Carers UK
Telephone 020 7490 8818
www.carersuk.org.uk
info@carersuk.org
Offers support, information and advice on all aspects of caring to carers and professionals.

CarersLine
Freephone 0800 808 7777
Wednesday and Thursday 10am-12pm; 2–4pm. Free advice service

Crossroads Caring for Carers
England and Wales
Telephone 0845 450 0350
www.crossroads.org.uk
Scotland
Telephone 0141 226 3793
www.crossroads-scotland.co.uk
Northern Ireland
Telephone 028 9181 4455
www.crossroadsireland.co.uk
Provides practical care and support in the home to give carers a break from their caring responsibilities

The Princess Royal Trust for Carers
London office: 020 7480 7788
help@carers.org
Glasgow office: 0141 221 5066
infoscotland@carers.org
Northern office: 01257 234 070
infochorley@carers.org
www.carers.org
Information, advice and support for carers

Carers in Cancer
www.carers-in-cancer.co.uk
Support group for carers

Three years ago, Fran Carter (pictured) and her husband Richard were looking forward to the birth of their second child. Then Richard was diagnosed with bladder cancer. Mr Carter had surgery and chemotherapy and was told he would not be able to have more children.

Mrs Carter had to look after her husband, three-year-old daughter and the new baby. She found being a carer ‘very isolating’. ‘You feel under pressure to be positive for the person who has cancer. While at the same time wondering how you’d cope if they died,’ she says. Mrs Carter’s Macmillan nurse put her in touch with a local support group, the Carers Centre for Brighton and Hove, which she found ‘hugely helpful’. ‘For every emotion you’re going through, someone in the group has been there before,’ she says.

Macmillan Cancer Support, the council and charities gave support including helping to pay for a roof repair and a weekend family break.

Nurses can help make life easier, Mrs Carter believes: ‘I know nurses are busy but, if they could talk and listen to carers – just for a few minutes – that would be really helpful. ‘If they could check we’re in contact with the right people to support us, such as a Macmillan nurse, and answer questions about procedures they’re doing – which we might need to do – that would make all the difference.’
SMOOTHING THE MOVE TO ADULT SERVICES

Planning the transition from children’s to adult services is vital to meet patients’ needs, says Julie Griffiths

When Mohammed Karim from Birmingham was diagnosed with osteosarcoma, aged 20, he was treated on an adult ward alongside much older patients. ‘It was lonely,’ he says. ‘I had all these elderly people around me and it was quite depressing.’

When he transferred to a teenage cancer unit, Mohammed says the care was more appropriate to someone of his age. There was internet access, a widescreen TV with DVDs available, PlayStations, Xboxes – and people his own age. ‘It helped me a lot. It was a morale boost,’ says Mohammed, who is now 22.

Mohammed is not alone in finding it an isolating experience to be surrounded by older patients when undergoing treatment for cancer. For those who started their cancer journey in children’s services, it is often even harder.

Debbie Holland, teenage and young adult (TYA) cancer nurse specialist at Addenbrooke’s Hospital, says it is common for patients to find it difficult to move from children’s to adult services. ‘They build up a relationship with a team they trust and there is a fear in having to get to know a new set of people,’ she says. ‘It’s like a healthy young person getting used to a teacher and a class, doing really well, and then being dragged out of it.’

Even the physical environment is different, with the brightly coloured walls of a children’s ward changing to the muted tones of an adult ward.

Ms Holland, who is funded by charity CLIC Sargent, says that planning the transition is vital to meet patients’ needs (see box).

Ray Scullion, senior development manager for Macmillan Cancer Support in the East Midlands and north of England, says many young patients would stay in children’s services if they could. In the past, it was common for them to do so. ‘If someone was diagnosed in childhood they’d be followed into adulthood by their paediatric consultant. All their treatment and outpatients’ appointments would be in the children’s and teenage clinics, sometimes until their mid 20s,’ says Ms Scullion.

But as cancer patients and survivors get older, they have different physical, emotional and psychosocial issues than children, which paediatric services can be ill-equipped to deal with. Common issues are infertility, problems with higher education or work and an inability to get insurance for a mortgage or travel because of a cancer diagnosis or late side-effects from treatment years before.

‘It is possible that, if an adult gets a new cancer after having had cancer as a child, that the adolescent cancer is a consequence of the treatment they had before,’ Ms Scullion says. ‘There’s a need to understand the impact that might have on the patient.’

Macmillan Cancer Support understands that young people have different needs and runs two websites to support them: www.click4tic.org.uk supports teenagers and www.why bother.org.uk helps children.

In 2005, the unique needs of teenagers and young adults were recognised in NICE guidelines. These recommend a shared care approach with child and adult services working together and patients aged 16–24 should be offered referral to a specialist cancer treatment for young people.

Teenage Cancer Trust has nine of these units around the UK, which means that four out of 10 teenagers have access. The charity aims to build enough units so that by 2012 every teenager with a cancer diagnosis will be treated in one.

Last year, the Department of Health issued guidance on commissioning services to improve the outcomes for young people with cancer.

Ms Holland welcomes the DH’s recognition that this patient group have specific needs. ‘We need to create TYA as a specialism in its own right. These patients are much more vulnerable than others. They’re still developing into adults and working out who they are.’

For information, go to: www.macmillan.org.uk; www.teenagecancertrust.org; www.clicsargent.org.uk.
There is a small but growing body of research looking at the effects of cancer and its treatment on survivors. Research in this area has a dual role. First, it builds a picture of the long-term impact of treatment, which is particularly relevant where treatment choices are available. Second, it provides information about the physical and psychological impact of having had cancer.

In the longer term these will enable research to focus on how to alleviate the effects of cancer and its treatment.

Recent papers demonstrate the scope of survivorship research.

A follow-up of patients treated for early stage ovarian cancer in the 1980s showed how long-term effects of treatment varied depending on the treatment option (Engelen et al, 2009). While 50% of patients treated with adjuvant chemotherapy or radiotherapy following surgery had long-term side-effects – mainly gastrointestinal – only 13% of a control group who had no adjuvant therapy, just surgery, reported long-term side-effects. Skaali et al (2008) looked at the psychological impact by assessing fear of recurrence among 1,336 long-term survivors of testicular cancer. A quarter of survivors, who on average had been diagnosed 11 years previously, reported thinking about recurrence ‘quite a bit’ in the previous week and 7% ‘very much’. The amount that survivors dwelt on survival was inversely related to their quality of life, self-esteem and ability to cope.

Most research on the effects of cancer and its treatment has been done in adult survivors of childhood cancer.

The Childhood Cancer Survivor Study tracks the health status of US adults diagnosed with cancer between 1970 and 1986. Oeffinger et al (2006) found that survivors of childhood cancer have a high rate of illness owing to chronic health conditions. Among 10,397 adult survivors, two-thirds had at least one long-term condition, with over a quarter having a severe or life-threatening one.

A Dutch study has shown that the way in which parents deal with their child’s cancer may affect its impact for the young person in the long term (Robinson et al, 2009). Children whose parents reported being very distressed during diagnosis and treatment were more likely to be distressed as young adults.


Excluding those who were unemployed before their diagnosis, half experienced no changes in their work situation following cancer diagnosis, 17% were working fewer hours, and 34% had stopped working or retired. Those who were older, had co-morbidity or being treated with chemotherapy were most likely to have a change in work pattern.

Macmillan Cancer Support held a UK-wide public consultation to identify priorities for cancer research followed by a systematic appraisal of the research evidence to see how well these areas have been researched (Okamoto et al, 2007). This found that some of the key themes identified in the consultation are currently under-researched, and that the scope and quality of some studies was lacking.

The National Cancer Survivorship Initiative (NCSI) includes a work stream to identify what is and is not known about the health and well-being of cancer survivors and interventions to improve them, and recommend areas worth considering for future research.

Jim Elliott, research adviser at Macmillan and support officer for the NCSI research work stream, says: ‘There are significant gaps in our knowledge of what happens to cancer survivors as a result of their diagnosis and treatment.’

Dr Elliott says the researchers are working with other partners to map those gaps and then to commission research to make that information available.

‘We are also commissioning a comprehensive review of the evidence base for cancer survivorship, which will include both published and unpublished papers, ongoing studies and identify collections of clinical and research data that could be used more effectively to answer many of the questions.’

References


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FILLING THE GAPS IN SURVIVOR RESEARCH

Research could show how to alleviate the long-term effects of cancer and its treatment. Kathryn Godfrey reports
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